hep

It Takes A Village

April 20, 2020 By Rick Nash

Working in childcare for as long as I had, the notion of “it takes a village to raise a child” was ever-present. The idea that our community influences help prepare us for the challenges we face in life, as much as those immediately closest to us do.

Working on the helpline at Help4hep, and connecting with others in Harm Reduction, I learned of an unfortunate side effect of Hepatitis C which stigma helps propel, deservedness.

The topic of deservedness among those of us who have survived and those still battling Hepatitis C is one of the hardest fights. Because as much as I, as a peer who has experienced one of the worst potential outcomes of Hep C, End State Liver Disease and Liver Failure, I’ve always struggled with helping people remove themselves from their own feelings of blame. A handful of people who have Hep C, blame themselves for getting it because they knew it was a risk if they shot up, or they knew the other person they were snorting with had Hep C.

And in truth, as someone who received Hep C through vertical transmission (mother to child), I never personally understood that deservedness, because from age 12 on, it was just a part of who I was. My mother had acquired it while working in a dental surgery office, likely in the early 80s. But even that was speculation.

10% of people with Hep C never or don’t know the source of their infection. And I can’t stress this enough; the source is mostly irrelevant to successfully treating and beating Hep C, and like in my family’s case, knowing it and not talking about it only makes things harder.

Stigma allows the pressure of society to increase a person’s feeling of deservedness, stigma reinforces the idea that our actions, when we’re aware or not of the potential danger, deserve the response and all of that potential danger. But this concept does not help anyone understand or grow, it only allows us to sink further into the isolation of deservedness.

So how do we talk to deservedness? How do we help those of us who feel like their actions “gave them” Hep C?

In my conversations with those who felt they deserved it, I’ve asked them why they believe “they earned their stripes.” Sometimes they claim to have known their friend whom they were sharing with had Hep C, sometimes they had no idea the risk but knew that their behavior was risky because society labeled it as such. In my experience, labels are useful for objects, terms, and concepts, but seldom for people or actions unless our goal is to Other.

My first point is that Hepatitis C is a virus, and it has one goal in its being: to survive and procreate. It is neither good nor bad; it merely wishes to survive. Just like us, when those of us get Hep C, we too want to survive. The virus did not choose anyone as a host, it merely saw the opportunity to continue doing the only thing it does, and did just that. Assigning blame or guilt to something which simply is doing what nature intended, will only make us more frustrated. It's akin to yelling at the wind, perhaps that release may help allow us some catharsis, but ultimately, we know the futility of a grander design.

My next point is that as people, the only way to move forward is to accept things as they are, and to seek to understand them, so that we may learn to grow with them. When we find acceptance, we begin to be able to talk about these feelings, and that often requires peers. Peers are those around us with similar views, in our neighborhood, or we share an otherwise common bond with. The power to overcome deservedness requires us to cast out the shame from stigma. And shame can be overcome with resiliency. Peers can provide resiliency in more ways than one. In a very physical and real sense, they provide support, a shoulder, an ear, a friend. In a crisis, peers can even be the source of helpful information, and sometimes its delivery may not always click at first, but it helps.

I say these things as a peer counselor, a public health student, and a fellow human. But everything I've mentioned above is not only applicable to those of us in the Hep C community, but also to those of us trying to understand and live with the ongoing Coronavirus Pandemic. As a person in Public Health, when I see the protests happening in Lansing, San Diego, and elsewhere, at first I was outraged by their selfishness. But then when I saw friends saying they should waive their right to treatment for their actions.

It gave me pause to remember why I am here in Public Health. I am here to help others survive and thrive. I know that deep down those friends don't wish ill upon others, they just want people to be more considerate of how these social distancing interventions help reduce the likelihood we may accidentally infect someone close to us or decrease the likelihood of more hospital workers getting it due to less surges from gatherings, or how less compliance prolongs the entire lockdown because of the resurgence of cases. The challenge is that when we choose to label these protestors and their actions, we validate their fight when we respond in kind. The important thing here is to open and continue a dialog. We all have real fears about COVID-19, and we all have different perspectives and access to different information. No one deserves to get COVID-19.

When some of us have more accurate information regarding what's best to do, we must help those who are more reluctant to participate in social distancing and other safe interventions, by doing the most human thing we can do: talk to each other.

I’m reminded of Mr. Rogers, who understood that the first step is often talking about something, “Anything that’s human is mentionable, and anything that is mentionable can be more manageable. When we can talk about our feelings, they become less overwhelming, less upsetting, and less scary.”