

TIME

## How Revealing Personal Health Conditions Helps Fight Stigma



Actress Kristen Bell attends The Bump Moms: Movers and Makers Awards at The Millwick in Los Angeles on May 3, 2016. Jason LaVeris—FilmMagic

BY WILLEMIEN KETS JUNE 30, 2016

IDEAS *Kets is an assistant professor of managerial economics and decision sciences at the School of Management at Northwestern University and a fellow in The OpEd P. Public Voices Fellowship.*

Recently, radio legend **Garrison Keillor** and rapper **Lil Wayne** announced that they had suffered seizures. Last month, *Frozen* star Kristen Bell **wrote** about her fight against depression and anxiety, and *Star Wars* actress Daisy Ridley

revealed on social media that she has endometriosis, a serious but common women's health problem. Epilepsy, mental illness and endometriosis are stigmatized but largely invisible conditions. If these celebrities had kept quiet about their condition, they could have passed as healthy.

Should others follow their lead and disclose that they have a stigmatized health condition? As a social scientist and someone who has epilepsy, I believe that there are good reasons for doing so.

I was diagnosed with epilepsy almost nine years ago, and I recently started speaking out publicly about the challenges associated with my condition. Of course, I worried about how other people would react if they learned I have a neurological condition. Arguably, our brain is our most important organ. It controls our actions, allows us to think and feel, and stores our memories. Acknowledging that such a central part of you isn't always working properly is a big step.

Nevertheless, I never doubted that "coming out" was the right thing for me. While social stigma often has a long history, it is a social construct, and, as such, can be eradicated by the same social forces that created it. In other words, a vicious circle can be turned into a virtuous one. If there is stigma associated with a health condition, then few people will reveal that they have the condition, and the stigma will persist. On the other hand, when people learn that someone they know and value has a stigmatized condition, it undermines the stigma. For example, people who know someone who has AIDS blame people with AIDS less for their condition.



### The Brief Newsletter

Sign up to receive the top stories you need to know right now. [View Sample](#)

[SIGN UP](#)

Changing public perception this way may seem challenging, as it appears to

involve the concerted action of a large number of individuals. However, the actions of a small number of individuals can have a dramatic impact on societal outcomes. This may seem counterintuitive, but **the basic mechanism is simple**. A key observation is that it is easier for some people to speak out than for others. For example, a celebrity who has already built an impressive career is less likely to be judged based on his or her condition than others who are just starting out. Once individuals begin to speak out, it becomes easier for others to do so. This creates a snowball effect whereby more and more people disclose their condition, thus eradicating the stigma.

This dynamic can be extremely powerful. During the past few decades, more and **more gay people have started to speak openly** about their sexual orientation. **As a result**, more people know a gay person. This has changed many people's perception of homosexuality: today, a **majority of Americans** have a positive view of gay men and women, a tremendous increase of 18 percentage points in only a decade.

To be sure, revealing that one has a stigmatized health condition can be risky. Discrimination of people with stigmatized conditions is far from uncommon, both in the **workplace** and **elsewhere**. That does not mean, however, that people with a stigmatized health condition have to keep it under their hat. Those who are at risk of experiencing considerable social stigma can wait until the stigma has diminished to the point where they feel comfortable speaking out.

Of course, the power of individual advocacy and increased visibility does not diminish the scope for public-awareness campaigns. Such campaigns can provide much-needed knowledge. Indeed, while **more than 1 in 4** people have concerns about working with someone with a neurological condition, the majority of those indicate that this is in large part because they don't what to do if a co-worker fell ill. However, awareness and information are not a panacea. For example, parents may know at the rational level that seizures are not dangerous or contagious, yet they may **keep their child from playing** with a classmate who has epilepsy. Stigma cannot simply be rationalized away.

Moreover, by being open about one's health condition, it is possible to deliver nuanced and multi-layered message. **Social stigma** occurs when there is a recognition that certain traits differ from the norm and these differences are evaluated negatively. To counter the stigma, the key is not to deny the differences, but to take away any negative connotations and to stress that there are also many commonalities. As a **mother of a transgender child** says about the visibility of the transgender community on social media: "It's not all about activism. It's just being out there as a regular person, and being known as a normal person—to show that it's not salacious, that trans people are really just normal people who talk about movies and music and who post silly cat pictures, as normal as everyone else."

Likewise, there is no denying that epilepsy affects me in a multitude of ways. But, in many ways, I'm still the same person I was before I had my first seizure

Right now, we're in a vicious cycle where stigma begets lack of advocacy, and a lack of advocacy translates into a **lack of funding and research**. Breaking this vicious cycle is not as gargantuan a task as it may seem. Simply by being themselves, people with a stigmatized health condition can be their condition's best advocate.

**Contact us at [editors@time.com](mailto:editors@time.com).**

---

IDEAS *TIME Ideas hosts the world's leading voices, providing commentary on events in society, and culture. We welcome outside contributions. Opinions expressed do not necessarily reflect the views of TIME editors.*