



A light for patient advocacy goes out, too soon

By Chelsea Rice | August 19, 2016

“There’s no reason that only 4.75% of outpatient visits and .08% of my hospitalizations are spent actively treating my condition. There’s no reason that I spent two solid months (1540 hours, 64.2 days) of this year waiting instead of healing. So, please, stop wasting my time. Stop wasting my life.”

– Jess Jacobs “On Wasting My Time - The Numbers”

Jessica “Jess” Jacobs, a 29-year-old healthcare IT professional and patient, wrote these words in her blog in November 2014. In the post, she categorized the relative usefulness of the time she had spent in the healthcare system that year, in a range of specialty visits, phone calls, and hospitalizations. Like much of her writing, it was a depressingly honest account of the state of today’s patient experience: somewhere closer to useless than useful.

Jacobs died on Saturday, August 13. Her passing was a shock to many in the healthcare world, from policy makers to clinicians to patient advocates to journalists who had followed her story on social media for years. On Sunday, her friends and online community launched a Twitter chat in her honor,



Jess Jacobs
@jess_jacobs


Happy Unicorn Day to my fellow Unicorns! @MandiBPro @HealthcareWen @TiffanyAndLupus @MsWZ #UnicornMoment

7:39 AM - Apr 9, 2016

1 2 11

sharing their favorite messages and memories with the hashtag #UnicornJess.



Farzad Mostashari 
@Farzad_MD



I miss @jess_jacobs laugh and her voice already. I feel that Healthcare failed her, and so did I twitter.com/CarlyRM/status...
10:35 PM - Aug 13, 2016 · New Hampshire, USA

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Jacobs suffered from a rare “unicorn” cardiology disorder called postural orthostatic tachycardia syndrome (POTS) as well as Ehlers-Danlos Syndrome, a hereditary disease that affects the connective tissue. She chronicled her journey through the disconnected healthcare system for years on blogs and social media, highlighting how difficult the system is to navigate, how terrible patient experience can be, and how ineffective and disconnected medicine is today – even for a patient as knowledgeable about healthcare as she was.

“I want people to understand how screwed up our health care system is. Jess was incredibly smart, and well connected, and we could not make it work that she could get well, or even stable,” chronic illness advocate and patient Carly Medosch wrote in a tribute to her friend. “Her long pain, the abuse she suffered, and the fact that she is not here now are all absolutely unacceptable.”

Jacobs dedicated her life to improving healthcare. As a director with Aetna’s Innovation Labs, she piloted clinical design solutions. At the Office of the National Coordinator for Health IT (ONC), she helped launch the Investing in Innovations initiative. She also co-founded the Food and Drug Administration’s Center for Drug Evaluation and Research’s Health IT Council. Her work focused around improving the systems that have the potential to make healthcare work as it should – but unfortunately, change didn’t come in time to help her.

“The sad thing is...I know my experience is not unique within the community of patients suffering from chronic disease. Every day patients are harmed by the one-size fits all approach to medicine which makes no room for those with ill-defined syndromes and default to patient blaming. And these

real problems can’t be solved with hospital wide technology updates or private rooms.”

– Jess Jacobs, “On the Worst Healthcare Experience of My Life”

This summer, Jacobs moved from Washington, D.C. to California to be closer to her family. But even in her final months, she had to waste time navigating the challenges of transferring medical information and coordinating care from one coast to another. From finding a new doctor willing to take on her complicated case to even getting her medication transferred within the same pharmacy system, there were roadblocks at every step.



Jess Jacobs
@jess_jacobs



True story. I'm moving and the realization that I'll likely run out of pain meds is majorly stressing me out.
twitter.com/IsaJennie/stat...

3:06 AM - May 30, 2016

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Jess Jacobs
@jess_jacobs



Ah, healthcare, I'd almost forgotten your absurd disconnects: spending my day connecting DC & CA branches of a national pharmacy chain.

12:41 PM - Aug 9, 2016

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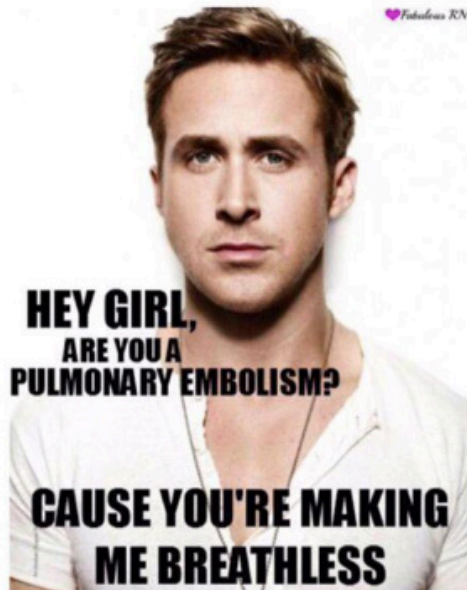
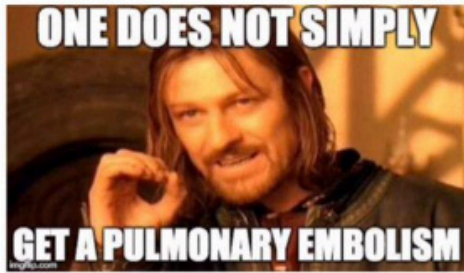
Jacobs’ writings conveyed the frustration of her experience, but humor was her constant companion. As Aloha Health cofounder Mandi Bishop wrote in a tribute on Medium: “Revisiting her Twitter feed today, I’m struck by how truly FUNNY she was, even as she was facing injustice and indignity that would have enraged Mother Theresa. Her way of screaming about the horrors she faced as to be snarky as hell. And we listened.”

In one shocking but hilarious moment, Jacobs captured how social media filled a hole in her medical record about a pulmonary embolism.

Despite all of her frustrating experiences, what was most remarkable about Jacobs was her persistent optimism that the system will get better. She

JESS'S DAY IN HISTORY: SEPTEMBER 25

1 YEAR AGO THU



Jess Jacobs
@jess_jacobs

Drs couldn't find my PE in their #EHR. Thanks to @Timehop I could let them know it's been exactly one year. #hcsms

10:02 AM - Sep 25, 2015 · Washington, DC

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dedicated her life – and even her final moments – to being a catalyst for positive change. Her impact, on the system and the people she encountered, will live on. In honor of her powerful voice, we'll give her the last word.

While there's a huge focus on prevention and population health (as there should be), we need to be careful we don't forget the 1% of unicorns who make up 20% of healthcare spending. And, while there's obviously no easy answer, there is an answer. We (yes, we as in me and you), as the people who've fallen in love with Mars Curiosity's delightful personality, can figure out how to deliver care that's individually appropriate on Earth. We can. I believe it."

– Jess Jacobs, "On the Worst Healthcare Experience of My Life"

Photographs in top photo courtesy of Ted Eytan, MD, a friend of Jacobs. (View on Flickr.com)

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