CAPS
Consumers Advancing
Patient Safety

December 2019

Holidays and Healthcare



Around the World, December is a month of many celebrations. December can be a happy but also a stressful time. When you are a patient or a loved one is a patient, the emotions of the time can be even more complex. Trying to celebrate amidst the angst of illness can be very difficult.

The first three years my youngest child was alive we were inpatient in the local Children's hospital on Christmas Day. Trying to keep the holiday special for my other two children at home was a real challenge. I grieved the loss of normal traditions while trying to project joy and a sense of holiday cheer. My child was too young to know the difference between a holiday celebrated on its official day and another day another week. I knew, though.

A few years later we did not have to be inpatient on the holiday. I, however, had to navigate the back halls of the largely quiet hospital to find the inpatient pharmacy. I had to get a rare, usually hospital-only, medication to treat a bad respiratory infection. I remember feeling physically ill at having to be there on Christmas Day.

My kiddo has major airway disease and had a nurse at night to manage a tracheotomy for over ten years. Two of those years, on New Year's Eve night, right around Midnight, my kiddo stopped breathing. While brief apneic episodes were fairly common, major events where breathing stopped altogether for a minute or more and the heart slowed were rare. Both years this happened on New Year's Eve, the Nurse, Janice, was able to get respirations going again and the heart rate back up. We did not transport to the hospital. But Janice staggered out of my home on New Year's morning shell shocked from the night's event. Janice and I marvel every year at those memorable nights.



First Christmas with a tracheotomy – 1993.

Holidays and other important events can be hard for patients, families and healthcare providers. On Thursday, December 12 at Noon Central time, CAPS will share a webinar, "A Person-Centered Approach to Meaning Making: Rituals and Traditions in Healthcare Settings." Join our subject matter experts, Rachel Weissman and Claudia Hubbard, to learn how ritual and celebrations promote connection and well-being. Information about how to join the Webinar is listed in this Newsletter.

We also interview Jen Dingman, a Patient Advisor hailing from Pueblo, Colorado. Jen has inspired many persons to pursue patient safety advocacy.

We hope you and yours enjoy the season and have a Happy New Year! Thank you for being a member of the Consumers Advancing Patient Safety community.

-Lisa Morrise

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Consumer Advocacy Panel (CAPS CAP) Interview – Jen Dingman

CAPS: When did you start your advocacy?

Jen: I started after my Mom passed away due to medical error in 1996. Her situation actually happened over several months. She most likely had a reaction to a medication and despite raising concerns, the medication was not changed. During her final hospitalization, medication error, poor communication, providers "anchoring" in a diagnosis and dismissing valid family concerns all culminated in her coma for seven weeks and eventual death.

Other family members of other patients who had also experienced medical error approached me and we started a very small support group. I ended up putting an advertisement in the local, Pueblo, Colorado, newspaper seeking others who similarly were grieving loss due to medical error. This was the beginning of PULSE.



CAPS: How did your advocacy evolve?

Jen: The little group started meeting kind of informally. Then, one night, I had the inspiration to name the group "PULSE." The name "Persons United Limiting Substandard . . . " came to me, but I couldn't figure out the word for the "E." At about that time, a dear woman I know called me every day to check on me. She was the one who said the word should be "error." So, PULSE became Persons United Limiting Substandard Errors.

PULSE was initially nurtured by an organization in our area called Hope Alive. We incorporated in Colorado in 1997. As we told our story and purpose, we were able to nurture chapters in other states, including New York, California, Illinois, Florida, Michigan, Washington, Delaware, Maryland and other states. Not all the chapters still exist, and some have evolved. PULSE of Colorado still provides support and outreach to promote patient safety and recovery after error.

CAPS: What do you recommend to persons who have been harmed by medical error?

Jen: I think it's important for persons to build some new memories with loved ones, if possible. I'd like to start a foundation that would send persons bereaved by medical error on trips, kind of like Make A Wish, where they could have some new, happy memories.

Our group started as a support group. Persons need a safe place to go to be able to work through their concerns about care. We need to stop ignoring collateral damage in the healthcare system.

Also, it's important to understand that the same members of one family group may process the situation differently. Patient Advocacy is not for everyone. Some people just want to put the incident behind them and move on. Others want to take up the cause of improving healthcare quality and safety.

CAPS: What do you recommend health systems do to improve Quality and Safety?

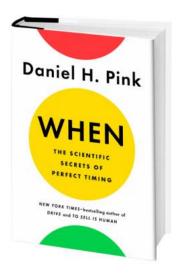
Jen: 1. LISTEN to the patient and family. 2. Customize care to the individual. 3. Figure out the payment issues that cause persons to not seek care they need.

CAPS: Jen continues to champion Patient Safety Day in the United States, commemorated each July 25 since 2008. (WHO celebrates Patient Safety Day on a different day.) For information about how your State can issue an official Patient Safety Day proclamation or reolution, contact Jen at jenatpulse@gmail.com.

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CAPS Book Club



A Patient Advisor I interviewed when working on the Transforming Clinical Practice Initiative highly recommended that I read the book, When: The Scientific Secrets of Perfect Timing, by Daniel H. Pink. She said anyone interested in patient safety should read When. I told her I like to listen to audiobooks, and she advised I purchase the print version because I would want to see the illustrations and graphs.

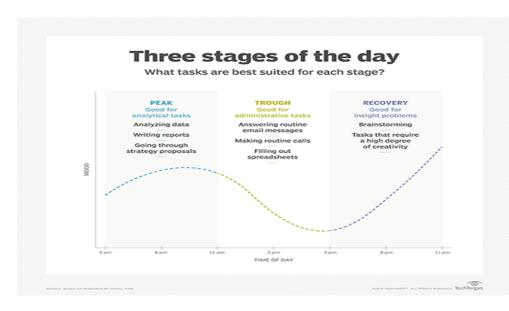
I purchased both the audiobook and a paperback copy.

The book specifically addressed timing in healthcare along with several other professions. Among the data that Pink presents includes gems like, "Adverse events were significantly more frequent for [surgical] cases

starting during the 3 p.m. and 4 p.m. hours." Pink cites a research study done at Duke for information regarding human performance during the trough, or time of day when most persons' energy is at a natural ebb.

One thing I appreciated about the book was that Pink did not just cite issues with timing in healthcare and other fields. He also offers proven methods for mitigating the impact of timing. For example, time outs and check lists can counteract the impact of surgery scheduled during the time of day when the providers circadian rhythm is at its lowest.

When: The Scientific Secrets of Perfect Timing has been a bestseller. You may find the insights Pink offers can be helpful in many aspects of your pursuit of Quality and Safety in healthcare.



When author Daniel H. Pink is the author of several books, including the New York Times bestsellers, When, Drive, To Sell is Human, and A Whole New Mind. His books have won multiple awards and have been translated into thirtynine languages. He was host and co-executive producer of the television series Crowd Control and appears frequently on NPR, PBS and elsewhere.



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Webinar Planned:

Rachel Wiessburg, MA, CAPS CAP and

Claudia Ricks Hubbard, MDiv, BCC Senior Staff Chaplain / Educator Children's Mercy Hospital Kansas City, Missouri

Will Address

A Person-Centered Approach to Meaning Making: Rituals and Celebrations in Health Care Settings

December 12, 2019 – Noon Central Time

Please join my meeting from your computer, tablet or smartphone.

https://global.gotomeeting.com/join/761745677

You can also dial in using your phone.
United States: +1 (224) 501-3412

Access Code: 761-745-677

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Webinar Objectives:

- 1. The attendee will understand the importance of providing whole person care and how that alleviates the sense of stress and isolation a person may encounter.
- 2. The attendee will learn JACHO and Chaplaincy standards for serving the needs of all patients, families and staff with awareness of cultural humility for various traditions.
- 3. The attendee will learn the importance of connection in meaning making and how staff can support patients, families and other staff.
- 4. The attendee will learn how ritual and celebrations promote connection and well-being.

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Please send us information about what you are doing to Advance Patient Safety. Send it to capspatientsafety@gmail.com

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