



## A Health Equity Conversation

A few years ago, the Iowa Healthcare Collaborative asked me to attend their annual meeting and offer a session on how to implement PFACs. In the presentation, I talked about the importance of health equity and how equity means equitable outcomes, not necessarily doing the same thing in the same way for everyone. I noted that I have family members that do not look like me, and that sometimes sub-prime care had been experienced by MY family. We visited about how we need to talk to persons to work with them on their healthcare in a context relevant to their lived experience.

After the session, a lady approached me. A nurse, she tearfully shared that she had adopted two children who are persons of color after her several biological children were all school age. These beautiful children, she said, were treated differently than her other children. It bothered her, because the only difference she could see is that her youngest family members were a) adopted and b) children with darker skin than hers.

At CAPS, one of our core values states:

*“We believe that diversity, in all of its forms, is a valuable asset and a source of strength. We believe that creative tension, brought about by honest and natural differences, is a catalyst for change and generates optimal solutions.”*

We need patient and family voices of all backgrounds to help us know how to develop care that will result in optimum, safe outcomes across the board.

I visited with a group in Alaska once about challenges they were having supporting their Native population in achieving hypertension and diabetes health goals. They kept trying different strategies, but nothing seemed to affect the health lifestyle changes they were looking to achieve. I suggested they ask a few of their patients to tell them how to achieve those goals. When we LISTEN to our patients, they will tell us how we can achieve healthcare equity.

Inequity in Policing has been a focus in the United States. COVID-19 has starkly illustrated the inequity in healthcare. Minority communities have been disproportionately impacted by the Pandemic. Clearly, a one size fits all Public Health effort will not suffice. Just translating information into different languages won't work. CAPS Board Member Dr. Ron Wyatt says messaging and outreach needs to be carefully targeted to meet the linguistic, cultural, social and environmental needs of the people we are trying to support.

We will feature Dr. Wyatt's insights into achieving equitable care on a "COVID-19: Patients, Families and Providers in Conversation" YouTube video. A series of these videos, including one discussing Hospitals and COVID, one on experiencing COVID and one that looks at returning to elective procedures during COVID can be found on the CAPS YouTube Channel: <https://www.youtube.com/channel/UC7f7J8ynAwpDQpJWQX9mjQQ>. Over the next several weeks, our partnership of CAPS, Project Patient Care and the Healthcare and Patient Partnership Institute will produce more videos about important COVID-19 Healthcare issues. What would you like to see us address?

### In this Newsletter, read on for:

- What's it like to be a caregiver during a Pandemic? Thoughts from Diann Folkersen
- Don't miss how Erica Steed is supporting patients during COVID in our CAPS CAP Profile.
- Links to the YouTube Series "COVID-19: Patients, Families and Providers in Conversation."

-Lisa Morrise



## A Caregiver Perspective from Diann Folkersen, CAPS and Comagine Health Patient Advisor

Another voice in the conversation concerning COVID-19 casualties comes from patients who need medical care and attention and are not sick with the Coronavirus.

I am a caregiver to my Mother who has complex medical conditions. She lives alone and can't get herself to any place for medical care. My Mom is a stroke survivor and she also has Post-Polio Syndrome, clotting disorders, a heart condition and experiences frequent UTI's. From the Post-Polio Syndrome her muscles are weak; and her lung function is diminished. I attend all of her doctor appointments with her to advocate for her needs. I take notes on the instructions given by the physician and review them with her afterwards. My review helps ensure she understands what she is supposed to do.

Blood pressure issues cropped up about January. Then around February Mom started waking up early in the morning feeling like an ice cube. Her temperature was around 95 F. We started tracking her blood pressure and her temperature every day. We were able to get in to see her Primary Care Physician the first week of March. At that time a change was made to the time of day for one of her heart meds. Her Primary Care Doctor decided it was best to make an appointment with her cardiologist to see if any other changes should be made or if something else needed to be addressed. We made an appointment and were scheduled a few weeks out.

Within in a week of that visit our area experienced an earthquake and Salt Lake County was asked to shelter in place while city and utility workers verified the safety of bridges, buildings, utility lines, etc. Then came the "Stay Home. Stay Safe" directive from the Utah's Governor related to COVID-19. We received a notice from the Cardiologist that he was postponing all of his appointments until further notice.

Considering whether to take Mom to an emergency or not was a stressful experience. Trying to evaluate not only what is the next step but what would follow that step and be the next. What would the path be for each option? Questions included:

- How dangerous was it to go to the hospital emergency?
- What treatment options would be available to her there?
- Is the healthcare system over-burdened?
- Does her condition truly warrant time and attention being taken from Coronavirus patients?
- If she is taken to an emergency, will she end up being alone?
- Is it better to keep her at home and utilize other avenues of medical care?
- Is there some other option?

My Mom has restrictive lung disease from Post-Polio Syndrome. If she were to contract any virus that affects her lungs, her lungs would struggle to recover. Something as severe as the Coronavirus is especially concerning. She possibly would not recover at all.

In the early days of the virus outbreak many people went to the emergency when they were sick. The hospitals were creating mitigation plans as quickly as they could. They were trying to take every precaution to prevent spreading the Coronavirus and every measure to prevent cross contamination from one patient to another, as well as from patients to providers and staff. The risk of exposure was real.

Mom needs another person to facilitate the communication process, especially when the intake, triage, nurse, resident, and then physician each ask the same questions. The repetition leads to irritability and aggravation for her. She depends on the second person taking notes of her instructions for reference later when she can't remember what she was told. She relies on the reiteration and explanation from the second person to be sure she understands what is happening and what is expected to happen from the visit. I found the possibility of taking her to an emergency room and her being left alone frightening for me as well as Mom.

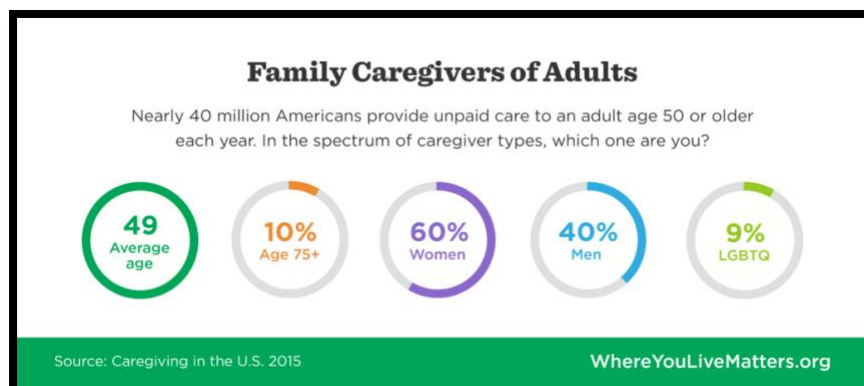
She pretty much was not eating anything but chicken noodle soup with crackers or bread and toast. Everything else made her gut hurt more. Even those foods made her gut hurt, but not as much as other foods. I managed to arrange for a telehealth visit with her Primary Care Physician. I thought during the video visit it was helpful for him to see her lying in bed. She would try to sit up and talk to him and slump right back down. He changed her anticoagulant from an oral to an injection medicine and started her on an antiemetic. I asked if home health could come help with the injections and monitor her vitals. Having home health provided an opportunity for a trained provider to observe her condition on a daily basis. They could communicate with the physician in a timelier manner than I could. She would not have to leave her home.

One recommendation the physician made was a GI work-up be done. He gave us a list of places that might allow an endoscopy or a colonoscopy. Both procedures were considered non-essential. Not until our Governor relaxed the non-essential restrictions in early May, did I get a response from someone who would do the work-up. In order for her to get the work-up done, she had to have a negative test for Coronavirus within 48 hours of the procedure. From the time she took the test until she had the procedure she had to be quarantined.

I am grateful for my experience as a CNA and as a parent of a child with cancer. I am familiar with the medical environment and with a variety of treatment possibilities and remedies. That was useful. I knew that when her blood pressure was dangerously low to push fluids. I knew how to get her warm when her body temperature dropped below 95 F. I knew that antiemetic drugs could be asked for and knew I could ask for home health if it was not offered to me. All that experiential knowledge came in handy. I can't imagine if I were not an "experienced" person how it may have played out differently. And even though I am a relatively seasoned person in the patient care world, it was still a fearful time. It was confusing what the best course of action was and to some degree still is confusing.

I think it is to the public detriment to have the media, through commercials and broadcasts, emphasizing the worst of the situation over and over again. I agree the general public needs to know how serious the problem has been, and the difficulties presented to our society. The repetition from everywhere breeds fear for when someone needs medical attention that is not related to the virus.

The governmental restrictions have been effective in reducing how quickly the virus spreads, which prevents the healthcare system from becoming overwhelmed. I am not sure that the restrictions have been good for the general public with other types of medical needs. The doctors have been limited on what they can and cannot do for their patients. In my Mom's case we didn't come out "worse for the wear," so to speak, but we easily could have. It was fearful, confusing and produced a great deal of anxiety for both she and I. I think there is wisdom in restricting non-essential treatments, procedures, and surgeries AND I think the physician should be able to determine if it is something that needs to be done or can wait. **-DF**





## Consumer Advocate Panel (CAPS CAP)

### Interview with Erica Steed

With a BS in Information Technology, a BBA in Marketing and an MBA, **Erica Steed** brings an impressive talent stack to her Patient and Family Engagement Advocacy for Quality and Safety.

#### **CAPS: When did you start your advocacy?**

**Erica:** When my son Ellison was born in 2007, I was hypertensive and seeing floaters. My Doctor chose to ignore my symptoms, chalking them up to hypochondria. When I went in for my first post-delivery appointment, my blood pressure was very high, and I was referred to the Emergency Room and admitted.

While in-patient I was given mercury as part of the treatment. Not until I asked about side effects, after several doses, did anyone notice I had been breastfeeding. The staff said they were shocked that a young black woman was breastfeeding. They also were shocked I was married and that after seven years of marriage, Ellison was eagerly planned and anticipated. They also assumed I had Medicaid insurance, which was not the case.

Sadly, Ellison's development was impacted by the medication he absorbed during that time. Later, when I was seeking answers about possible developmental delay, the Dr. wrote a diagnosis down and put it in an envelope to take to a Specialist. It was heart breaking to me that she did not trust me to be able to handle the news that Ellison would need special care. I opened the envelope before getting to the specialist and read her notes. Ellison was diagnosed with an Autism Spectrum Disorder (ASD), Pica and Apraxia.

I have had to advocate for Ellison, in many settings. One time I took him to a bulk goods store and he had a complete meltdown. Someone called the police and accused me of child abuse. It was scary to be profiled in that way. Since then, we make a point to try to wear items like shirts and bracelets that identify that Ellison is on the Autism Spectrum. That seems to help people be more understanding and not judge.

Recently, given the issues the country is facing, my neighbor asked what she could do to support us. I suggested she continue to have my kids over to her home and her kids over to my home so they would not grow up seeing persons of different skin tones as different.

I did not have similar complications with my daughter Elian, who recently turned ten years old. Elian is an Honors Student. Ellison is now in Junior High and is doing very well.

#### **CAPS: How has your advocacy evolved?**

**Erica:** We have gone from just advocating for Ellison and his IEP meetings. I teamed up with a great Advocate, Naomi Williams, to run an Autism Support Group that morphed to incorporate support for families with children with all special needs. Naomi continues to help families and her son, Noah, with workshops about hygiene, IEP meetings, Katie Beckett Waivers and ABA thru the school and more.

I also evolved to advocate for Geriatrics. I see many commonalities between ASD and Dementia. Both populations have challenges with attentiveness and being "in their own world." Both often have trouble articulating their thoughts and may have advocates. They may have cognitive delays. I'd like to see "all-age" friendly facilities and see more Geriatric Units at hospitals.

I evolved to working professionally at the Medical College of Georgia as the Manager of Patient Experience in the PFCC Department. I looked at data to see how work in process improvement actually impacted the Patient Experience and Quality and Safety.

I currently work at the Wellstar North Fulton Hospital in Roswell in Patient Centered Care. I oversee Patient Relations and Patient Experience Process Improvement. I participate in daily “Voice of the Customer” huddles with all department leaders. It’s a 15-minute conversation that’s specific to checking the experience pulse of the patients that are currently within the hospital. We have a 202-bed facility that sees a complete range of patient needs. North Fulton Hospital is 1 of 11 hospitals within the Wellstar Health System.

## **CAPS: What projects have you worked on?**

**Erica:** With Covid-19, I have worked to quickly deploy comfort kits to patients, who are isolated without normal caregiver support. Our kits include things like coloring books and pencils for the patient to pass their time as able. What I’m really proud of though is arranging for IT and hardware to facilitate communication between the patient and their loved ones and the patient and our staff.

We started with using Samsung tablets to support challenging end-of-life conversations, bringing the provider, patient and loved ones together. People could see each other, which was better than just having a verbal conversation. Since then, we have rapidly morphed into using a variety of platforms (Skype, Messenger, Google Duo) for patients to communicate with their family.

Then we utilized the tablets to help with rounding. We were doing purposeful hourly rounding on our COVID patients. That meant 24 changes of PPE per patient per day. By using the tablets to conduct an assessment every other hour, we saved 12 masks and gowns per patient. Of course, if the patient needed an in-person visit, that was done.

Next, we expanded to including the patient and their family in Interdisciplinary Rounds (IDR). Up to 14 family members can be invited to the IDR and given a time to sign in. They wait in a virtual waiting room until the team is ready for their family member’s case. Then the patient, family and the Team meet. Team members may include the Hospitalist Physician, Nurse, Care Coordinator, Physical Therapist, Pharmacist and sometimes a Dietician and Surgeon. (My colleagues, Dr. Sonia Camphor, Victoria Dune-Chari and Adriana Shults spearheaded this project, too.)

## **CAPS: What recommendations do you have for other Patient Advocates?**

**Erica:** I always encourage someone to not be discouraged when they don’t feel heard the first time they offer their thoughts. Or, to be understanding if another person later shares the same thought and they are heard when you may not have been. This happens. Don’t make it about you. Make it about getting something done for the patients, regardless whose idea it may be.

To have sustainable change, you need to make sure it is made part of policy and becomes part of standard operating procedures.

Patient Advocacy sometimes has to go slow and steady. Patient Advocates need to measure twice and cut once. Remember, early adopters among staff may be gung-ho and on board with proposed initiatives. However, those late adopters who are not on board must be won over before any real change will happen. Don’t give up!

## **CAPS: What recommendations do you have for facilities that want to improve Quality and Safety?**

# Consumers Advancing Patient Safety

June 2020



**Erica:** Please don't be defensive. We all want to make healthcare safer and higher quality. You need to **truly** want change. Don't make it all about you. Keep the patient at the center of all decisions.

If I don't hear the word, PATIENT, in a meeting in the first 15 minutes, I always bring it up. I say, "Just who are we working for here?!"

**CAPS: What do you see happening in your future?**

**Erica:** Eventually I'd like to open some type of resource center in my community for advocacy at large. I'd like to be able to help link people to support groups for different disease issues and needs. I'd like it to be a safe place for persons and caregivers who deal with special needs. Maybe it would be a place where spouses, who have so much relational stress due to their family member's issues, may be able to get therapy. It would be a safe place where you could let your guard down. If only I had a Magic Wand!

**Thanks, Erica! Do you have a question for Erica? You may reach her at [egollett@yahoo.com](mailto:egollett@yahoo.com).**

**COVID-19**

CAPS  
Consumers Advancing  
Patient Safety

Healthcare and Patient  
Partnership Institute  
2 Voices, 1 Conversation  
H2Pi.org

PROJECT  
PATIENT  
CARE.ORG

**Patients, Families and Providers**  
*Three Voices, One Conversation*

Here are the first videos in a series of COVID-19: Patients, Families and Providers in Conversation. These videos are a collaboration of three organizations: Consumer Advancing Patient Safety (CAPS), Project Patient Care (PPC) and Healthcare and Patient Partnership Institute (H2Pi).

- Preparing for a Hospital Visit: <https://youtu.be/gsjmZ4AnlN8>
- Learning from COVID-19 Patients: <https://youtu.be/4-bSUO4NH-o>
- Elective Procedures in Hospitals: [https://youtu.be/Esv63GMN\\_vk](https://youtu.be/Esv63GMN_vk)
- The Important Role of Telehealth: <https://youtu.be/wiYpluoU2Lc>

*Consumers Advancing Patient Safety often partners with other organizations seeking to improve Quality and Safety. When possible, we support their efforts here.*

## Walking/Running/Riding for Patient Safety by Marty Hatlie



For the last year I've been part of the planning group organizing a March for Patient Safety in Washington, DC on this year's World Patient Safety Day, September 17, 2020. World Patient Safety Day was established by a [2019 World Health Organization Resolution](#) calling upon every nation to do more to reinforce prevention of harm in healthcare as a global priority, based on lessons learned in the last 20 years. Our objective is to raise public awareness of the need for a healthcare system in the U.S that is systems-based and adequately resourced to keep both patients and healthcare workers safe.

The event is being organized through the [Patient Safety Movement Foundation](#), a California nonprofit whose mission is to achieve zero preventable harm in healthcare. I've been active in the organization as a volunteer for several years, co-chairing its solution development around engaging patients and families as partners.

Prior to the Pandemic, we had all the permits pulled for a March of 5,000+ people from Freedom Plaza, near the White House, down Pennsylvania Avenue to the U.S. Capitol. Because of the Pandemic, there's been quite a lot of reconsideration of this plan as issues in healthcare safety morph! We've kept our permits, and still plan on doing a symbolic March of 50 to 100 people if possible, marching in accordance with social distance guidelines. In addition, last Friday we retooled and launched the Walk for Patient Safety with the goal of collectively achieving One Million Miles by September 17<sup>th</sup>.

**Invitation to Participate:** The Walk for Patient Safety kicked off on May 22, with a [commitment from Dave Mayer](#), Patient Safety Movement Foundation CEO and an ardent sports fan, to walk to every spring training site in Arizona within a week. Several other people are running. I'm biking 500 miles a month on Peloton. We're counting steps/miles through an app called [CharityMiles](#). It's free, and once you register, it tracks steps/miles on your fitness tracker or other device and points them to the charity of your choice. If you choose Patient Safety Movement Foundation as your charity, CharityMiles will aggregate our collective steps to both support the message and fundraise for the March.

There also is the option to make a financial contribution to support the Walk at CharityMiles, by sponsoring someone who is walking/running/riding like Dave or me. Another option is to set up your own fundraising pledge and ask people in your network to support you. So, for example, if you wanted to commit to walk 20 miles for patient safety, you can create a pledge to do that and ask your network to donate. All contributions pledged through CharityMiles goes to Patient Safety Movement Foundation.

Although financial donations are welcome, you and those you know will support the Walk for Patient Safety just by letting us count your steps. One Million Miles is definitely a stretch goal, but we're going for it and could really use your help! Here's more information on [how CharityMiles works](#). Feel free to email me at [mhatlie@p4ps.net](mailto:mhatlie@p4ps.net) if you have any questions. Thanks for considering! -MH

## Speaking of Information . . . Pandemic Related Resources:

COVID-19 Resources from CDC:

- [People who are at higher risk for severe illness](#)
- [If You Are Sick or Caring for Someone](#)
- [Prevent Getting Sick](#)

Resources curated by the Institute of Healthcare Improvement – a vast treasury of COVID-19 resources may be found [this link](#).

CMS Guidance on Visitation and Discharge for Covid-19 Infection control and prevention:

- Medicare and C-19 landing page: <https://www.medicare.gov/medicare-coronavirus>
- Hospitals, Psychiatric Hospitals and Critical Access Hospitals: <https://www.cms.gov/files/document/gso-20-13-hospitals-cahs-revised.pdf>
- Nursing homes: [https://skillednursingnews.com/wp-content/uploads/sites/4/2020/03/QSO-20-14-NH-REVISED-3-13-2020\\_0.pdf](https://skillednursingnews.com/wp-content/uploads/sites/4/2020/03/QSO-20-14-NH-REVISED-3-13-2020_0.pdf)

Project Patient Care guidance on visitor rules in hospitals and nursing homes: <https://www.projectpatientcare.org/wp-content/uploads/2020/04/ppccovid19april5.pdf>

Vizient *Covid-19 Resource Page* (updated daily): <https://www.vizientinc.com/covid-19>

Patient Safety Movement Foundation (updated frequently): *Helpful Covid-19 Resources* (<https://patientsafetymovement.org/helpful-coronavirus-covid-19-resources/>)

Centers to Advance Palliative Care (CAPC): *COVID-19 Response Resources* (<https://www.capc.org/toolkits/covid-19-response-resources/>)

- CAPC provides a toolkit on communication during end of life/palliative situations customized to Covid 19 situations

University of Wisconsin: *Best Case/Worst Case: ICU, with Special Content for Patients with COVID-19* ([https://www.hipxchange.org/BCWC\\_COVID-19](https://www.hipxchange.org/BCWC_COVID-19))

- Designed to help palliative care clinicians and other clinicians navigate daily conversations with patients' families. It also informs critical care clinicians about the lives of the patients they are caring for and supports families who are absent from the patients' bedside.

Advanced Directives and End of Life Care

- Maryland Office of the Attorney General guidance and forms: <https://www.marylandattorneygeneral.gov/Pages/HealthPolicy/eolcare.aspx>
- AARP forms for all States: <https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/>
- Respecting Choices: *Covid-19 Resources*: <https://respectingchoices.org/covid-19-resources/>



Project Patient Care podcast, *Advance Care Planning During “Normal” and Covid-19 Times*:  
<https://www.projectpatientcare.org/podcasts/>

**Recommendations for and by Patients, Families, and Caregivers for Elective Surgeries and Invasive Procedures During COVID-19 Pandemic:**

Patient Safety Movement Foundation:

- *Guide to Medical Care at a Distance*:  
<https://www.dropbox.com/s/m052xhjxsjsjrjv/Guide%20to%20Medical%20Care%20at%20a%20Distance.pdf?dl=0>
  - This infographic outlines what patients, families, and advocates can do to engage from a distanced during hospitalization. Organized by four stages:
    1. Admission
    2. Daily, during hospitalization
    3. Discharge
    4. After discharge
- *Hospital Plan of Care* (Form designed for family caregivers to use to get the necessary information from the care team):  
<https://www.dropbox.com/s/ro06j84zpqmsqgnw/POC%20Blank%20April%2019.pdf?dl=0>

Centers for Disease Control and Protection (CDC): *Coronavirus Disease 19 Daily Life and Coping*  
(<https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/index.html>)

National Alliance on Mental Illness (NAMI): *COVID 19 Information and Resources*  
(<https://www.nami.org/Support-Education/NAMI-HelpLine/COVID-19-Information-and-Resources>)

American Association for Retired Persons (AARP)

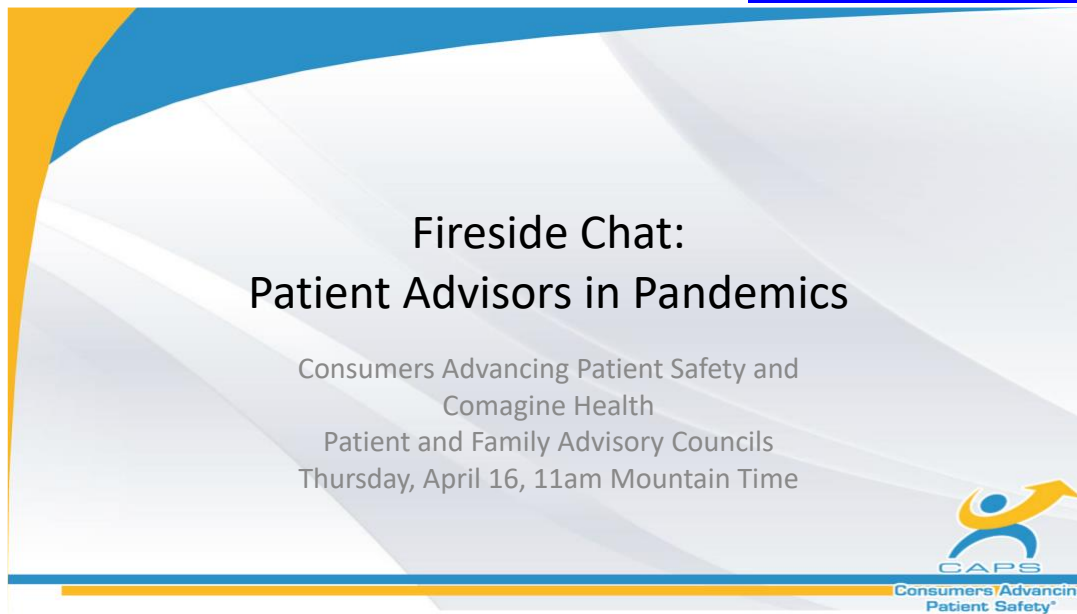
- *6 Questions to Ask if Your Loved One Is in a Quarantined Facility*  
(<https://www.aarp.org/caregiving/health/info-2020/questions-for-quarantined-facility.html>)
- *The COVID 19 Imperative: Keep Family Caregivers and Long-Term Care Facility Residents Connected*  
(<https://blog.aarp.org/thinking-policy/the-covid-19-imperative-keep-family-caregivers-and-long-term-facility-residents-connected>)

Morale & Gratitude:

- Blog post: *In a pandemic, does patient feedback still matter?*  
[https://blogs.bmj.com/bmj/2020/03/30/james-munro-in-a-pandemic-does-patient-feedback-still-matter/?utm\\_source=twitter&utm\\_medium=social&utm\\_term=hootsuite&utm\\_content=sme&utm\\_campaign=usage](https://blogs.bmj.com/bmj/2020/03/30/james-munro-in-a-pandemic-does-patient-feedback-still-matter/?utm_source=twitter&utm_medium=social&utm_term=hootsuite&utm_content=sme&utm_campaign=usage)
- Twitter thread: *7 tips on boosting the effects of gratitude*:  
<https://twitter.com/GiskinDay/status/1241303041015513088>
- AARP: *Innovative ways to say thank you*. <https://www.aarp.org/health/conditions-treatments/info-2020/tributes-to-health-care-workers.html>

Thanks to CAPS Board Member, Marty Hatlie, JD, for compiling these resources.

Please check out this archived event [At this YouTube link.](#)



Please visit:

Our web page at [www.patientsafety.org](http://www.patientsafety.org). Find resources, archived recordings a form to share your story or sign up for this newsletter!

And, please like our Facebook Page: <https://www.facebook.com/patientsafety.org/?ref=bookmarks>

## Do you have information for the CAPS Newsletter?

Please send us information about what you are doing to Advance Patient Safety.  
Send it to [capspatientsafety@gmail.com](mailto:capspatientsafety@gmail.com)

[UNSUBSCRIBE](#) | [GIVE FEEDBACK](#) | [CONTACT](#)

Consumers Advancing  
Patient Safety  
321 N. Clark Street  
Suite 500  
Chicago, IL 60654  
312-445-6477  
[PatientSafety.org](http://PatientSafety.org)