



## Perception and Reality

The first year my youngest child was alive, we experienced sixteen hospitalizations. Each time, serious mistakes impacted us, some for a lifetime. I thought, “How come we seem to have such bad luck?”

Later, I found patients and caregivers may have an expectation for safe care, but don’t understand that the care they receive is less than optimum. Many others feel errors in their care are isolated, unique mistakes.

The isolated nature of receiving care and sense that mistakes are one-off events contributes to the low demand for improvements in care. This is exacerbated by systems that choose to avoid ownership of mistakes or act as though problems don’t happen. Perhaps counter intuitively, systems that acknowledge and track error openly end up with lower rates of error.

Recently I wrote about my experience as a coronavirus patient. While I have technically recovered, I do have lingering issues. A yearly physical about a month after I had stopped having symptoms showed a precipitous drop in my kidney function. During my coronavirus emergency room visit with respiratory distress, it occurred to me that a blood work-up was not ordered. With the large number of persons who have multi-organ impact from COVID-19, was not ordering bloodwork a mistake? Was it too early to have established protocols where these vital diagnostic tools would be utilized? It would be nice to have a reading of what my kidney function was at the time of that visit, not just six weeks later.

The CAPS Consumer Advisory Panel weighed in recently on issues they have noticed around the handling of COVID-19. Here is some of what we learned:

- Many Advisors feel confused about the messaging they hear. This is especially true around testing. While in one area testing is readily available, it may not be in another area. Patients do not understand **who** should be tested, **when** they should be tested, **where** they should be tested and **how** to get results. This remains an improvement opportunity.
- Some hospitals have moved to virtual PFACs and continue to receive input from their patients and caregivers. These hospitals report hearing from their Advisors that messaging across their facility was inconsistent. The Patient Engagement leaders at these facilities went from office to office and to various points of contact to make sure each had consistent, accurate messaging for patients. This may also be an improvement opportunity for your facility.
- Our Advisor colleagues are growing weary of what they see as politicization of the handling of the virus. They feel this is interfering with proper understanding of risk and mitigation. Messaging should remain politically neutral.

Patient Safety Day 2020 takes place on September 17. See a message from the Patient Safety Movement Foundation posted below for how you may get involved! CAPS values your work in Patient Safety and your input. While we clearly have more to do, together we will continue to work to achieve better healthcare.

-Lisa Morrise

### In this Newsletter, read on for:

- Our interview with **Janice Tufte**, a hard-working Patient Advocate from Seattle.
- We have included another popular **Graphics Garden** for you!
- Links to the YouTube Series “COVID-19: Patients, Families and Providers in Conversation.”

## Consumer Advocate Panel (CAPS CAP) Interview with Janice Tufte

*Janice Tufte advocates for social needs and health policy from her home in Seattle, Washington.*

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

**Janice:** My advocacy really started in 1978 when I was a resident counselor and trainer working with adults moving from residential care facilities. Our Program for Independency taught daily living skills so individuals could live independently effectively and be able to advocate for themselves. As a multi stakeholder citizen group, many of us attended the Handicapped Congress in 1977 and 1978 to advocate for wheelchair access in government and school buildings. My Father used a wheelchair for mobility access when I was a child, our home was retro-fitted for access. I learned as a child caregiver how challenging getting in and out of buildings can be.

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

**Janice:** Many years passed where I used my voice on health and social needs related legislative issues. In 2008 I founded the Islamic Civic Engagement Project (ICEP). In collaboration with diverse groups we advocated for [CHIP](#) and expansion of the existing [FPL limit](#) requirements. The ICEP also worked on affordable housing and food insecurity bills, all were successful in passing. I brought in leadership from five Islamic organizations. I also initiated and worked alongside leaders to pass the '[Respect for Holidays of Faith & or Conscience](#)' [SB5173 bill](#) in my State of Washington, which allows individuals from diverse beliefs to have the opportunity to take two unpaid days off of work and or be excused from school for their respective Holidays without any negative repercussions.

In 2012 I was asked by an individual in governance in my health system if I might be interested to apply for the position of Patient Co Investigator on the [LINCC](#) Kaiser Washington Health Research Institute KPWHRI - PCORI project. I had been recommended to the Research Institute while serving as a PFA where my background in [developing projects](#) around the social determinants of health fit the research position. This moved into Health Services Research and Quality Improvement efforts on food insecurity, digital divide and telehealth, transportation and housing. Decades of work have really come together for me in the last two years, where I am now advising both in evidence work and open science projects Internationally.

### **CAPS: What projects have you been involved in?**

**Janice:** I have been a consumer voice on the Northwest Health Law Advocates Low Income Populations workgroup, Healthcare for the Homeless governance and for Medicaid Title XIX HCA Washington. I currently serve on the American College of Physicians Guidelines Panel as a Public Panel member my fourth year now. I've also been serving on measurement panels or committees with NCQA, Mathematica, Acumen, Camden Coalition and the National Quality Forum. I'm surprised at how little input there has been in evidence synthesis work including patients and caregiver voices! We really can help bring relevance to both measurement and into guidelines. I was on a committee that was looking at opioids and, until I brought it up, there was no consideration of patients who utilize both benzodiazepines and opioids. I enjoy evidence synthesis development and or taking evidence and translating that into health policy.

It's important that people realize that research guides measurement and measurement is often tied to financial incentives. Current best evidence informs health policy for projects and clinic implementation and should include patient engagement.

## **CAPS: What do you recommend to a person who wants to advocate for Quality and Safety?**

**Janice:** It's very important to be at the table in evidence review, research and measure development. The consumer needs to be involved in the systematic review process, guideline development and in writing articles and opinion pieces. We need to be present on calls with public comment opportunities. We need to serve on committees at all levels. Our role includes helping to ground all work in what is relevant and important to the end user, us.

## **CAPS: What do you recommend to Healthcare Systems that want to improve Quality and Safety?**

**Janice:** Have patients and caregivers at diverse tables in all healthcare or payer systems. Ask your clinic champions to suggest patients who might be interested in deeper engagement, whose story should be heard. Be sure to include stories from consumers in your work. Be sure to thank, even pay, your patient advisors, their/ our time is as important as all of the paid stakeholders.

## **CAPS: What are your future plans?**

**Janice:** Since being involved with social determinants of health and disparities work, I've been asked to participate in work nationally and now internationally. One exciting project is working with the LB Institute on the patient and public voice on prioritization processes in research, Open Science, in Austria.

I've most recently worked with the Camden Coalition to develop out a set of core competencies for providers working with individuals with complex care and social needs. I too am serving locally on a work group prioritizing COVID19 research projects with ITHS/UW. I look forward to future involvement with measure endorsement and guidelines development processes and am open to new collaborative efforts and partnerships with individuals who want to effect and innovate for positive sustainable change.

*Learn more about Janice Tufte on her website, <https://janicetufte.com/involvement>. Janice may be reached at [janicetufte@yahoo.com](mailto:janicetufte@yahoo.com) or 206-375-6706. Some references Janice shared:*

- CHIP <https://www.medicaid.gov/chip/index.html>
- CHIP FPL by State <https://www.medicaid.gov/medicaid/national-medicaid-chip-program-information/medicaid-childrens-health-insurance-program-basic-health-program-eligibility-levels/index.html>
- Holidays of Faith and or Conscience Bill  
Story <https://muslimgoodnews.com/post/82356489177/washington-state-legislature-passed-sb-5173>
- Actual SB5173 Bill that passed <https://apps.leg.wa.gov/documents/billdocs/2013-14/Pdf/Bill%20Reports/Senate/5173-S%20SBR%20APS%2014.pdf>
- LINCC PCORI Project Successful CRS Intervention Scaled System wide <https://www.kpWASHINGTONresearch.org/news-and-events/blog/2019/december-2019/shaped-research-crs-program-addresses-social-needs-primary-care>
- Emergency Muslim Resource Guides <https://janicetufte.com/muslim-resource-guides>



# Consumers Advancing Patient Safety

September 2020



These are the 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). You can view all of these videos on the Consumers Advancing Patient Safety YouTube Channel. Please go the link below and be sure to hit subscribe **and** notify so you will know when a new, relevant video has been uploaded!

<https://www.youtube.com/channel/UC7f7J8ynAwpDQpJWQX9mjQQ>

- **New! A Physician/Patient point of view on the importance of your continued care.** – a conversation with Dr. George Bakris
- **Preparing for a Hospital Visit** – a conversation with Rosie Bartels
- **Learning from COVID-19 Patients** – a conversation with Josh Weissburg
- **Elective Procedures in Hospitals** – a conversation with Kellie Goodson
- **The Important Role of Telehealth in Mental Health** – a conversation with Wendy Hayum-Gross
- **Health Equity During Covid-19** – a conversation with Ron Wyatt, MD, MHA, IHI Fellow
- **Finding Hope and Meaning through stories** – an introduction to stories with Tracy Granzky and MedStar
- **How has the COVID-19 Pandemic affected you personally** – the first of several conversation videos with Helen Haskell, Crystal Morales, Josh Weissburg, Vonda Vaden-Bates, Tim McDonald, MD, Pat Merryweather-Arges, Steve Burrows, Margo Burrows, and David Mayer, MD
- **What stories have you heard or experienced that are COVID related that we can't forget?**
- **What technology or innovations look transformative for the future as a result of COVID-19?**
- **What will this teach us for the future of healthcare?**
- **COVID-19 Testing** – a conversation with Moira P. Larson, MD, MBA
- **Long Term Care Facilities Part One** – a conversation with Pat Merryweather-Arges
- **Long Term Care Facilities Part Two** – a conversation with Dr. Swati Gaur

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



## A Message from the Patient Safety Movement Foundation:

This month, we will celebrate the 2nd annual World Patient Safety Day designated by the World Health Organization. The Patient Safety Movement will be participating by hosting a free three-hour virtual event — [#UniteForSafeCare](#) — on YouTube Live starting at 5 pm

# Consumers Advancing Patient Safety

September 2020



(Eastern) on September 17, 2020. Our event will unite patients, healthcare workers, policymakers, celebrities, and global citizens for the common goal of discussing ways to advance patient and health care staff's safety — and what you can do to protect yourself and your loved ones. Over 1500 people have already RSVPed and we anticipate many more by September 17th.

**#UniteForSafeCare** will be celebrated globally to emphasize the importance of patient and healthcare worker safety and raise global awareness. In our recently published poll [results](#), over 79% of Americans don't know that the safety of patients is compromised every day in healthcare. Our esteemed keynote speakers include President Bill Clinton, a long-term supporter of the Patient Safety Movement Foundation; Tedros Adhanom Ghebreyesus, Director-General of the WHO; The Right Honorable Jeremy Hunt MP, Former Secretary of State for Health and Social Care, The UK Government; Joe Kiani, Founder of The Patient Safety Movement Foundation; Mary Dale Peterson, MD, President, The American Society Of Anesthesiologists; Peter Lachman, MD, Chief Executive Officer, The International Society for Quality in Health Care (ISQUA), and Leah Binder, President and CEO, The Leapfrog Group; and many more well-known leaders in patient safety. Our event will also feature entertainers, politicians, physicians, patients and family members of patients harmed or lost in the world's health care systems.

**#UniteForSafeCare** will include memorials and tributes to those who have been lost from preventable medical errors. We will celebrate those who have survived these errors, who will be sharing their stories and providing words of wisdom and tips to the public regarding how to stay safe. There will be musical performances, testimonials, and political talks about how we can improve safety in healthcare. We will reach zero preventable patient deaths by 2030, and on the way to this goal, we will also achieve a very significant reduction in preventable patient harm.

Nobody intentionally sets out to harm patients, but the truth is that hospitals are not hardwired for safe care for every patient, all the time. Improved transparency is needed. That's why we need every hospital to provide the best practices and be a high reliability organization. We can a

Mike Ramsay, M.D.  
Chairman, Patient Safety Movement Foundation  
President, Baylor Scott & White Research Institute, Dallas, TX

The poster is blue with white and orange text. It features a stylized human figure icon on the left. The main title is '#UNITE FOR Safe Care Virtual Event' with the date and time 'SEPTEMBER 17 • 5 PM EDT / 2 PM PDT'. Below this, it lists 'Bill Clinton 42nd US President' and 'Dr. Tedros WHO Director General'. A section titled 'WITH APPEARANCES BY' lists several other speakers: Senator Barbara Boxer, Senator Sheldon Whitehouse, Senator Dick Durbin, Jeremy Hunt, Leah Binder, Mary Dale Peterson, Peter Lachman, Jeff Brady, Danielle Ofri, Zubin Damania ZDoggMD, Helen Haskell, Alicia Cole, Nikki Silvestri, Belinda Carlisle, Dariush Eghbali, Stix, Sierra Mercier, Jake Lyon, Joe Kiani, Michael Ramsay, David Mayer, and 'AND MORE'. The bottom corners of the poster have decorative orange and white geometric shapes.

## The Graphics Garden:

When it comes to sepsis, remember **IT'S ABOUT TIME™**. Watch for:

- TEMPERATURE**  
higher or lower than normal
- INFECTION**  
may have signs and symptoms of infection
- MENTAL DECLINE**  
confused, sleepy, difficult to rouse
- EXTREMELY ILL**  
Severe pain, discomfort, shortness of breath

Watch for a combination of these symptoms. If you suspect sepsis, see a doctor urgently, CALL 911, or go to a hospital and say, **"I AM CONCERNED ABOUT SEPSIS."**

**sepsis.org** ©2020 Sepsis Alliance

### WHEN DO I NEED TO WEAR A FACE COVERING?

Are you leaving your house?

- YES: Will you be around people?
  - YES: Is your mask uncomfortable?
    - YES: Well, so is the ICU.
    - NO: Bring a mask just in case.
  - NO: Can you guarantee that?
    - YES: Bring a mask just in case.
    - NO: No mask needed.
- NO: Is anyone coming over?
  - YES: No mask needed.
  - NO: No mask needed.

Face Covering Needed, **COVER YOUR FACE HOLES**

SALT LAKE COUNTY HEALTH DEPARTMENT

### A special needs parent fell in a hole...

**Doctor:** Can you keep a diary of your experience in the hole?

**Local authority:** Sorry, we don't have enough money for a ladder.

**Charity:** Here's a form. Fill it out to get on a waiting list for a ladder.

**Family member:** What hole?

**Another special needs parent:** I'm here! I'm on my way down! I've been there before, I know how to get out, and I won't let you do it alone!!



thebmj Visual summary 

## “Long covid” in primary care

Assessment and initial management of patients with continuing symptoms

Post-acute covid-19 appears to be a multi-system disease, sometimes occurring after a relatively mild acute illness. Clinical management requires a whole-patient perspective. This graphic summarises the assessment and initial management of patients with delayed recovery from an episode of covid-19 that was managed in the community or in a standard hospital ward.

### An uncertain picture



The long term course of covid-19 is unknown. This graphic presents an approach based on evidence available at the time of publication.

However, caution is advised, as patients may present atypically, and new treatments are likely to emerge

### Managing comorbidities

Many patients have comorbidities including diabetes, hypertension, kidney disease or ischaemic heart disease. These need to be managed in conjunction with covid-19 treatment. Refer to condition specific guidance, available in the associated article by Greenhalgh and colleagues

### Safety netting and referral

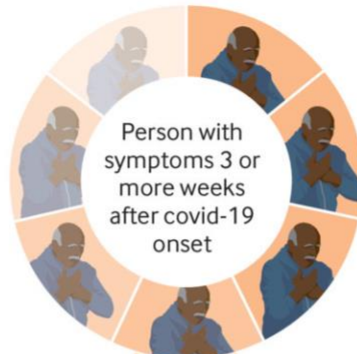
The patient should seek medical advice if concerned, for example:

- Worsening breathlessness
- PaO<sub>2</sub> < 96%
- Unexplained chest pain
- New confusion
- Focal weakness

Specialist referral may be indicated, based on clinical findings, for example:

- Respiratory** if suspected pulmonary embolism, severe pneumonia
- Cardiology** if suspected myocardial infarction, pericarditis, myocarditis or new heart failure
- Neurology** if suspected neurovascular or acute neurological event

**Pulmonary rehabilitation** may be indicated if patient has persistent breathlessness following review



Person with symptoms 3 or more weeks after covid-19 onset

### Investigations

Clinical testing is not always needed, but can help to pinpoint causes of continuing symptoms, and to exclude conditions like pulmonary embolism or myocarditis. Examples are provided below:

#### Blood tests

- Full blood count
- Electrolytes
- Liver and renal function
- Troponin
- C reactive protein
- Creatine kinase
- D-dimer
- Brain natriuretic peptides
- Ferritin – to assess inflammatory and prothrombotic states

#### Other investigations

- Chest x ray
- Urine tests
- 12 lead electrocardiogram

### Clinical assessment

**04**  
Full history  
From date of first symptom

Current symptoms  
Nature and severity

#### Examination, for example:

- Temperature
- Heart rate and rhythm
- Blood pressure
- Respiratory examination
- Functional status
- Pulse oximetry
- Clinical testing **If indicated**

Assess comorbidities

Social and financial circumstances

### Social, financial, and cultural support

Prolonged covid-19 may limit the ability to engage in work and family activities. Patients may have experienced family bereavements as well as job losses and consequent financial stress and food poverty. See the associated article by Greenhalgh and colleagues for a list of external resources to help with these problems

### Medical management

- Symptomatic, such as treating fever with paracetamol
- Optimise control of long term conditions
- Listening and empathy
- Consider antibiotics for secondary infection
- Treat specific complications as indicated

### Self management

- Daily pulse oximetry
- Attention to general health
- Rest and relaxation
- Self pacing and gradual increase in exercise **if tolerated**
- Set achievable targets

- Diet
- Sleep
- Quitting smoking
- Limiting alcohol
- Limiting caffeine

### Mental health

In the consultation:

- Continuity of care
- Avoid inappropriate medicalisation
- Longer appointments for patients with complex needs (face to face if needed)

In the community:

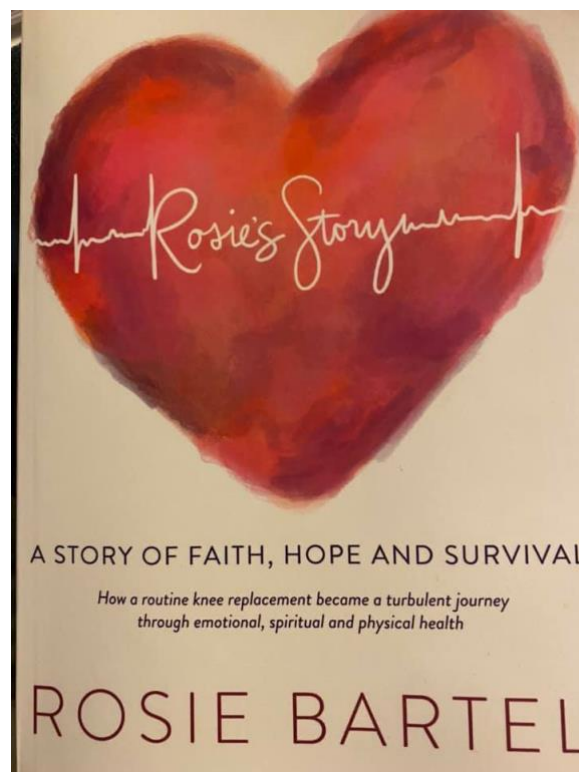
- Community linkworker
- Patient peer support groups
- Attached mental health support service
- Cross-sector partnerships with social care, community services, faith groups

## CAPS Book Club:

A review of ROSIE BARTEL's self-published book, **Rosie's Story**:  
"Friends I just finished this book and let me tell you it was truly inspirational. It's a great read and will open your eyes. It is a true story, real life and it's the life of my dear friends' mom, Rosie. If you're looking for a book that will grab you and keep you reading this is your next book." -Michelle

### Rosie shared: How you can purchase my book:

- I will mail anywhere in the world.
- Do you have a Venmo account? If not, you can create a Venmo account on the Venmo app. Once you have an account please send me your username. Then I can request the amount for the book.
- I also have a PayPal account. You can connect with it with my email, bartel1949@gmail.com or by Rosemary Bartel.
- Or you can do it the old fashion way of sending a check to me at 893 S. Irish Road, Apt. 9; Chilton, WI 53014.
- I am mailing copies for 15.00 each. If you order, please send me your address."



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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)

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*Consumers Advancing Patient Safety is a 501c3 not-for-profit organization that envisions a partnership between consumers and providers to create global healthcare systems that are safe, compassionate and just. CAPS champions patient safety led by consumers in partnership and collaboration with providers.*

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