

# BEHIND OUR SILENCE

Having compassionate conversations about #FamilyPresence in Alberta

@ChangeDayAB

@aircalgary

@Pts4Chg

# OUR MOM

- Born preemie twin in farmhouse, 2 brothers.
- Nurse then military spouse. Enjoyed travel.
- Loved family, friends, hummingbirds, & life.
- Mother of four, grandma to six. Celiac diet. Lots of other allergies. Dementia (Lewy body?) slow onset ~ 1997.
- Cycled through several family docs for diagnosis; one great doctor hung in there. Specialists, pharmacies, Home Care, Day program, Handibus, falls, surgery, home renovations, self-managed care, live-in caregiver, transition services for 2 facilities.
- First great-grandchild born just weeks prior to her death 2013.



- I usually visited mom on Wednesday evenings by myself, after work. Different staff every time, still getting to know people since mom moved from 'first available bed -100 km away' to a facility closer to home. Mom had been there only a month.
- When I arrived, I thought she'd been in an art class. It looked like charcoal on her face.
- A (brave) staff person walked up to me and said "I bet you're wondering where all the bruises on your mom's face came from? All I can say is that the bruising was unreported & undocumented".
- I later walked around a grocery store till my shock wore off and I could start phoning our family.
- After two weeks still no one in our family heard reasons, nor apology and so made complaint to Seniors Continuing Care/AB Health - no Seniors Advocate at that time.
- 5 months later, received response that cleared the facility from abuse under Act. Upon request, report chastised facility re poor (lack of continuity of) communication, amongst staff & with family, between facilities & shift changes.
- Impression that mom's aides afraid to document that she could be combative during personal care. Investigator said mom hit by metal in swing lift, during transfers. (We knew mom needed 24-hr support to safely manage both her care & dementia behaviours)
- 2012 requested a disclosure of harm meeting; politely awkward-no apology.

# SMALL STEPS CAN MAKE YOU A #FAMILYPRESENCE HERO

## **Board Members & Continuing Care leaders**

### Collaboration

Learn about the value of DUMO (Disclosure of Unanticipated Medical Outcomes) and take that training for you and your front-line managers/nurses.

Engage Family Advisors in quality improvement.

## **Site Managers, Charge or Unit nurses**

### Respect and Dignity

Please promote a trusting culture with your healthcare aide (HCA) staff. Provide extra support, and your genuine praise for their tough work. Consider simulation training with some staff who may think any mistake means a job loss. Families need your leadership to ensure HCA documentation improves; clear communication at care transitions occurs, and more rapid learning from unexpected incidents is enabled.

### Information Sharing

Sharing information frankly with our family, and apologizing about communication gaps re mom's injuries in a timely way would have prevented the breakdown of our trust in you.

## **Front-line Healthcare Aides**

### Courage to participate with family

I don't know your name or role. I will forever remember you as the only brave staff person to approach me as a caring family member, open the discussion and kindly share the facts as you knew them, with me.

### Gratitude and teamwork

I would like you to know that all of our family members saw & understood how hard you work, for so little thanks or pay. We welcomed all your news, even your bad news to us. Somehow it is validating to learn of your struggles. As family, we struggled. Our "best" was not good enough for mom's best care at home. We needed you and you were there for us. Thank you from the bottom of our hearts.