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17th National Conference on Gerontological Nursing
Theme: *"Personhood and Caring: Honouring the Older Adult's Life Journey"*

ESTHER'S VOICE: A Daughter Reflects on a Family's Journey

I am honoured to be invited to address you this morning as **Esther Winckler's daughter**. The fact that there is still interest in her story certainly validates our family's emotional and sometimes confusing and confounding 13 year journey through the Canadian healthcare system.

In fact, recently a hospital administrator who played a key role in the changes that were precipitated by our mother's case took time to write to tell us that our mother's story continues to be the beacon that guides and grounds her work in quality healthcare improvement. As an educator herself, Esther would have seen this as a fitting legacy.

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It's always hard to know how to approach the telling of this story … as 13 years seems so long ago. But in other ways, as anyone dealing with grief can tell you, at times it feels like it all just happened yesterday. I've decided to go back and give a little of a summary for those who might not be familiar with Esther's story.

And then, because this is a conference with a vision and commitment to create a different future for seniors than what our family experienced 13 years ago, I also want to move forward in the storytelling. To tell you all a little about what has transpired since Esther Winckler's death was declared by the Coroner as 'Death by Accident' following her 15 day stay at Chilliwack General Hospital from February 20th to March 5th, 2000 after elective hip replacement surgery.

Officially, the Coroner's Judgment of Inquiry concluded after thorough investigation:"Esther Elsa Winckler died on March 5, 2000 from ischemia and infarcation of the bowel and brain due to prolonged post-operative oxygen de-saturation and hypotension."

To our family, however, those findings would not come until two years and two months later. At that time in 2000, we had very limited understanding of the healthcare system and, given the longevity of most of our relatives, thankfully we had not had to deal with it to any real degree.

All we knew was that something didn't feel right and we needed to figure out what. The why would come later.

On Esther's last days -- March 4th and 5th – I left Vancouver and arrived at the hospital fully expecting to hear that she was ready to come home. This was after two weeks of some serious post-operative 'ups and downs' following what was supposed to be surgery under a spinal anesthetic, but what was contraindicated and very much against her wishes -- a general anesthetic from an anesthesiologist that didn't know her and didn't follow the pre-op consult plan. It was this decision that set the stage for the serious complications that followed.

Yet fighter that she was, Esther survived these significant post-op issues, and over the 14 days to come was making her way through the Chilliwack hospital system.

To the best of our knowledge on that day in March, things were finally looking up and we were certainly associating her progressive transfer from acute care ward, through the nursing unit, and finally to the activation ward as sign of her improving health.

Esther had entered the hospital as a lively, active, interesting and interested senior planning to take another long cruise with our father after the hip fully recovered.

She had done due diligence on selecting the hip replacement clinic going in. She had had a number of pre-admission tests and interviews and had prepared for coming home, right down to the last frozen casserole for Dad and hobbies waiting by her bedside for her recovery.

In short, Esther believed she was a pretty savvy consumer of the healthcare system, in control of her destiny, and we believed in turn this was how she would return to us.

We could not have been more wrong.

On this last day of her life, this is what I recorded in my Journal:

"About noon, I came into Ward 5, Room 535, and couldn't see her from the door. There was no medical staff around. I went into the room, rounded the far corner curtain and was met by a woman strapped into an old wheelchair, near naked, eye area bruised, nose bleeding, scabs on the side of her face, and in an extremely agitated state.

She was making no sense and was desperately trying to pick at the leather strap to get it off her stomach. She kept complaining that it hurt. It hurt. A nurse's aide came into the room and saw me and immediately started going on about how difficult my mother had been all night. How she was completely agitated and taking sheets and clothes off herself *and* the woman in the bed next to her.

In awhile, the RN came down and I talked to him in the hall. Told him that this was 100% different than the person we'd known. He said that he was glad that I had told him about her as they had no idea that this wasn't her personality.

I then took my father home as he was visibly upset and confused.

I came back to stay with Mum through the afternoon and tried and tried to find a doctor available to come and see her. The nurse's station told me that the doctors did not like to be interrupted at home on weekends…

Just before dinner a GP that didn't know her came in and patted me on the hand, told me to go home and get some rest as visiting hours were over on the activation ward ... but not before getting the signature on the 'no code' order – a decision I've had to live with for all these years, not fully appreciating the implications of the decision at the time. Esther was pronounced dead at 3 in the morning of March 5th and we were phoned and informed by yet another unknown doctor who assured us that she had gone peacefully with the assistance of morphine – this despite a known past history of hallucinations and a 'no morphine' note regarding that drug.

This was the final memory I had .. and this was the memory to last the next two years while the system investigated her death. I suspect

that there might not have even been an investigation without our insistence … and certainly the Pathology Department of the hospital seemed anxious to get us to sign off on the body.

But our family knew something was not right and we politely yet relentlessly wrote literally dozens of letters to all levels of hospital administration, government, and professional institutions to ensure that this case did not get swept under the table.

One of the head doctors at the hospital tried to reassure us that this 77 year old woman had lived a good long life (in his words). This was until he was met with our cold stares and harder-to-argue-with facts: Her brother and sisters at the time were 92, 96 and 99 years old respectively. He realized we were NOT going to go quietly into that good night. Nor was Esther, even in death.

Against all odds, two years and two months later, a diligent and meticulous Coroner published the Judgment of Findings that highlighted 15 days of specifics including: dehydration, malnutrition, fractures to the 5th, 6th, and 7th ribs from undiagnosed and unreported falls, blackened bowels from no one noticing she hadn't had a bowel movement in many many days, almost non-existent charting, little pain management, no continuity in attending physician's care, and premature transfer to a general ward while still agitated with facial droop, dementia, and inability to communicate clearly.

That was May 6th, 2002 when the report came out. On May 22nd, I woke up to a front page story with two huge internal pages chronicling our mother's case in the Vancouver Sun newspaper.

Not that much later, the first call we received was from the nurses of the then RNABC who were first to say, "This is not right; we need to face this head on, and we need to make change."

And so my friendship began with a group of the most caring nurses one could have hoped for. Nurses who dedicated countless hours of their own time to set up the Acute Care Geriatric Nurses Network and then the Geriatric Emergency Nurse Initiative – both in part as Esther's legacy.

And the collaboration with the Ministry of Health and Nursing Directorate and the Fraser Health Authority also began to take shape. All around this story of Esther.

Our family called it 'Esthers Voice' and the hub became a website that still continues today. Our family made available all of the findings, and all of the correspondence on the case freely, and we are frequently told that the site is used as a teaching tool from hospitals throughout BC and Canada. We've also received letters from nursing programs around the world including Malta and Britain

Again, the lovely irony of our mother being an educator seems to always be at work.

An excellent book by Susan McIver and Robin Wyndham called *After the Error* was also just published and our mother's story was highlighted as one of the chapters. And again, we continue to receive letters from many members of the public who found the case resonated with their own experiences.

My brother's and my heart goes out to these families. We tell them that their journey through the grief will be exclusive to them. We can only share what our journey was like taking a position of working *within* the system as opposed to against it. But this approach isn't for everyone.

My father died feeling 'not heard' and believing that a lawsuit would have been the only evidence that the system cared about Esther Winckler.

I have come to know this is absolutely not true. This despite the wall of silence that built up from the medical community from 2000 to 2002 and that continues to be maintained with the College of Physicians and Surgeons, (who on record chose to negate some of our and the Coroner's evidence) concluding simply with these words that 'It is recommended by the Committee that the degree of supervision was probably less than Mrs. Winckler required."

How truly and tragically disappointing. The College had a rare opportunity to mirror the RNABC and promote dialogue -- with no fear of litigation -- and they chose instead to take a different tact, basically saying that the family and the Coroner got many of the facts wrong.

In our family's opinion, they continue to not deal with issues like 'informed consent' or the place for family in the College's disciplinary process. We feel despair about this, but then something happens that buoys our spirits and keeps us on track.

An example is an email from a General Practitioner in the Lower Mainland who asks if she can link to our site as she wants her patients to have all the information they can so they are vigilant when navigating the healthcare system.

This is when we know we're on the right path and just have to stay the course.

We've seen positive movement in the case of both the level and knowledge of geriatric nursing in our healthcare system, and in the initiatives at the health authority level and we thank them for keeping our family in the loop.

Looking back there was no question that our mother was seen as a bed blocker by many in 2000. Most of the caregivers did not know her name. No one knew or seemed to care that the woman who came in was not the woman they were seeing in front of their eyes. They seemed to have no idea of how to identify those 'geriatric giants' of falls, delirium, dementia etc.

And to be honest, I truly believe that the system had come to a place where they didn't even know how to care anymore. Those who WERE caregivers actually needed a lot of care and support themselves to keep moving forward.

How do we know that? We heard from them. Dozens and dozens of emails from nurses who have taken time to write my brother and me. A fourth year nursing student in Courtenay, BC wrote that "Esther's case has taught me not to make assumptions about what is happening with a client, but instead rule out causes with evidence-based practice, lab tests, physical assessment skills, collaboration with other health care personnel, and with families who possess the most knowledge about their loved one." She went on to say that she feels "a great need to act as a stronger advocate for my clients and to find my own voice as a future nurse leader."

We loved that she included families and recognized our value. Families WANT and DEMAND to be involved. We are often last to be invited to the seat of the medical dinner table, but we offer great conversation and we deserve to be there. The College and even some of the Health Boards and Administrators will have you believe that we can't be invited because we don't have the credentials and might do something untoward. Like launch a lawsuit? At least we assume this is what they are fearing?

But the truth of the matter is, people who feel heard, who ARE meaningfully heard as an institutionalized part of the process, DO NOT, as a rule, sue. Especially in Canada I might add where we've learned that our mother's life would have been valued in the court's eyes at less than $7500.

Those of us families who are your clients are there to help you in a partnership around the journey of the older adult.

If there is a shortage of staff as there was in our mother's case, let us know and we will patiently sit for hours and add an extra pair of hands. We are certainly there at the end of the phone if the person is exhibiting worrisome behavior as *we* are the people that know their quirks.

We are the ones who can help you if you work to find an efficient and non-interfering way to incorporate our knowledge and concern into your daily health care plans and protocols.

In other cultures where the medical personnel are few and far between, families sit at the beds of loved ones and bathe and cook for them. While not going that far, there must be something we can do so that 15 days of hell and neglect, broken ribs, bleeding nose, dehydration and malnutrition don't become an acceptable outcome.

The adversarial climate that has been so inherently part of this system CAN be replaced with one that has words like Honouring, and Journey, and Care, and Personhood, at the heart.

This climate that has nurses afraid to 'bother' a physician at home, or that has someone stating that a 77 year old has had a 'good long life' MUST be on its way out.

This change might not be fast enough for many of us who view it sometimes as a big rusty tanker that we're trying to bring into drydock for a retrofit. But it is changing and when our family met nurses like Pamela Ottem, Phyllis Hunte, and Marcia Carr, among many others, and administrators like Cathy Weir who bravely stood up and said this must be different, we knew we could take heart.

The Fraser Health Authority has, and is continuing to put together a report on what has changed since Esther's death in our community.

We will share it with everyone on the website Esther's Voice.com when we receive it.

In the end, we are often asked what we've learned on this journey and I've never really been satisfied with the answers I quickly give to others as they sound simplistic.

So I sat down last night and really tried to summarize this journey of ours.

We've learned:

- You need to take the anger and do something forward-leaning with it or it will consume your life.
- You need to acknowledge that everyone's journey through grief is different when they are trying to make sense of an often senseless medical error … and honour their own process. There is no right or wrong way to do this 'grief thing.'
- As family, you need to view your role as worthy equals in the healthcare equation and not be intimidated by the professions and institutions. Respect them but don't hold them to untouchable heights.

- You need to really consider that the best weapon against uncaring, hurried, or even occasionally just bad medicine is public disclosure and awareness.
- You need to NOT be naïve and realize that this is a system that is like the rusty tanker and your loved one is not going into a hotel or spa. You need to document their journey and be their advocate. Ask questions and be polite. But be firm when something feels wrong.
- And above all, if I could have a do-over for Esther Winckler I would have put the picture we took of mum the day she left for the hospital over her hospital bed. The one where she is in the garden perched on a chair bossing the handyman around, and I'd have put a sign over it that said: "Hi. I'm Esther Winckler. I came into this hospital on February 20th for elective hip replacement surgery with a local anesthetic approved in my pre-surgery consult. I was gardening the day I came in, reading a novel, and planning a cruise. I'd appreciate coming out the same way." And then I'd put my family's phone number right under that.

Thank you so very much for listening to Esther's story – for many of you I know this is not the first time.

We also know there are many like us. Esther Wincker is just one story. One life. But her story shows us all that meaningful change can sometimes be precipitated by just such a simple equation.

And wherever on the healthcare continuum you are today, if you can ask yourself the question -- What am I personally doing today that will prevent a recurrence of Esther's journey? And if you can then dedicate a life of accountability to answering that question -- then our family's journey will have definitely proved that we are all on the right path.

Thank you.