



# What if the family had known more?

By Heather Ibbetson, BN BA and Linda Moss

*For Linda Moss, the 92.1 FM radio station in Southern Ontario holds a special meaning; it was one of her father's favourite channels. When her dad, Bob Wilson, became hospitalized, she brought a radio to the hospital so he could listen to his station. The radio covered up the loud noises from the medical machines and provided a better healing environment. While driving home from work, she would listen to the radio and know her dad was listening too. Today, listening to the station reminds her of her dad and of the patients and families across Canada who are coping with pressure injuries—and it encourages her to continue the advocacy journey that arose from her love for her dad.*

**W**ell-documented practices exist to detect and prevent the development of pressure injuries. Unfortunately, this information is often not passed along to people who could help patients. Frequent turning, appropriate surfaces, a healthy diet and proper skin protection are all important factors. But for fam-

ilies such as Bob Wilson's, these factors often go undiscussed and unaddressed when health professionals are focused only on treating a primary health issue. Bob Wilson's family did not learn about the risks related to pressure injury until it was too late.

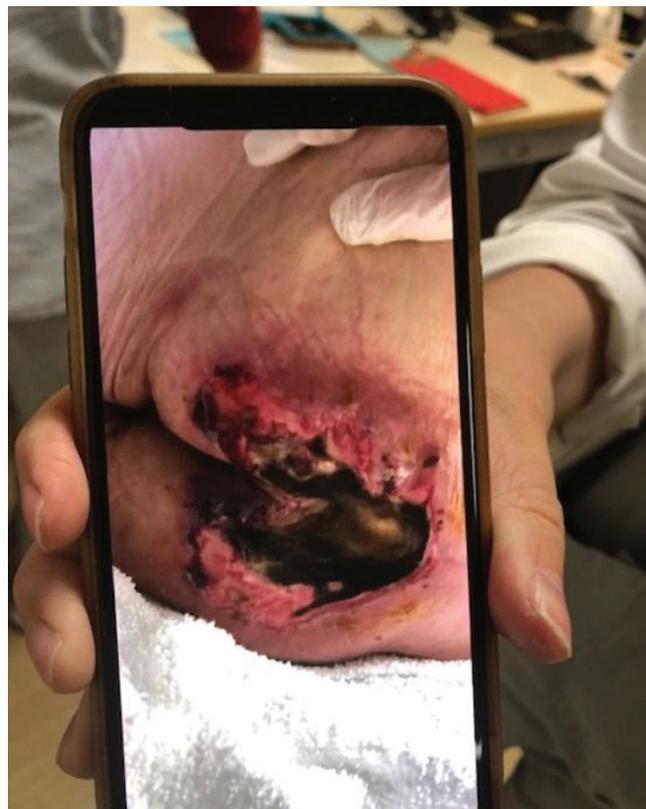
Bob Wilson was a devoted father and grandfather. He loved to spend time with his daugh-



ters, was active in several recreational sports and enjoyed vacationing in Florida. After sustaining a brain injury when falling down the stairs taking out the recycling, Wilson had successful neurosurgery and was then transferred to a second hospital for rehabilitation. For months, his family was notified only about his neurological progress, the primary reason for his hospitalization.

One day, the family noticed a nurse preparing for a dressing change and asked what was going on. They were told that Wilson was beginning to develop a wound, and that it was approximately the size of a toonie. The family was reassured that the health-care team was taking care of it and so focused their attention back on his brain injury. This was a missed opportunity to educate the family about the dangers of pressure injury and have them participate in the care plan.

The family did not hear about the wound again until Wilson was transferred back to the first hospital for a skin flap procedure. After he had been transferred, his family was notified that he was both septic and emaciated. They were called into



**Figure 1:** Image of Bob Wilson's unstageable pressure injury from the surgeon's phone

a meeting. According to Moss, “the surgeon told us that the surgery was now cancelled and she showed us a picture of the pressure injury she took from her cell phone” (see Figure 1).

Moss and her family felt shock and heartbreak. The family had been grateful early on for the care Wilson received at the second hospital but could not understand why they were not notified about the growing severity of the wound until he had been transferred.

While the health-care team implemented different treatment plans, the wound continued to deteriorate. After a month back at the first hospital, Wilson and his family learned that the ulcer had progressed into bone and bloodstream, causing osteomyelitis. Shortly after, his family learned there was nothing else the health-care team could do aside from palliative care.

*“Wounds are a silent killer . . . and as his daughters, we weren’t going to look under the sheets.”*

*—Linda Moss*

### **Sharing Their Story**

Moss and her family decided to speak up after seeing the picture on the surgeon’s phone. They felt like they needed to share Wilson’s story and educate others. Moss and her family continue to hope their story will prevent another family from going through the shock and heartbreak they



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**Figure 2:** The pressure injury following debridement. The wound had started to improve, but at this point it was too late.

did. They also made the decision to share the photograph of his wound. The photo was highly impactful and went viral online. The devastating reality of the photo has helped others understand the severity of pressure injuries and the importance of acting to ensure something like this never happens again.

### For Families

Moss has connected with families across the country who are going through a similar journey. She has created a Facebook social media page called Wound Care Aware to help provide information and support. Participating in these spaces allows families to express their feelings and find support. She has also been an advocate for various committees, public speaking events and webinars, and she recommends that other families become involved too. These activities provide a means to raise awareness and promote self-healing.

Moss encourages families to:

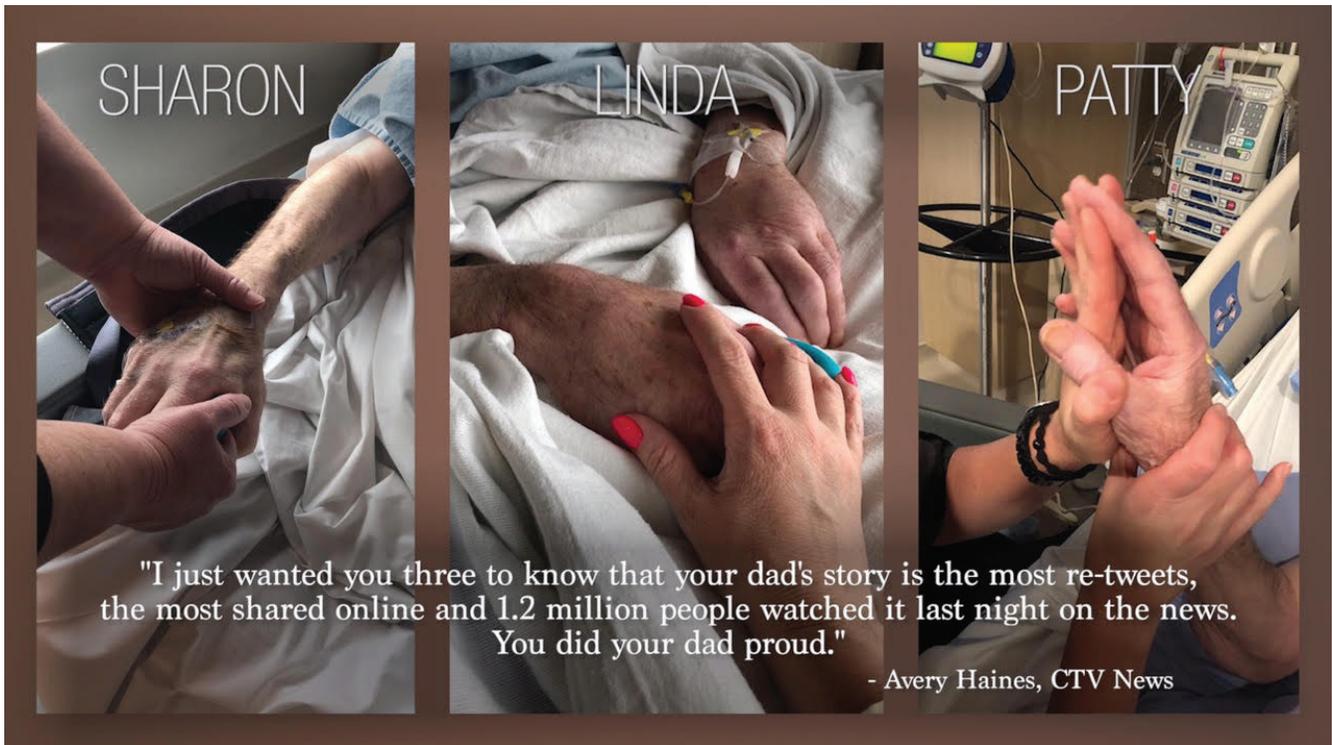
- Ask questions and become a part of care planning. From firsthand experience, she understands that families want to help but may not

know how to get involved or may feel they may get in the way.

- Be present, when possible, when physicians are making rounds. It can be difficult to get time with the physician, but families should not be afraid to request a meeting or ask questions.

*“It hit us like a hammer . . . We were there every day and some days for five or six hours a day. We were told the bed was moving him, and we rarely saw him being turned. We could have helped turn him. When I think about the times when he held my hand really hard, or when a tear came down, was that his way of telling us something was wrong? He couldn’t talk. We were his voice but we were unaware what was festering under those sheets. This is something our family will live with—and it haunts us.”*

- Ask about medications or treatment, and document everything. The health-care team may not be able to disclose everything, but it is important to ask anyway.
- Find an advocate, if one is available, at the hospital. Patient and family advocates can help



bridge the gap between the family and health-care team.

- Remember that Communication, Comfort, Companionship and Champions are essential in Care.

### For Health-care Professionals

Moss emphasizes that the staff were kind and professional during their interactions with her and her family. However, the prospect of a deteriorating pressure injury was never mentioned. When reflecting on her interactions with the health-care team, she has some suggestions that may ensure families are better informed.

- Present information to patients and families upon admission on associated risks to hospitalized patients for conditions such as pressure injuries. This information can help prepare and guide patients and families during hospitalization.
- Share with patients and families on a timely basis information on the patient's current health status, including primary and secondary concerns. In Wilson's case, it appeared that each health-care professional assumed another per-

son had or would inform his family about the wound. It is important to reach out to family members, when appropriate, and provide them with a full understanding of the situation. Barriers to information sharing can be challenging for health-care professionals to navigate, so it is important to understand what can and

*"The most painful thing was watching him pass away in front of us and knowing that we didn't have a chance to try and save his life."*

cannot be communicated. Health-care professionals should also advocate for policies that are inclusive of families.

- Provide the family with care-related tasks to help reduce the workload of health-care professionals. Families often want to help but feel

unsure of how. In Wilson's case, he could not speak or press his call bell. His family would assist with providing whatever he needed, such as warm blankets and entertainment. Moss and her family were present each day and could have done more had they been taught what they could do and how to do it, such as help turn her dad and attend to his other needs. She notes that families do not require a complex understanding of the situation to participate in the care. Explaining broad concepts is enough.

- Include families in the care planning process. At minimum, families should be notified of the care plan upon the first week of admission.
- Refer patients and families to advocates and social resources. These resources can help families navigate the health-care system and improve their health literacy. This could be included during onboarding.
- Facilitate transparent and effective communication so health-care professionals and families can work together on creating and implementing a care plan to benefit the patient.

## For Policy Makers

The prevention and treatment of pressure injuries requires change at all levels, and governments and policy makers are essential change agents. Moss and her family noticed drastic differences between hospitals regarding the protocols and procedures for pressure injuries. One hospital made sure that Wilson was constantly on an incline to reduce the risk of aspiration; however, this position also limited his ability to be turned and added more pressure to the wound. Another hospital followed a position-rotating schedule to ensure that the pressure was redistributed away from the wound.



After seeing these differences, Moss recommends that:

- Standardized pressure injury prevention and treatment based on best practice must be implemented in all settings and supported by policy.
- Each hospital and long-term care facility should have a wound specialist available along with a visible pressure ulcer prevention chart.

After Wilson's story appeared in various media outlets, the second hospital hired onsite wound care spe-

cialists. But it shouldn't have taken a story like Wilson's to spur the needed changes.

Just as 92.1 FM reminds Moss of her father, we must also be reminded that we each have a role to play in preventing potentially fatal pressure injuries. Families, health-care professionals and policy makers can all work to achieve better outcomes for at-risk patients. Linda Moss and her family continue to advocate for Bob Wilson and other at-risk individuals, raise awareness and heal. 🩹

Linda Moss participated in a discussion panel for Canadian Patient Safety Week in late October 2021. This year's theme was about patient engagement and partnerships for safety, with a focus on essential care partner programs. There is clear evidence that the presence of essential care partners benefits care, experiences, safety and outcomes. Guidance and evidence about essential care partners will be shared with health policy implementers, patients and essential care partners to make this process better understood.

**#EssentialTogether**  
**#StopPressureInjuries**



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manage what  
you can't see.*

*Il est difficile de  
gérer ce que l'on  
ne voit pas.*

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