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Patient-care initiative is a success

Families included as full partners

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GUEST COLUMN

Invite families to be full partners in patient care. That's the message Patrick Conlon wants hospitals to hear after his own experience through his partner's 15-week hospitalization. Since his first guest column appeared nearly a year ago, Conlon has given Star readers occasional progress reports on a bold new initiative that's gaining wider acceptance in a system traditionally cautious about including families in the care team. This is his latest update.

Any good public speaker knows you can always tell if you have your audience's full attention just by being alert to some obvious signs. Fainting is not on the list.

One recent afternoon Jim and I were at a large local hospital, talking about his harrowing 15-week illness and about how I became an active contributor to his care as his long-time partner. Out of our positive experience in a health-care system that takes a lot of knocks, we were there to advocate a new initiative that formally writes every willing family into the care plan for the patient, that stops treating families as annoying intruders and starts respecting them as potential partners in achieving shorter bed stays and better outcomes. At the point in our little show-and-tell where I was recounting how the staff at Mount Sinai ICU had stepped forward to help Jim past his fear of a necessary tracheotomy, parking their professional veneers to give him welcome personal support, a man leaning against the back wall began to slide slowly toward the floor. Then he disappeared from view.

Was it something I said?

Fortunately, he didn't have to go far for help in a room full of doctors and nurses. They moved quickly to his side and soon confirmed he'd fainted from lack of food. Several of them wheeled him out the door on an office chair and then returned a few minutes later, behaving as though nothing startling had happened. All in a day's work.

That was one of 12 presentations we've made in the past six months or so to hospitals and groups who've invited our input, all the result of my occasional *Star* columns advocating this new patient-care initiative.

We've helped make a video for Trillium Health Centre and spent time with staff in their intensive care

unit as well as in ICU at Toronto General and Mount Sinai. We've addressed groups at Rouge Valley Health System's two hospital sites, Scarborough and Ajax/Pickering, and were featured panelists at the GTA Rehab Network's annual Best Practices Day, a popular symposium that draws physiotherapists and occupational therapists from all over the region. Dr. Tom Stewart, director of critical care at Mount Sinai as well as the three hospitals in the University Health Network, recently invited us to be the first community members of Sinai's adult critical care team, a multi-disciplinary group that sets ICU policies and practices. The unit is already known for its family-friendly attitude but Stewart wants ICU to do an even better job of improving the patient experience.

We've heard from other facilities, too. The Centre for Addiction and Mental Health (CAMH) is now committed to including families in all aspects of patient care at the facility's four sites, says Family Council co-ordinator Betty Miller, and she'd like us to add CAMH to our speaking rounds. So would a senior instructor at George Brown who believes student nurses might benefit from our story. And the list of hospitals curious to know more about the initiative is starting to grow. At the rate we're going, we should be leading experts on hospital food by the end of the year.

It's been rewarding to watch the looks on the faces of doctors and nurses as they listen to Jim. He was down for the count in those early days of his illness. He was not expected to live. He's considered a win for these people, and it's touchingly obvious they seldom face walking evidence of their care and skill. Most survivors just never come back to visit, too busy racing away from an awful experience to see the value in simply acknowledging the amazing rescue work that may have saved their lives.

Most providers agree in theory that family-inclusive health care is a good thing and that it can even help ease stretched staff and budget resources. But many have difficulty actually seeing it in practice. How do you integrate family in a meaningful way? How do you quickly build a team with clear role and responsibility guidelines? Simple questions with complicated answers.

All I've done in our sessions is mention some of the chores I was able to perform at Jim's hospital bedside, cite the role I played in the clinical continuity of his care and report that staff told me he got better more quickly and went home sooner because I was actively there. But every hospital faces its own unique challenges, among them the need to examine an entrenched hierarchy that often ranks families as extras in the unfolding drama of a crisis.

Still, there's been a lot of encouraging feedback. We always allow time for questions, the part of the presentation that seems to divide those who get the idea from those who don't, and the smartest ones come from nurses and doctors who've been on the family side of the bed themselves. They know how it feels, they've experienced the ache of helplessness, and I think it makes them better practitioners as a result.

But the most enlightened comment came one day from a doctor sold on the idea. He was growing impatient with some of his resistant colleagues. "Look," he said to us, "it's really simple. We know the illness — but the family knows the patient." That's a good start to a useful partnership right there.

There's also been serious talk about the need for a conference with family-centred care as its theme, a chance for hospitals to share their practical experience with one another because there's not much out there by way of literature that grounds the concept in day-to-day reality. Most facilities are learning as they go. But Rouge Valley is way ahead of the pack in implementing the idea and is now willing to take a leadership role in convening a big round table for interested professionals.

Maybe a book could also be useful. Raincoast Books has commissioned me to write two. *No Need to Trouble the Heart* will be published next spring. That's the story of our personal journey through Jim's crisis. It'll be followed a year later by *By the Bed: Building a New Patient-Care Partnership*, and that one will gather the voices of doctors, nurses, patients and families for pragmatic suggestions on actually delivering family-centred care. Kind of an owner's manual for hospitals keen on expanding the care team.

As for the poor guy who fainted that day, his prescription was a bowl of soup. Worked wonders, we're told. Maybe it's just additional proof that healing is more than chemicals and technology.

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