

Palliation in a pandemic

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Leslie stopped me outside of Lucille's room in the intensive care unit (ICU).

"Lucille has decided she doesn't want to do this anymore. Could you go talk with her?"

I grimaced behind my mask. Practising a year into the COVID-19 pandemic was taking its toll, and energy and morale were running low in our ICU. This conversation would have been difficult at the best of times, but increasing barriers to communication with patients and families — more personal protective equipment, more patients and restrictions on visitation — made it even more challenging. Tasks that were once commonplace now felt monumental. Requests we would normally go out of our way to accommodate were met with the same response — "No." The repercussions of the pandemic were becoming obvious, and as with so many of our colleagues,¹ the word "burnout" was increasingly common in our ICU vernacular.

My suggestion that the social worker come and talk to Lucille was immediately dismissed. Lucille had a plan, and she wanted to discuss it with her doctor.

Lucille was in her early seventies and enjoyed an active lifestyle. She and her husband had built an entirely off-grid bed & breakfast that they had operated until their retirement five years earlier. Since then, they had spent their days outside gardening, walking the miles of trails on their property and visiting their (mostly) domesticated partridge named Harriett. But then everything changed. Lucille was on a stepladder, cleaning some curtains, when she fell and suffered a spinal cord injury that rendered her quadriplegic. Though she had initially agreed to a tracheostomy and chronic ventilation, she suffered from neck pain that was difficult to manage, and an unhappiness for the loss of the life she loved. She had decided

that she no longer wanted life-sustaining therapy and wished to transition to comfort care, with one condition: she wanted withdrawal of life-sustaining therapy (WLST) in the comfort of her rural home, surrounded by her loved ones and pets.

Over the next couple of days, we explored the reasons for Lucille's change of heart and whether there was anything we could add to her care plan. We consulted the pain service to see if they could manage her pain more effectively, but Lucille was resistant to using any medications that she feared would cloud her mind. Consultations with our psychiatry and spiritual care teams were offered, both of which she declined. She refused an assessment for medical assistance in dying, stating she did not want the mandatory 10-day waiting period. Lucille was steadfast in her plan to go home, and we did our best to reassure her that we would try to make necessary arrangements, recognizing all along that moving a patient home on a ventilator is a considerable undertaking and we would be setting Lucille up for disappointment if we couldn't pull it off.

Palliation at home for ventilated patients from the ICU is uncommon, but is frequently requested by patients and their decision-makers when discussing end-of-life care.² When given the choice, patients who are terminally ill prefer to die at home, and families report higher satisfaction with care, support and respect for cultural and religious beliefs when WLST occurs at home.³ Data on ventilated patients taken home for WLST come mostly from case reports, highlighting that this approach is possible, but is beset by logistical challenges and a lack of guidelines.³⁻⁵ These challenges are now further exacerbated by the COVID-19 pandemic. Respiratory therapists (RT) are indispensable in busy ICUs. Paramedic services cannot commit to nonurgent

ambulance transfers. Public health restrictions limit travel, cap the number of people who can gather indoors and outdoors, and impose rules for masking and social distancing.

Despite the obstacles, this act of altruism struck a chord with our ICU team. Committing to this effort turned out to be what we needed to overcome the pandemic slump from which we were suffering. For the next six days, the ICU was a flurry of activity: compiling lists, gathering supplies, organizing any intervention that would make the trip comfortable and dignified. A small army of staff contributed, even volunteering to accompany us on their day off. The hospital gave us all the equipment we needed and arranged a patient transfer. The RTs taught us how to troubleshoot the ventilator and wean the patient without setting off alarms. Our pharmacist arranged all the medications. Lucille's family doctor joined the effort and set to work to arrange all of her home care needs, including palliative care nurses and equipment, so he could assume care once the ventilator was removed.

Seven days after her request, the staff bathed Lucille and got her ready for her trip home. The halls of the ICU were lined with well-wishers who were grateful to have contributed to Lucille's final wish and keen to give her a grand send-off. We settled in to make the three-hour trek to her home, and though we managed to make small talk and crack a few jokes, the gravity of what we had accomplished was settling in and the emotion on everyone's faces was obvious, despite our masks.

Lucille emerged from the transport to blue skies, without a cloud in sight. She was in her idyllic garden, eyes closed and smiling, feeling the warmth of the sun on her face. Snow was melting, revealing the numerous flower beds she had lovingly tended. Songbirds feasted on seeds left on

the patio, harassed by greedy squirrels looking for a snack. Even Henrietta had begrudgingly allowed herself to be caged so that she could say goodbye. Lucille's friends lined the driveway and though the family ensured that only immediate family were in the house, it was obvious the neighbours had been there; every surface was covered with an assortment of sandwiches and baked goods. Lucille's favourite country music was playing in the background and the fragrance of dozens of bouquets of her favourite flowers hung in the air. We transferred Lucille to the hospital bed in her living room and slipped out to the patio to give the family space to visit. We sat just outside the door, and though we were no further from her bed than the desk would be in the ICU, we were miles away in terms of the care we were providing.

At the end, the remote bed and breakfast that served as a wilderness retreat was Lucille's refuge from the noisy, busy, beeping ICU. Her husband crawled into bed with her along with their dog, whispering to her and singing along to the songs on the radio. Medications for comfort were titrated through Lucille's intravenous line and the respiratory rate on the ventilator was slowly decreased, then disconnected. She was serene and quiet, and gave just the slightest shake of her head when asked if she felt short of breath. She passed away peacefully a couple of hours later.

The benefits of WLST at home for Lucille and her family were obvious. She was able to die in her home and have control at the end of her life, control that her injury had otherwise stolen from her. Her family was grateful for the opportunity to spend a precious couple of hours with her that would not have been possible with the visiting restrictions in place at the hospital.

The experience also had a profound effect on the members of the ICU team. Working through the pandemic has taken a toll on health care providers; the moral distress and distance it has created resonates deeply in our daily care. This act of kindness empowered us to overcome this distance — to listen, to collaborate, to capitalize on the expertise, thoughts and opinions of our diverse group, and to build a robust multifaceted plan that focused on our patient. We were unified in our common goal and overcame the challenges

the pandemic threw in the way. After a year of saying “no,” our morale was lifted by the ability to finally say “yes.” We were buoyed by the opportunity to honour our patient's wish; however, the incentive was larger than that. In a time when compassionate end-of-life care was more challenging than ever, bringing Lucille home showed us that, although the circumstances may be different, the opportunity to bestow the empathetic care we are accustomed to providing is possible with the engagement and creative thinking of our exceptional team.

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This article has been peer reviewed.

This is a true story. The patient's husband gave signed consent for it to be told.

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