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patients first?: End-of-Life health system navigation

Andrew D. Scarffe and Paul Kirkconnell wrote this case under the supervision of Professor David Barrett solely to provide material for class discussion. The authors do not intend to illustrate either effective or ineffective handling of a managerial situation. The authors may have disguised certain names and other identifying information to protect confidentiality.

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On March 3, 2017, Russell Stewart collapsed in his retirement home, hitting his head, and was rushed to an acute care hospital in Toronto, Ontario. Diagnostic tests completed at the acute care hospital determined that Russell had suffered from a major hemorrhagic stroke. A hemorrhagic stroke was the result of “a blood vessel rupturing and bleeding within or around the brain. Bleeding cause[d] blood to accumulate around the broken vessel and compresse[d] surrounding tissue, leading to extreme pressure in the head and brain damage.”[[1]](#footnote-1)

The immediate days after the adverse event were the most indicative of a patient’s ability to recover from a stroke, and younger patients ultimately recovered more quickly than older patients due to their brain plasticity. The care Russell received in the acute care hospital was nothing short of outstanding. The staff were attentive and empathetic toward both his and his family’s needs, and they were exceptionally knowledgeable about the care plan and pathways required for patients who had suffered from hemorrhagic strokes. Despite the exceptional care, however, the prognosis was that he was unlikely to recover. The family wondered what was next.

The Patient: Russell Stewart

Russell Stewart embodied every aspect of the stereotypical farm-boy persona. One person described him as “Raymond Burr looks and a Jimmy Stewart personality.” These characteristics were instilled in Russell from his early years on the family farm, which was next to Georgian Bay in Bruce County, Ontario. True to his persona, Russell was exceptionally driven: he was a hard worker with a charismatic and humorous personality. Russell joined the Canadian Air Force, and at the conclusion of the Second World War, he found himself in the small community of Batawa, Ontario, near the Trenton Air Force base, where he entered the management training program for a local manufacturing company. Throughout his time with the company, Russell spent his energy pursuing two endeavours aside from his professional obligations: In the evenings*,* he worked toward becoming a certified general accountant, earning a gold medal for highest academic accomplishment in the province of Ontario. He also courted the executive secretary to the company president, Irene Shaw. Russell was successful in both pursuits, and he and Irene were happily married for almost 65 years.

Russell spent the better part of his professional career climbing the corporate ladder. In 1986, after a career as an accomplished international corporate executive, he retired from Nortel Networks after 37 years of service. Russell’s departure was well before the highly publicized global collapse of Nortel Networks. He had held key roles in the company as it had evolved from a local manufacturer dependent on the Western Electric Company in the United States to become one of Canada’s most successful technology companies.

In labour-management disputes, Russell had been known to side with his employees when it was appropriate, rather than just following the management line. He took it upon himself to learn some of the languages and cultural customs of his immigrant employees, he remembered and celebrated birthdays, and he made a point of always acknowledging people by name. Russell embodied the role of the benevolent patriarch within both his immediate and extended family and his many business and social circles. This was not because of a desire to be the centre of attention, as he was an intensely private individual. Rather, it reflected his innate and genuine ability to connect with people from all walks of life and to unlock their hidden potentials.

Even in retirement, Russell was a man with a sense of adventure. He and Irene travelled the world three times over in the first decade of their retirement, before slowing down. He also had a distinguished, impeccable sense of style and took great care in his appearance—not out of vanity or elitism, but as a sign of respect for those he met with. Russell was known to attend even the most casual family functions in a jacket and tie.

Above all else, and regardless of circumstance, Russell made his family and friends his highest priorities. A net giver to society, he contributed significantly to the world he lived in. Without exaggeration, he was the embodiment of society’s hopes and expectations for its citizens. As such a person, his only wish was to be treated with the same respect he gave everyone else. Russell had lived the life everyone would want to live, and he had still more life in him. He had made plans for an upcoming Blue Jays game on Father’s Day with his son and grandchildren. But fate had other ideas.

The Son: Paul Stewart

Paul Stewart had been a senior corporate executive and a venture capitalist in the health care and life sciences industry for the past 30 years. In order to effectively grow his various corporate and entrepreneurial ventures, Paul had learned to work with various system stakeholders at all levels of government in Canada, the United States, and Europe. His decades of experience and work in health care had given Paul knowledge of how health systems functioned, as well as contacts and relationships with senior executives throughout the health care system.

As Russell’s son, Paul held power of attorney for his father—that is, he had the legal right to act on his father’s behalf[[2]](#footnote-2)—and he also had his father’s living will—a document that expressed his father’s explicit wishes in the event that he were to become ill and unable to communicate his wishes about treatment. In concert, these documents meant that Russell had entrusted his son with ultimate responsibility to determine the course of treatment that would be consistent with his wishes, and Paul felt passionately obligated to fulfill this duty. Russell and Paul had also discussed Russell’s wishes in detail before the stroke. As part of this pre-planning, Russell had specifically refused the option of tube feeding to prolong his life. These were Russell’s considered and rational personal wishes.

In the face of this family crisis, Paul was forced to juggle competing thoughts. As an experienced health system stakeholder, he was aware of the demands for acute care beds. As a son, Paul was intimately concerned for the well-being of his father. As his father’s power of attorney, he recognized the enormity of the decisions he had to make to ensure that his father’s wishes were fulfilled.

Ontario’s Patients First Act

In 2012, the Government of Ontario had proposed Ontario’s Action Plan for Health Care, which focused on creating a health system that would provide patients with better access to care, higher quality care, and better value for money.[[3]](#footnote-3) As a follow-up, in 2015, Ontario’s Minister of Health at the time, Eric Hoskins, proposed the next phase of the provincial government’s commitment to transforming the health system into one that made the needs of patients a central priority. That plan was known as Patients First: Ontario’s Action Plan for Health Care (Patients First).[[4]](#footnote-4) The Patients First plan had four key objectives: (1) improve access and provide faster access to the right care; (2) deliver better-coordinated, integrated care in the community, close to home; (3) support people and patients, providing the education, information, and transparency they need to make the right decisions about their health; and (4) protect the universal public health care system by making decisions based on value and quality to sustain the system for generations to come.[[5]](#footnote-5)

Hospital Transfers

Once Russell was stabilized in the acute care hospital, he needed to be transferred to a tertiary care facility for the prolonged hospitalization and rehabilitation his condition would require. Paul and his family had expressed their wish to have Russell transferred to the tertiary care centre that was closest to Paul’s home and immediate family. This tertiary care centre had a post-stroke care ward for highly complex patients, which meant both the hospital and the family would be in the best position to provide ongoing support for Russell during his recovery. Despite these wishes, it was communicated to the family that the provincial policy was to transfer patients to the rehabilitation hospital closest to the patient’s personal residence—in this case, Russell’s retirement home. This location, determined by policy, was not convenient, and, in this case, did not have a post-stroke care ward; rather, the chosen tertiary care facility mixed highly complex stroke patients in with general care patients.

Paul leveraged his connections within the health care system to circumvent policy and arranged for a bed at the family’s preferred hospital, thus having his father transferred to the hospital of his choice. For all intents and purposes, Paul had navigated the system to find a solution that truly put the patient first. The transfer was scheduled to occur on the morning of March 13. However, on the evening of March 12, Russell was scheduled for immediate transfer to the tertiary care centre closest to his retirement home—not the facility selected by Paul and his family. A niece, who happened to be visiting Russell at the hospital at the time, notified Paul of the pending transfer. Given only three hours’ notice, Paul was unable to stop the transfer. He was informed that “which hospital he [Russell] goes to is not a medical issue. Therefore, the well-being of the patient is no longer a criteria when evaluating how we efficiently do this.” Despite Paul’s insistence that moving his father to the alternative facility would make it tremendously difficult for him and his family to continue to provide support and care for his father—and notwithstanding Paul’s having informed the acute care hospital about the arrangement he had made with the rehabilitation hospital 10 minutes from his home, which was scheduled to occur the following day—Russell’s transfer from the acute care hospital to the less desirable tertiary care centre was completed as scheduled.

Despite his personal grief, Paul considered people without his level of knowledge and experience within health systems, without similar financial resources, and without the same access to hospital and industry executives. If he was finding the system difficult to navigate, how difficult would this experience be for someone who was less familiar with the forces at work or who was not fortunate enough to afford private assistance? Above all else, what was most perplexing to Paul was that the provincial government had recently launched its Patients First mandate, but for Russell, the experience could more accurately be described as “patients last.”

Patient Care and Coverage

What was most shocking to Paul and his wife Val was the difference in the standard of care between the acute care hospital and the tertiary care centre. Although the standard of care should have been consistent across all health care facilities, Paul and Val knew that this certainly was not the case. Upon arrival at the less desirable tertiary care centre, Russell was admitted as a stroke victim and laid flat on the bed to wait for the intake process. (Stroke patients run the risk of pneumonia if they are laid flat, and the chance of complications with feeding tubes also increases if patients are laid flat.) It was not until Val intervened and insisted that her father-in-law be raised up in the bed that Russell received the standard of care he required. Frankly, it was clear that the tertiary care facility did not have stroke expertise. The only reason Russell had been admitted to this facility was its proximity to the retirement home. How could this put the patient first? Should the quality of care and the expertise of the health service providers not be paramount? How did geographical locale trump quality of care?

This was not the only incident where the care Russell received fell below the prescribed standard. Russell’s great-niece, Jackie, who worked in an emergency ward on the east coast of Canada, flew to Toronto at her own expense to be with her Uncle Russ and ended up working alongside the nursing staff. Jackie’s actions highlighted her commitment to ensuring her patient received the highest possible standard of care and exemplified the love and loyalty the entire extended family had for Russell.

In an effort to compensate for the inadequate care, both Paul and Val, supported by Jackie, worked to learn about standard of care best practices so they could insist that Russell receive the highest standard of care. For example, Val noted an incident where Russell’s nurses were administering an antibiotic through his feeding tube, which was considered the standard of care. However, the attending nurse did not flush the feeding tube with water prior to or after administering the antibiotic to ensure the antibiotic could enter his stomach successfully, and this was not consistent with the expected standard of care. Although Val was able to successfully ensure that Russell’s tube was flushed with water both before and after future administrations of food or antibiotics, she was acutely aware that she had to be careful not to alienate the nursing staff.

Jackie and Val were effectively providing standard-of-care guidance to the nurses, some of whom were appreciative and some of whom were not, and this created a stressful diplomatic challenge for the family. As Val noted, “When nurses are angry, they can be very harsh. . . . They are rough . . . they’ll go through the motions, but it’s much different than when they are not. . . . When they aren’t angry, they’re just jerky, meaning their movements are jerky, which can be very dangerous.”

Although Paul and Val dedicated an inordinate amount of time to Russell’s care, their personal and professional obligations meant that they could not always be at the hospital to oversee the care Russell received. On a fundamental level, both Paul and Val believed, as Val said, that “if we had not been there, they would have left him flat, with oxygen, and not attended to him all night. I truly don’t believe they would have gone into the room.” Moreover, because nurses worked on a shift-based work schedule and physicians (residents) rotated through different units within the hospital on a regular basis (weekly, in Russell’s case), there was no way to establish consistent continuity of care.

Data management, and therefore Russell’s prognosis, was a constant source of anxiety for the Stewart family. Beyond the difficulty of having Russell’s medical records transferred from the original acute care hospital to the tertiary care hospital, the constant turnover of staff (both physicians and nurses) placed tremendous strain on Russell and his immediate family. Because resident physicians and attending consultants tended to rotate almost weekly, and allied health professionals such as nurses often worked in rotating shifts, it was difficult for Russell and his immediate family to keep track of who was providing care. This turnover of providers also often resulted in repeated tests and/or conflicts in Russell’s prognosis.

Each new doctor came with a different prognosis and therefore different information for the family and different standards of care. Russell’s prognosis could change dramatically after only days, when there was no evidence that Russell’s actual status had changed that dramatically. On several occasions, Paul was given conflicting prognoses; the grimmest prognosis was that Russell had weeks to live, and the most optimistic was that Russell would have another 18–24 months.

Moreover, much of this medical opinion seemed to be guided more by doctors’ individual belief systems than by Russell’s actual situation. For instance, one doctor suggested that Russell only had 6–12 months to live, which opened the door to the possibility of more aggressive pain management. However, the next day, a new doctor, who clearly opposed aggressive pain management and the palliative care[[6]](#footnote-6) option, simply changed the prognosis to 18–24 months, which limited Russell’s access to a whole range of pain relieving medications and procedures that could otherwise have been used. It was apparent that Russell’s health status had not changed dramatically enough within 24 hours to merit such a vastly different prognosis. Rather, the change was symptomatic of the uncertainty surrounding Russell’s prognosis, which perhaps resulted from the continual rotation of attending physicians and their personal biases regarding pain management protocols. Moreover, there was no check in the system to force any consistency; each physician was free to render their own opinion and, subsequently, to prescribe care for Russell that was completely unencumbered by the actions or prescriptions of the previous doctor.

As one might imagine, this took a tremendous emotional toll on Paul, Val, and the entire Stewart family, and it affected the long-term care plans the family would have to make for Russell. If the prognosis were only a couple of months, the Stewart estate might be able to compensate for the extraordinary costs of privatized care, whereas if the prognosis were 18–24 months or more, the estate would not be able to cover those costs and also support Irene for the duration of her life.

All of these challenges in the standard and continuity of Russell’s care led to the family’s decision to invest in a Home Instead[[7]](#footnote-7) nurse. Paul and Val hired a nurse to complement and augment the care Russell was receiving in the hospital; this cost them approximately $6,000 per week.

Interestingly, many of the floor nurses at the hospital were truly appreciative of the additional support from Home Instead. The nurses were stretched well beyond their capacity by Russell’s needs, which were acute compared to those of the general care patients, and they appreciated the extra help. The Home Instead nurse represented extra staffing, which the nurses thought was clearly needed to support Russell, and which simultaneously freed them to support the needs of other general patients on the floor, whose care was all they were actually staffed for. In hindsight, this demonstrated that a roving nurse dedicated to patients with high needs, or a step-down unit,[[8]](#footnote-8) might provide flexibility in staffing, especially in hospitals without specialized acute care wards.

Enabling Caregivers as Part of the Care Team

Due to the frequent turnover in physicians and allied health professionals, Paul and Val frequently found themselves caring for Russell in his declining state of health. Of course, it was not possible for Paul and Val to tend to Russell every minute of every day, so to minimize the impact on Russell’s care, Val took to writing notes for Russell’s care team, reminding them, for example, that he was to remain elevated. Val even left her personal cell phone number for the care team so that they could call her if they had any questions about the proper care protocol for Russell.

Before Russell was transferred to the less desirable tertiary care facility, he had seen a continual flow of occupational, motor, physical, and speech therapists to accelerate his recovery from the stroke. Knowing that Russell was a goal-oriented person, this integrated care team of physicians and physical, occupational, and speech therapists created a list of tasks that Russell needed to complete to accelerate his recovery. While Paul and Val were led to believe that the improvements they were seeing in Russell’s physical state were critical to the care he would receive at the next facility, they later found that the real purpose of this intensive intervention was only to stabilize his condition so that he could be moved to the next facility. Moreover, when Russell was finally moved to the next facility, there were no social workers present to explain the transfer process or next steps to Paul or Val, and there were no occupational, motor, physical, or speech therapists to provide the standard of care necessary for Russell’s recovery. This left Paul and Val feeling vulnerable and unsure of what to expect next. Their feelings of vulnerability were exacerbated when, upon transfer to the tertiary care facility, Russell was left waiting in a hallway for three hours—needing antibiotics and needing to be changed—before he was seen by an attending physician, at Val’s insistence.

After the transfer, Russell was fortunate that he had a loving family who could surround him with supportive care while he was in the tertiary care centre. Paul, Val, and other family members took turns staying at Russell’s bedside in eight-hour shifts. This added to the attention he received from the Home Instead staff the Stewart family had hired to complement the medical care Russell was already receiving in the hospital.

What was heartbreaking to the Stewart family was the knowledge that the individual in the next bed in Russell’s shared room, who had a similar prognosis, had just one son, who was trying, all on his own, to provide the same level of 24-7 care as Paul, Val, and their extended family. This young man was effectively living in the sleeping chair next to his father’s bed. Although his efforts were admirable, Paul and Val knew this must be taking a devastating toll on this individual, and they wished he had the same support system Russell had created.

It quickly became apparent during Russell’s hospital stay that it was atypical for family members to provide the level of complementary care that Russell was receiving. However, it was abundantly clear that without the level of oversight Paul and Val provided, Russell’s care would quickly deteriorate: medications would be missed, adjustments and bed positioning would be inaccurate, and Russell might not receive the standard of care he required. This ultimately placed Paul, Val, and Russell in a difficult situation; they wanted Russell to obtain the highest level of support and care, but, at the same time, they felt that their presence was alienating some of the health service providers.

Advanced Medical Directives

Russell, anticipating that his health would eventually decline to a state where he would no longer be able to make his own medical decisions, had given Paul power of attorney and had prepared a living will with advanced medical directives that explicitly said that he (Russell) did not want a feeding tube administered in any scenario.

Russell had contemplated his personal mortality well in advance of his stroke. He had not contemplated this out of despair, but rather as a man of Christian faith; he knew that, like everyone else, he would eventually succumb to an aging body—a body canvased with sun spots, wrinkles, and laugh lines, all signs of a life well lived. Being aware that he was mortal, Russell wrote a draft of his own eulogy for Paul. Paul, of course, was allowed to make minor adjustments and revisions, but it went through scrupulous rounds of editing by Russell first. This careful consideration illustrated that Russell was aware of his own mortality, which further substantiated the importance of his advanced medical directive and confirmed his capacity when he had made those decisions. It also emphasized his detail-oriented nature; he left nothing to chance, including his own eulogy. That is to say, he would not have made the advanced medical directive to not receive tube feeding lightly.

The challenge of this situation was that the health team providing care for Russell when he was initially deemed ineligible for palliative care adamantly believed that he needed a feeding tube. When the lead physician approached Paul for permission to administer the feed tube, Paul explained that he had been given explicit instructions from his father: under no condition was he to be administered a feeding tube. Yet, rather than abide by Russell’s living will and advanced medical directive, the physician responded that because Russell still retained cognitive ability, the living will, advanced medical directive, and Paul’s status as power of attorney had no authority—even though Russell had explicitly told the physicians that Paul was empowered to make all medical decisions on his behalf.

Russell’s attending physicians then attempted to coerce Russell into receiving tube feeding, and these actions were based on personal belief as opposed to medical evidence. The coercion by the physician at Russel’s bedside was witnessed by a family member, who immediately telephoned Paul, who was in another part of the hospital. When Paul arrived, Russell was visibly flustered and confused, but relieved that his son was now there. Demonstrating some level of cognitive ability, Russell made it clear, in no uncertain terms, that Paul was to have the last word on all future care directives.

The Great Escape

Above all else, what Russell wanted was the opportunity to visit Irene back at the retirement home. After almost 65 years of marriage, Russell’s prolonged absence from Irene was having a noticeable effect on his morale; he missed Irene dearly. The attending physicians agreed to arrange transportation for Russell to visit Irene at the retirement home under one condition: that he consent to receiving a feeding tube. The attending physician who had tried to coerce Russell said that it was medically necessary for him to receive the tube in order to go.

Based on what he had been told by the attending physicians, Paul told his father that he would have to consent to the tube in order to see Irene again. Because of this requirement and his desire to put family and Irene above his own well-being, Russell consented to the feeding tube. Paul signed the paperwork authorizing the feeding tube in order to make possible what the Stewart family referred to as the “great escape”—Russell’s visit to Irene in the retirement home. Once the paperwork was on file, Val coordinated with the hospital floor staff, transportation services, and retirement home to arrange the visit on Saturday, March 18.

However, Paul discovered that Russell was scheduled to get the feeding tube on Sunday, March 19, rather than before leaving the hospital to visit Irene. Upon further investigation, Paul was told by floor staff that the tube was in fact not required for the “great escape.” The doctor had lied to Paul, who had in turn lied to his father on the basis of that misinformation, thereby getting his father’s consent; further, he had signed paperwork that explicitly contradicted his father’s wishes.

Paul tried to stop the administration of the feeding tube, but the paperwork was signed, and there was no one on duty on the weekend who would or could deal with the issue; the attending physician who had signed the paperwork declined to make herself available. (Technically, she was no longer the attending physician on the ward, as her rotation to her next assignment had commenced shortly after she signed the paperwork at the end of the day on Friday.) Russell was “conveniently” first on the procedure list for Monday morning, and the new physician would not see him until noon on Monday.

As her last act on the ward, the previous physician had put the bureaucratic machine in motion and then left it on “automatic pilot”—and there was no one with the authority to turn it off until it was too late. Having dealt with the physician’s coercion, the family felt strongly that she had used passive-aggressive tactics to enforce her will on Russell and the family and then had avoided all accountability and responsibility. The family’s subsequent attempts to follow up were thwarted, and, frankly, the family had other issues to deal with concerning Russell’s future.

Rehabilitation Plans

Once the feeding tube had been inserted, Russell’s life expectancy nominally increased. Of course, his quality of life was significantly diminished, but, without consideration for Russell’s quality of life, his prognosis by the newest physician was an additional 18–24 months or more. Yet Paul was concerned about the level and quality of care his ailing father was receiving in the hospital. Notwithstanding their experience in the industry (Paul was knowledgeable but certainly not a medical professional), Paul and Val often felt unsupported in understanding the medical professionals’ prognoses, which seemed to be based either on the physicians’ personal belief systems (which were distinct from Russell’s) or on desires to meet the institution’s immediate needs at the expense of Russell’s well-being. In addition, individuals at the tertiary care facility had noted the presence of Home Instead staff, and Paul believed they had concluded that he had the financial means to support Russell in a private care facility. Paul felt that privatized care facilities were now being pushed on the family as a better option for Russell, in an effort to free up bed space.

The countervailing force against privatization was Russell’s retirement residence, which wanted to terminate Russell’s existing apartment rental contract. His old contract had considerably better terms for the tenant than newly signed contracts, so the retirement residence was keen to terminate Russell’s contract and replace him with a higher-paying new resident. The residence claimed that provincial legislation required residents on feeding tubes to have 24-7 nursing care, which would have driven Russell’s residency costs to $700,000 per year. Paul’s mother was already receiving care at a cost of $150,000 per year. The combined total cost of $850,000 per year for privatized care would have completely depleted Paul’s father’s financial resources.

The hospital disputed this interpretation of provincial regulations, saying instead that nurses were only required at feeding time and that the retirement home was intentionally inflating the price to force Russell out of his room. This interpretation (i.e., the cost of the retirement residence plus two to three hours of nursing care per day for feeding) would have dramatically reduced the cost to an estimated $200,000 per year. Yet there was no accessible way to resolve what provincial regulations actually required, and while Russell and Irene had amassed a sizable estate through Russell’s successful corporate career and a lifetime of living well below their means, that estate had been earned over 30 years earlier, and inflation had subsequently reduced its purchasing power significantly. Moreover, since the estate also had to continue to support Irene, who was in relatively good health, into the foreseeable future, the private option was considered financially unsustainable, as it would use all of their resources in less than two years.

The hospital and the retirement home held a conference call where, rather than agreeing to steps to determine the reality of the provincial regulations, they simply agreed to disagree. Despite Paul’s experience in the health system, he was not familiar with the provincial policy, as it related to nursing and staffing requirements for patients with complex conditions such as Russell’s. Further, it became clear that neither the hospital nor the retirement home actually knew the policy or was willing to invest the time to investigate it. Once again, Russell was being treated as a burden to be passed around, based on the needs of the respective institutions.

While the specific provincial legislation regarding tube feeding and nursing service requirements in retirement homes could not be found or provided to Paul, what was known was that a nurse would be required at feeding time. If Russell were under the care of a community care access centre (CCAC),[[9]](#footnote-9) the service provider would need to “be available 24 hours a day, 7 days a week to provide Nursing Services to Patients accepted by the Service Provider through the acceptance of a Service Request.”[[10]](#footnote-10) The distinction between “available” and “on-site” was pivotal to this discrepancy. According to Ontario’s *Long-Term Care Homes Act, 2007*, “every licensee of a long-term care home shall ensure that at least one registered nurse who is both an employee of the licensee and a member of the regular nursing staff of the home is on duty and present in the home at all times.”[[11]](#footnote-11) Further, whether the CCAC could have complemented this service, or if the retirement home’s nursing staff would have been sufficient, was also a point of contention.

Paul had also been deceived by the social workers who were assigned to Russell’s case. While he had been led to believe that the social workers were there to support Russell and his family, Paul discovered that the social workers’ motivations focused more on “bed management” (i.e., maximizing patient throughput and minimizing patients’ length of stay to theoretically reduce overall costs to the hospital). These priorities became more apparent when a social worker assigned to Russell was overheard saying to other hospital staff, “I want this sack of potatoes moved out of my hospital as soon as possible.” It was clear to Paul that there were competing incentives and motivations at play, most of which were not consistent with the “patient first” mandate. In the words of one observer, Russell had become a burden with his varying prognoses, and a bureaucratic game of musical chairs was underway in which each respective institution worked to make sure it did not end up caring for Russell.

While the hospital was doing everything it could to get Russell out of its bed, where he was an “expensive patient” in a ward that was ill-equipped to serve him, the retirement home was doing everything it could to ensure that Russell did not return home, so that they could increase the profit margin on his room. Repeated attempts to contact the Ministry of Health and Long-Term Care or to find the specific requirements of the provincial regulations came to no avail. Nobody would talk to Paul on the record, and there was no dispute-resolution process to resolve the discrepancy between the hospital and the retirement home’s interpretations of the provincial regulations. Even if it were determined that the hospital’s interpretation was correct, there was no efficient mechanism to enforce such a finding on the nursing home or to otherwise hold the nursing home accountable. Generally, the off-the-record commentary suggested that the hospital was right and that the retirement home was abusing its position. Realizing the considerable cost of privatized care, Paul and Val were encouraged to explore publicly funded options.

Assessing the Alternatives and Access to Information

Beyond accessing Russell’s personal health information, which was subject to a number of different provincial legislations, including the *Personal Health Information Protection Act*, Paul and Val were frequently sent on challenging searches for additional information and resources that could complement Russell’s care. They were given a list of five CCAC’s in the Toronto area that would be viable options for the type of care Russell was going to require. However, the CCACs would not release information over the phone, and there was no information available online; this required Paul and Val to visit each of the CCAC organizations individually for in-person meetings about Russell’s care requirements. While this sounded like a straightforward process, Paul and Val discovered that it took three to four weeks per CCAC, including days waiting for phone calls to be returned, simply to arrange introductory meetings and that their personal schedules had to be completely flexible to accommodate the last-minute availability of the CCAC personnel.

Moreover, once the introductory meetings had been scheduled, but before they could take place, they learned that there was a six- to 12-month waiting list for patients to be admitted to one of the care facilities. CCAC personnel had no incentive to meet with the Stewart family when the waiting list was so long that there was a high probability Russell would transition from acute to palliative care before ever being admitted to the CCAC-supported facility.

Further, while Paul and Val were searching for information, they were unaware that the hospital social worker was independently negotiating with small, private nursing homes in their area—private homes that would otherwise be used for a different purpose. These nursing homes did not have the resources or the infrastructure to accommodate Russell’s acute care needs. The obvious mandate of the social worker was to vacate the bed, and she had clearly determined that having Paul and Val off doing something else would make her task of getting Russell out of the hospital much easier. Just as Russell had been moved once before to a facility with staff and resources that were inadequate for his care, the move was on to again downgrade his care—and to do so in a way that bypassed the family and Russell’s wishes—while at the same time, his needs increased.

Palliative Care

As Paul and Val struggled to find information that would empower them to make the best decision for Russell’s future care, it quickly became apparent that Russell was suffering terribly. This suffering was further exacerbated by his being forced to live in a manner that was contrary to his expressed living will and advanced medical directives, which he had only reversed so he could visit his wife. Russell was suffering and in constant, agonizing pain as a result of his rapidly deteriorating condition. On several occasions, Russell asked for pain management assistance, but the physicians refused to prescribe additional pain medication to alleviate his pain because “it could kill him.” Of course, Russell was aware of this likely outcome, but given his suffering, he was specifically and clearly asking for palliative care and pain management. It became clear to everyone that the original prognosis of 18–24 months, if realized, would be months filled with excruciating agony and was the least desirable outcome; palliative care was needed.

The family’s initial request for aggressive pain management and palliative care was refused by the attending physician because her initial prognosis regarding Russell’s life expectancy was on the record. However, Jackie discovered a few days later that the physician had in fact instructed the nursing staff to commence palliative care for Russell without consulting Paul or Val. She had apparently determined that her prognosis regarding life expectancy was too long and, without changing the record and having to justify the change, had commenced de factopalliative care without involving the hospital’s palliative care health professionals.

Although Paul and Val unwaveringly supported the decision for Russell to be placed on palliative care, it was their position that they should at least have been informed of the decision to shift the standard of care to palliative, and the available professional resources should have been assigned.

Next Steps

Toward the end of Russell’s life, he was no longer able to talk in full sentences, which frequently resulted in the use of adapted sign language for communication. In the brief moments when he could vocalize his thoughts, Russell told Paul, “I know you always have control of the situation and will make the right things happen,” thus signalling his confidence that Paul would do the right thing when Russel was unable to verbally express his thoughts. Paul felt that he had failed to live up to his father’s expectations in terms of managing his care and knew that his decisions would haunt him forever. Of course, Paul had done the best he could while being misled by health service providers who were supposed to be acting with Russell’s care and well-being in mind. Paul’s experiences led him to believe that the providers were focused on bed management and that many clinicians made care decisions for Russell based on personal beliefs and in the absence of supporting medical evidence. In his last moments on March 28, while tapping his heart, pointing to heaven, and squeezing Paul’s hand, Russell succumbed to his rapidly declining health state in the presence of love and support from Paul and Val, only 25 days after his initial stroke.

Russell had always been known for finding the silver lining in a situation, regardless of how bleak it may have been. If there was any way possible, Russell’s last weeks needed to be used to improve the health care system so that others would not experience the kind of non-patient-centric care he had received. The health system, in order to truly put patients first, had to be reconfigured to give everyone involved (e.g., health care providers, social workers, and related institutions such as retirement homes) positive incentives to include family members in patient care teams, and access to information had to be made available in a timely, transparent manner that was accessible to both patients and their families. The health care system needed to aggressively discourage abuse of patients’ rights through physicians’ privilege, lying, and coercion—whether perpetrated by hospital personnel or other involved institutions such as retirement and nursing homes.

In the wake of his personal experience, and acutely aware of the need for health system transformation, Paul thought about the potential for innovative solutions and wondered how they could be applied to transform the health system into one that truly put patients first. No other family or individual should have to experience what the Stewart family experienced in March 2017.

Appendix: Chronology of Events

Source: Created by the case authors.

1. “Hemorrhagic Stroke, What Is It?,” Harvard Health Publishing, July 2015, accessed January 17, 2019, www.health.harvard.edu/diseases-and-conditions/hemorrhagic-stroke-. [↑](#footnote-ref-1)
2. Office of the Public Guardian and Trustee, *Powers of Attorney: Questions and Answers* (Toronto: Queen’s Printer for Ontario, 2016), accessed January 17, 2019, www.attorneygeneral.jus.gov.on.ca/english/family/pgt/livingwillqa.pdf. [↑](#footnote-ref-2)
3. Government of Ontario, *Ontario’s Action Plan for Health Care* (Toronto: Queen’s Printer for Ontario, 2012), accessed January 17, 2019, www.health.gov.on.ca/en/ms/ecfa/healthy\_change/docs/rep\_healthychange.pdf. [↑](#footnote-ref-3)
4. Ontario Ministry of Health and Long-Term Care, *Patients First: Action Plan for Health Care*, Ontario Government, 2015, accessed January 17, 2019, www.health.gov.on.ca/en/ms/ecfa/healthy\_change/docs/rep\_patientsfirst.pdf. [↑](#footnote-ref-4)
5. “Patients First: Action Plan for Health Care,” Ministry of Health and Long-Term Care, last modified December 12, 2018, http://health.gov.on.ca/en/ms/ecfa/healthy\_change/. [↑](#footnote-ref-5)
6. Palliative care was specialized medical care for people with serious illnesses. Its focus was on providing relief from the symptoms and stress of a serious illness, and its goal was to improve quality of life for both the patient and the family. “What is Palliative Care?,” Get Palliative Care, accessed January 17, 2019, https://getpalliativecare.org/whatis/. [↑](#footnote-ref-6)
7. Home Instead was a care-giving organization that provided compassionate and reliable home care services to help keep seniors safe and independent wherever they called home. Home Instead (website), www.homeinstead.ca/. [↑](#footnote-ref-7)
8. A step-down unit is a nursing unit designated to providing care for patients who are stable enough to be discharged from the intensive care unit but are not yet ready to be cared for on a medical-surgical unit. The Free Dictionary, s.v. “step-down unit,” https://medical-dictionary.thefreedictionary.com/step-down+unit. [↑](#footnote-ref-8)
9. CCACs helped provide home care services for those recovering from illness or injury and for those with chronic illness or disability. Service providers could include case managers, community support workers, social workers, psychiatric nurses, occupational therapists, and even cleaning staff, who could visit individuals at home to provide help with daily living (e.g., meals, groceries, finances). Assertive community treatment team members could also conduct home visits. “Community Care Access Centres (CCAC),” eMentalHealth.ca, last updated March 22, 2019, www.ementalhealth.ca/index.php?m=record&ID=10462. [↑](#footnote-ref-9)
10. Ontario Local Health Integration Network, “Schedule 3: Services Schedule—Nursing,” 2014, accessed January 17, 2019, http://healthcareathome.ca/serviceproviders/en/Documents/PDF%20Cleans-Sept.%202%2C%202014/Schedule\_3\_-\_Nursing  
    \_Services\_Schedule\_%28Consolidated\_Services\_Version%29.pdf. [↑](#footnote-ref-10)
11. Government of Ontario, *Long-Term Care Homes Act, 2007, S.O. 2007, c. 8*, accessed January 17, 2019, www.ontario.ca/laws/statute/07l08#BK15. [↑](#footnote-ref-11)