

Trust after severe injury: a caregiver's perspective

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The story begins with a car accident. My wife, Lorraine, suffered a severe head injury and I, a lacerated spleen. Luckily, our two children, aged four and eight, were not injured. In the emergency department, I could see Lorraine in the opposite room through the glass. She was hooked up to a number of machines, including a ventilator. I was discharged on day 6; Lorraine remained in a coma in the ICU.

Since I was on convalescent leave, I visited her daily. A few days after admission, her neurosurgeon appeared in the doorway. Glad to see him, I walked over to talk to him. He looked at me over the top of his glasses and said, with a look of surprise and distrust, "And you are?" "I'm the lady's partner." Whereupon he replied suspiciously, "Ah, it's the first time I've seen you."

Although I was disappointed by his attitude, I asked him what areas of the brain were affected and the consequences of Lorraine's head injury. He replied, "The corpus callosum is affected, there are diffuse axonal lesions ..." and some other information I didn't understand. I insisted on knowing the consequences but he gave little new information.

That evening, I searched the Internet for information about diffuse axonal lesions and the corpus callosum, which made me even more worried. My first meeting with the neurosurgeon hadn't created a relationship. I felt he kept his distance, and I never established a relationship of trust with him throughout Lorraine's stay in hospital. However, I had confidence in the nurses, who were professional and attentive.

After a month, the head nurse informed me that the neurosurgeon wanted to talk to me. I asked my brother-

in-law and his daughter, a nurse, to be present. However, the day before the meeting, the head nurse told me that the doctor wanted to postpone it. I insisted that the meeting go ahead because arrangements involving two other people had already been made. The next day, he arrived, a little late, looking annoyed.

The neurosurgeon convincingly described a catastrophic situation.

"Forget the Lorraine you know. If she manages to get off the ventilator, she'll probably be in a vegetative state, and that's not a good quality of life." He said she had multiple axonal lesions. He said that patients on ventilators often develop pneumonias and other infections, and families tend to ask for the infections to be treated once, perhaps twice ...

I thought I knew what he was getting at, and after a few questions I ended the meeting by thanking him. Then I told my brother-in-law and his daughter that I sincerely believed Lorraine would come back to us. I later learned that the nurses and the doctor had spoken to my mother-in-law, my wife's family and even a friend to get them to influence me to "listen to reason."

Because I didn't entirely trust the neurosurgeon, and in an effort to get more information, I asked to see Lorraine's chart. It was over 12 inches thick. Not surprisingly, because I don't have a medical background, I couldn't make much sense of the notes and scribbles.

One morning when I arrived in her room, Lorraine was no longer connected to the ventilator, even though several previous attempts to take her off had been unsuccessful. No one had informed me of this very encouraging development!

A few days later, as I was taking my leave, Lorraine opened one eye, smiled at

me, raised her left arm and put her hand on my cheek! Overjoyed, I looked toward the nurses' station. No one was there! I would have liked to have had a witness. After a few minutes, she closed her eye again.

About three weeks later, I arrived at Lorraine's room shortly after my sister-in-law; as I put my coffee on the windowsill, I heard her exclaim, "She's awake!" The nurse came into the room and said matter of factly, "Yes, she's been awake since this afternoon." And I hadn't even been told!

Lorraine woke up for good, smiling and recognizing us, after two long months in a coma. Irregular and ineffective rehabilitation followed, and I felt that a rapid transfer to a rehabilitation hospital was necessary. However, it was difficult to convince the neurosurgeon to authorize the transfer; he didn't seem to believe in Lorraine's chances of rehabilitation.

Another doctor explained that it was a very important decision to transfer a patient to rehabilitation rather than to a long-term care centre, and that the professionals were not convinced that Lorraine would benefit much from rehabilitation. I understood these considerations, but I felt that it was my duty to insist on the transfer. I was convinced that we should try intensive rehabilitation rather than accept that Lorraine was going to live in a long-term care centre for the rest of her life. So I insisted, and obtained the transfer to a facility where a team of experienced therapists set about helping Lorraine progress through intensive rehabilitation.

We quickly established a relationship of trust with the physiotherapist, speech therapist, occupational therapist, social worker and nursing staff at the rehabilitation facility. Regular meetings were held with the entire team to discuss the

intervention plan and the progress made to date. We worked in partnership with the whole team. I sometimes had to express Lorraine's needs myself because of her speech difficulties.

Lorraine was granted weekend leaves and I soon realized that we would need to move to a new single-story home better suited to a wheelchair. When Lorraine's progress plateaued after six months of rehabilitation, we were told that she would soon be discharged. I negotiated an extension to allow us to complete the adaptation of our new home. All of this was done with respect for Lorraine, myself, our children and our plan, which was to move into the new home, continue private rehabilitation and live as normal a family life as possible. Although Lorraine is hemiplegic, needs a wheelchair to get around and has some speech difficulties, she is happy to be alive and to see her boys, now aged 21 and 26, evolve.

Lessons learned

I would have loved to have been able to trust the neurosurgeon and nursing staff in the ICU, but because they were not transparent with information and were dismissive of me and my wishes, I was rather wary and on my guard. In contrast, it was easy to build trust with the staff at the rehabilitation centre. The benefits of rehabilitation were immense, leading to a quality of life to which Lorraine has adapted very well.

To entrust means to hand over something precious to someone. On the other hand, trust is a spontaneous or acquired belief in the moral, emotional or professional worth of another person. It's not always easy to establish a relationship of trust, and it can be lost at any time. Once lost, regaining trust can be difficult, but it can be re-established with a genuine partnership between health care staff and patients and their families.

Health care professionals should aim for a partnership with patients and their families, respect patients' life goals, and take into account the physical and mental health of those directly affected and the needs of family members and children.

The suffering and uncertainty caused by the realization that Lorraine remained in a coma after days, weeks, a month, a second month, was unbearable for me and our children. Because I didn't feel I could trust the information I was given about her condition, the situation was even more distressing. Even though he believed Lorraine's prognosis was bleak, it would have been enough had the neurosurgeon shown compassion (i.e., empathy accompanied by a real desire to help), especially on our first meeting. Because Lorraine woke up for a few minutes after a month of coma, to me, this was an indication that there might be some chance that she would recover. It may have been perceived as not rational and logical, but it was nonetheless very important to me.

Communication and transparency are essential to creating and maintaining patients' trust in health care professionals. All relevant information about Lorraine's condition should have been communicated promptly and transparently to me when she was in a coma, and then to both of us once she had regained consciousness. Failure to communicate important information promptly undermines trust in professionals, whereas fluid, transparent and regular communication contributes to trust and partnership in care. The nursing staff were probably convinced that there was little hope of Lorraine coming off the ventilator and waking up from the coma in anything other than a vegetative state. However, they should not have talked with family members without me knowing. As Lorraine's spouse, I had a mandate in case of incapacity and was the best person to discuss the situation with our children and family.

At our first meeting, even if the neurosurgeon could not provide exact answers

about the consequences of Lorraine's head trauma, he could have explained to me that the situation was very complex and he couldn't be certain about the prognosis. My relationship with him, minimal as it was because he kept his distance, was poor throughout Lorraine's stay in hospital. I didn't trust him, although I didn't doubt his competence as a neurosurgeon. It was much easier to establish a relationship of trust with the staff at the rehabilitation hospital because Lorraine was conscious, she participated in the treatments and exercises, and we were seeing progress.

Proactively communicating good news is important as well. I had been repeatedly told that Lorraine was very unlikely to get off the ventilator. To find out for myself that she was breathing on her own was an excellent surprise. However, given how unexpected and exciting that event was, a simple call from the hospital to share the good news when it happened would have been sensitive, empathetic and a good human gesture.

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This article has been peer reviewed.

Lorraine has given her consent for this story to be told.

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