



A Mother's Letter to a Hospital CEO

(by Victoria Nahum, whose stepson Josh died from a healthcare-acquired infection)

Our son died in your hospital 7 days ago. He caught an infection there as a result of his medical care while being treated for something else that put so much pressure on his brain that it caused part of it to be pushed into his spinal column, leaving him a helpless ventilator-dependent quadriplegic and ending his short but unforgettable life among us all.

In the week since his death, the days I live have small worth to me. I am numb now. I bring my husband coffee in the morning but he doesn't smile or speak when I do; he doesn't even look at me. He sits, hands in lap, shoulders rounded, wearing a mask of pain that I have never seen before; it is not a face I recognize when he is wearing it. I wish it would go away.

His voice is low and quiet and I am uncomfortable with its somber tone. We speak infrequently lately because it feels like no good words remain for us. Our son is dead. What good thing can be spoken now?

Gentle words that others have for us fall inadequately upon deaf ears. Angry words I rehearse in my head won't help anything at all; spoken aloud they would change nothing for the better, they just sound mean, even to me. Explanations I seek out and find, full of swaggering, inflated medical terms come far, far - so ridiculously far too late.

Here, now my husband and I sit. We have too many questions and they are all useless. "**Why?**" is the most impossible one of them all. How I wish he would just stop asking me that. I have no proper answer to comfort him. I am momentarily lost.

So what then? And is it really, "What then?" or should it rather be, "**How then?**" **How then** might we prevent this from happening again to anyone, ever?

I wonder.

When our son was ill, I watched your nurses come in and out of his room by the hour and rather than just noticing random women with a regular job to do, I instead saw what angels looked like, masquerading in scrubs with name tags and stethoscopes to complete the disguise, caring for him generously and genuinely with real humanity integrated into their sense and deed of significant duty. I heard endearing compassion in their voices and saw true concern in their eyes that made me want to be like them somehow. Their gestures were warm and their care was competent. To them, our son was their own personal mission. They cared for him well; I would tell anyone – I believe they did their best. I know so.

• *I got to know your nurses. They are devastated by our son's death ... So that it doesn't happen again, I want you to empower them to save their patients with appropriate procedures and whatever rock-solid rules that they see fit to execute in the name of safer, better healthcare so they and you, may forego the sadness and futility you all must feel when a patient dies on your shared watch.*

• I spoke at length with your doctors who treated our son. I felt their frustration when their prescribed treatment did not work. I heard the disappointment in their voices when they spoke of how they did not succeed with their plan for his recovery; the failure they felt was noticeable. It hurt them to lose a patient ... So it doesn't happen again, I want you to help your doctors to achieve good, quality care with expected medical outcomes they can be proud of, even if it costs you another \$10 per patient or surgical procedure for a preventive measure or device you didn't want to pay for. In the end, the ounce of prevention costs so little in comparison to the loss of another life.

• I've listened to your administrators who seem ashamed and afraid and go blah, blah, blah, shrinking back at the issue of the death of our son. Shamelessly, instead of offering right words of authenticity and community, I hear cheap words of faked rationalization globbed in paralyzing fear. You do your hospital no good thing to allow them to act in this manner ... So it doesn't happen again, I want you to teach them to sincerely speak kind and genuine words that suggest shared knowledge of loss. Let them acknowledge fragility; perhaps even responsibility. Do not allow them to suggest that the status quo at your hospital is sufficient when our son is dead from his care. Empower your people to offer hope for a better future of proactive participation with a board of directors willing to improve care on every floor, in every room, for every patient. Demonstrate your honor and regret in appropriate amounts. Leave a significant mark in your community and make a deep imprint of high reputation and of real character that all great men and women do, as you take responsibility for deeds done under your own roof. It's called stepping up to the plate.

• I've been a patient as well as a caregiver, an advocate and family member. I've felt both trusting and helpless; I've acted as a participant as well as a bystander. I've had times when I was educated with full knowledge of an issue and I have been ignorant in my lacking of medical understanding ... So it doesn't happen again, I want you to show my family and me how we can contribute as important members of our own personal medical team so that we all, together with your staff, can effect our own best good, expected outcome. If you are unable to show us how to do that, then identify, invest in and empower those who can and do it as part of your chosen service to the practice of medicine. Respect that we can be capable, thinking, proactive partners in our own medical care instead of unsavvy outsiders who never went to medical school. Healthcare needs teamwork to work. We need to know how to "Prepare for Care" and we look to you for direction in doing that.

Dear CEO, I hope you read this letter, this PLEA FROM A MOTHER aloud. Tell your board that my husband and I do not want anything for the loss of our dear son but a dramatic and effective plan for change that will make a difference for others who trust healthcare in general and your hospital specifically. We look to you to partner with us as patients and caregivers so that we may all be safe and well, both now, and in the future.

Sincerely,
Victoria Nahum

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