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## Sick to Death

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Lorraine was a 42-year-old White female admitted to Massachusetts General Hospital for care of a deteriorating sacral decubitus ulcer. Lorraine's visiting nurse and her primary care physician felt the decubitus ulcer was getting worse because of the lack of help at home to perform dressing changes and Lorraine's worsening depression.

Lorraine's past medical history was long and complex. Some of her other diagnoses were microcytic anemia, chronic obstructive pulmonary disease, deep vein thrombosis, left above-the-knee amputation, pulmonary embolism [a blood clot in the lung], chronic abdominal pain, diarrhea and vomiting, obesity, gastric bypass surgery, paraplegia, depression, intravenous-drug abuse, polypharmacy [when a patient takes many drugs, some of which may not be needed], bacterial endocarditis [infection of the inner surface of the heart], colostomy, urostomy, and suicidal ideation and attempt. While this is not a complete list, it does exemplify how complex her medical history was. I am not sure anyone had a complete and accurate list of her diagnoses, as Lorraine went to multiple physicians, hospitals, clinics, and hospitals. She would only disclose certain aspects of her history to certain caregivers. However, as time went by during her last admission, she did disclose what seemed to be all, or at least most, of her history.

Lorraine had been on the medical service for about a month when I became involved with her care. I was asked to see her because I work as nurse practitioner on the medical team Lorraine was assigned to, and I follow the more complex patients with chronic illnesses and long lengths of stay in the hospital.

The day I went to review Lorraine's chart, she was in the hallway in her wheelchair. I quickly realized I knew her from an admission a year earlier, which was also for her decubitus ulcer and bacteremia [presence of bacteria in the blood]. I remembered that her ulcer was in fact one of the worst I had ever seen, and that she was not compliant with her care. She had been discharged home following that hospitalization and apparently had been "getting by" until this admission.

I also remembered some of the behavioral guidelines that had been put in place for her on that last admission. It was no surprise that the nursing staff on the unit now had difficulty managing Lorraine's behavior. That all being said, something happened to all of us during this, Lorraine's last admission, which changed at least my way of approaching and caring for a chronically ill patient who has behavioral issues.

Nutrition was a major focus of this hospitalization. Lorraine had chronic nausea and vomiting without, it seemed, relief from any type of medication. Since her decubitus ulcer could not heal without adequate nutrition, a gastrointestinal (GI) workup was initiated. Lorraine would not consent to the last test that was to be performed, which probably would not have changed the treatment plan, even if had been abnormal. Even without the final test, she'd had an extensive GI workup and nothing abnormal was found. Total parenteral nutrition, a specially mixed intravenous infusion of essential nutrients and calories, was tried, but Lorraine

found it disagreeable, saying it gave her a bad taste in her mouth. At times she shut it off. Lorraine was getting more frustrated with everything and everyone.

Staff on the plastic surgery service knew Lorraine from taking care of her in the out-patient clinic. They thought surgical flaps for her wound might help, but Lorraine refused to stop smoking, refused to stop sitting on her wound for prolonged periods of time, and refused to use a special bed in the hospital that would relieve pressure on her wound. The plastic surgery team did not want to do surgery if she was going to be noncompliant, which she readily said she would be. Lorraine knew throughout this last hospitalization that she could change her mind at any time and discuss surgery with the team. She opted not to change her mind, although she did see the plastic surgeons several times, which she said she did to make us happy.

As Lorraine's decubitus ulcer became even worse, it was clear we were going to reach a point where there would be no turning back. Her nutrition, even with many attempts, did not improve. Pain became a major issue, and the pain service followed her. They eventually took over control of her pain medication regime, as it became clear that we needed firm guidelines on when to increase or decrease doses of her medications.

Because of the bacterial infection in her blood, with the likely source being her decubitus ulcer, Lorraine was on a long course of intravenous antibiotics, and specialists in infectious disease (ID) were following her. Once her antibiotic course was complete, she still continued to have fevers, and questions arose about whether to start antibiotics again.

Lorraine spoke with her primary care physician, and, after thoughtful discussion, decided that if she was bacteremic again, she did not want antibiotics. She also did not want aggressive wound care. She decided she did not want cardiopulmonary resuscitation (CPR) if her heart stopped, and she did not want to be intubated if her breathing stopped.

Her decision, which on one hand I could understand, was still difficult for me to accept. Lorraine could have made different choices that would have made her life, in my opinion, easier, and perhaps would have kept her in better health. Since Lorraine had a long psychiatric history and the question of depression came up, a psychiatry consult was obtained. Lorraine declined to be interviewed in any real detail; a second consult and a third were obtained. The last consultant, after reviewing her history and speaking with her, determined Lorraine was capable of making her own decisions, including a decision to refuse treatment for bacteremia if it recurred. So, DNR (do-not-resuscitate) and DNI (do-not-intubate) orders were written.

I never doubted that Lorraine was capable of making decisions or that she knew she would be bacteremic in a matter of time. At times Lorraine seemed to want me to feel uncomfortable with the situation, at other times she seemed to want approval. I told her more than once that I couldn't make this decision for her, but since she made it, I would try to be sure she was comfortable and cared for.

Lorraine's behavior became worse before it became better. She tested everyone caring for her. At times she took her frustration out in verbal abuse, yelling, or simply not talking. At other times, she "acted out" by demanding more and more pain medication.

Every day brought a new experience for me when I went to see her. There were multiple meetings of the healthcare team about how to approach each situation. I never felt I was alone, especially since there was always an attending physician assigned to Lorraine who knew her case well. While I certainly was not running things, I became identified by the staff, Lorraine, and her family as the person who knew the most current plan.

Lorraine refused to let me talk about her condition and care in any detail with her family. While her mother and sister knew Lorraine was not doing well, that she was refusing treatment, and that she had made herself DNR/DNI, it was not easy to see them visit and not be able to talk with them about her. Lorraine said she did not want to worry them more than she already had, and that her mother was to be spared details that would upset her. Lorraine had a sister who had died a few years earlier, and she said that if she died she did not want it to be as hard on her mother.

While Lorraine had a new issue almost every day, I feel that each new thing was given serious consideration. Nothing was ever dismissed because of her prior behavior. The pain service, in particular, treated

Lorraine with respect, as did everyone else involved with her care. I developed a relationship with Lorraine in which I was the disciplinarian at times, the advocate at times, and just someone for her to vent to at other times. While it wasn't easy to learn why Lorraine acted the way she did, once I gained some understanding and especially once I gained her trust, I could see the person Lorraine was. She had interests and a good sense of humor, which was apparent when she was trying to give me a hard time about something and could not keep from laughing herself, and a love for her family that was always her focus, although it was not always apparent.

More than once I was the bearer of bad news for her, but at other times I was able to allow her to have some particular request met. Her family were strong advocates for her, and I must say, at the end, that while they may have had questions, they focused on her comfort and spirit more than on details.

After at least 14 consulting teams, numerous tests, many team meetings, tears, and laughter, Lorraine died quietly and in peace. She taught me to use all of the resources available to me, to never try to handle this type of situation alone, and that there does need to be someone involved with a complex patient who stays with the case and keeps things in perspective. I was fortunate to have a strong team of physicians working with me, teaching me how to interpret test results and challenging me to look at things in more than one way. I was also fortunate to have a nursing staff caring for Lorraine who were willing to discuss and contribute to her plan of care.

I feel I developed a relationship with her family that was built on trust and caring. It was not only my relationship with them, but the entire team, that enabled us all to care for Lorraine in a way that enabled her to die with peace and dignity.