To Die in Her Own Bed

"DO YOU make house calls?" asked a woman on the telephone whom I had not met, who had gotten my name from the County Medical Society. I did, sometimes, and after hearing about her elderly, housebound friend who lived around the corner from my office, I decided this would be one of those times. The patient, whom I shall call Alice J., was 82 years of age, arthritic with a touch of diabetes, and able to ambulate erratically, but she lived in her own home as she had done for many, many years. Her husband had died 12 years earlier; there were no children. The person who had contacted me (I will call her Mrs Rand) was an old friend who, with her husband, both about 50 years of age, looked in on Mrs J. and helped her maintain herself in her own home.

On examination, the patient was reasonably alert, with a resolving zoster of the right side of the lower face (which had precipitated my visit) and some arthritic deformities. I drew routine blood samples (with normal laboratory evaluation results), recommended a walker, and told the Rands to call me if they needed anything.

After 2½ more years passed, they did. Mrs J. was now bedridden; when I entered there was a foul odor in the room. Under her left breast was macerated, weeping skin, probably intertrigo turned to cellulitis. Her distal right foot was gangrenous and somewhat moist; some toes were black and about to drop off. The patient and the Rands expressed a strong desire for treatment at home; when I explained the possible consequences, Mrs J., although somewhat disoriented, made it clear that if death came, she wanted to die in her own bed.

I prescribed antibiotics, but she was unable or unwilling to take them. After discussion with the Rands, I got a home care nurse from the hospital to come to the house to evaluate the case and, I hoped, assist the patient, but the assessment was to hospitalize, not help the patient die at home. It did seem a few days of intravenous antibiotics and regular nursing care would not hurt, and I suggested this to the Rands, who had power of attorney for Mrs J. With marginal enthusiasm, they agreed. Their elderly friend was even less willing to go, and some subterfuge and pleading was used to get her into the hospital, for the first time in her life, "for a few days."

The Rands, whom I did not know well, struck me as self-sufficient types; they owned their own small business, and interfaced very little with the "system." Unfortunately, an entanglement awaited them beyond what I had anticipated.

Intravenous antibiotics and local care soon cleaned up the intertrigo and foul odor. Two necrotic toes autoamputated. A consulting vascular surgeon said an above-knee amputation of the leg was necessary. The patient refused.

Meanwhile, the hospital's discharge planners got involved and wrote in the chart that "considering evaluation of home condition and extensive needs of the patient at home it would be unsafe discharge plan to return Mrs J. to her previous living arrangements."

Then a psychiatrist was called to see if Mrs J. was competent to refuse her amputation. His consultation documented that "she wants to go home and die in her own bed," but he believed she had senile dementia and could not make the right decision.

Since the patient and the Rands were refusing surgery, the hospital administration had to decide how much of the establishment (eg, court orders) it wished to involve. I told them that basically the old woman was disoriented and senile but that she understood the difference between living and dying and her home and a nursing home and that she knew what an amputation actually was. I did not believe it was right to force her. We decided to have another psychiatrist see her. The second consulting psychiatrist agreed with me and believed the patient "understood the consequences of refusing surgery."

Twice before in my practice, patients (both quite competent) refused amputations. One, a 67-year-old diabetic, had osteomyelitis of a fifth metatarsal. He refused amputation of the fourth and fifth metatarsals and left the hospital. I gave him cephalexin for 3 months; he is still my patient 10 years later and is fine. The other, a 70-year-old nondia-

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betic man, had peripheral vascular disease with an ischemic foot. He refused an amputation, and 1 year later was walking reasonably well. (He has since moved.) Anyway, when a patient refuses an amputation, I do not panic. Moreover, losing her leg would pretty much commit Mrs J. to never returning home, as she lived alone.

Days passed. More toes dropped. Alice J. was now a disposition problem. The hospital's discharge planners searched for "an appropriate discharge option." Her home was considered unsafe unless a "24-hour support system" was put into place. A nursing home was acceptable to the hospital but not to the patient, who, through her confusion, remained constant on that point.

A meeting was convened with a social worker, a discharge planner, and the Rands (I sat in). Mr and Mrs Rand were informed that if Mrs J. returned home to what the hospital deemed an unsafe situation, they would turn the case over to Adult Protective Services (APS) who would then have their friend removed from her house, legally. The Rands winced visibly. In fact, I had never seen APS do much of anything. Another elderly patient of mine who lived alone with home health aides was frequently hospitalized with ecchymotic and purpuric hemorrhages (she alleged beatings); APS was handling that case and still, incredibly, this woman was repeatedly discharged home to the same environment. If APS could not relocate this poor soul, why would they whisk Mrs J. away from two people who actually appeared to care for her? However, I decided not to say anything yet.

Weeks passed. Dry gangrene spread slowly up the foot. The patient, now medically stable and decertified, was incontinent and disoriented, with a poor appetite, although always alert. The discharge planners submitted the paperwork to the Department of Social Services to arrange 24-hour home care: a licensed practical nurse 8 h/d and a personal-care aide for the remaining 16 hours. One week later, the DSS approved the 8-hour licensed practical nurse but denied the 16-hour personal-care aide. This result left the hospital with an unacceptable discharge plan, so they placed the patient on a waiting list for a nursing facility. Mrs J. still insisted on going home, and the Rands held to their promise to her: no nursing institution.

Although the Departmen of Social Services had approved a licensed practical nurse 8 h/d, no agency would supply a nurse unless the other 16 hours were accounted for (the home was "unsafe"); the Rands were unable to pay privately for such supplemental care. I did, about this time, let slip to them that I doubted APS would remove Mrs J. from her home, under the prevailing circumstances. The stalemate continued. The distal one third of the foot was gone, but there was no active infection. I asked Mrs J. if she knew who I was. "My husband?" she answered.

Then a bed became available at a skilled nursing facility 40 miles away. The Rands were informed of the hospital's intent to transport the patient "regardless of their cooperation"; they could appeal and continue the process from the nursing home. Instead, they arrived at the bedside of their aged friend, who signed herself out of the hospital, against medical advice. (She had previously been judged competent.) An ambulance, arranged by the Rands, came for her, and, after 2½ months, home she went.

We timed my follow-up house call to coincide 5 days later with the visit of the APS worker. I found our lady in bed, cheerful and alert. She seemed to have a good appetite and showed no signs of dehydration; she was no longer incontinent. I asked her who I was; "My doctor!" she replied. The APS worker, an aging bureaucrat, focused on the medical condition that resulted from the discharge against medical advice and the refused amputation. I stated that the patient appeared quite stable and in no imminent danger; her quality of life was superior to what it had been in the hospital; and quantity was unpredictable in any setting. He accepted this, and I am not aware that APS was heard from again.

Months passed. Mr Rand became my patient and came in twice yearly for his hypertension and diabetes. When I inquired about Mrs J., she seemed to be fine. About 1 year later, Mrs Rand called me to say that the old woman had developed "bronchitis" and could I call in an antibiotic? (I did.)

One Sunday afternoon, 2 years and 4 months after her extrication from the hospital, Alice J. died, at the age of 87. When I came to the house to pronounce her dead, the right foot was cleanly autoamputated halfway to the heel, and the left was beginning to show dry gangrene as she lay, otherwise intact, in her own bed.

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