

When the oncologist arrived on the unit the next morning with the signed consent forms and began explaining the new protocol to David's nurse, she

"Doctor, give him all the experiments it takes. We're not gonna let him get away."

was shocked. Sensing her disbelief, he explained: "Julie, I know how you feel about this. I know what he's been through. I don't like this any better than you do. I mean . . . what the hell am I supposed to do? He's all they've got, you know?"

Julie was rocking back and forth on her heels. She began swinging her arms. She looked at him: "You can't. Oh God, not David. Another Phase II protocol? Do you *have* to?" She was crying now: "Oh Jesus. They don't even know what's going on. Don't they know how he feels? What he's been going through? Did they even talk to him about it? He's all they've got! I'm so sick of hearing that!"

As he turned to continue writing in the chart, she grabbed his arm: "We can't. I mean, it's wrong. You can't. I mean, you're David's doctor. There's got to be something you can do. I mean . . . I mean, I'm not going to give him any more experimental poison. I'm not going to put him through any more. What about the case conference? You agreed to the new care plan, remember?" She stopped crying: "I'm not going to let this happen. He's my patient too, you know. I have the feeling *I'm* all he's got."

Sheila and Nick and the World

by Julie Heide

Is this where I'm s'posed to be at? Is this the place? You all are nurses? This guy says you wanna know how to relate to your patients better. He said he'd pay me if I came here and talked. Is that right? What do you want me to say? You know, this mighta been a mistake. I'm jus' not sure where to start.

Tell them about your experience with the Veteran's Administration. Your boyfriend Nick has been a patient at the VA. Tell us about Nick.

Okay. Nick is a United States Army veteran. He was in Viet Nam. He went over in 1966, when he was 17. He was an army paratrooper. He jumped outta helicopters into the jungle, and went on search an' destroy missions. Most of the time, Nick he wore the radio. See, that shit's heavy. They usually give it to a big man, like Nick. Course when you're carrying that shit on your back it makes you a good target. Charlie liked to knock out the radio, see—so the unit'd be cut off. They taught him to kill people—he was good at it. He knows somethin' 'bout survival. 'Lotta his buddies died. He caught a little shrapnel, nothin' too serious. Mosta his wounds is invisible.

I met Nick in 1988 when he was doing time at Lansing. This girl I was living with, her ol' man was in the pen and he asked her to get somebody to write to Nick and come out for visits. So I started writing and visiting, and 'bout a year later they let him out on parole. We been together ever since.

Nick had gone to barber school in the penitentiary. Thought he could get a license to be a barber. I told him from the beginning, I didn't think so. He's too big and he's got too many tattoos. He's a good lookin' man, but he's not exactly somebody a stranger would want cuttin' on him. You wanta see a picture? That's from back in '88. They took that picture at the prison on Mother's Day. I don't know if you can recognize Nick from this picture, he's gotten pretty skinny since he's been sick.

When Nick got out he tried to get that barber's license and then he gave up an' got him a part-time job loading boxes and running a forklift. It was a good job. We started out livin' in this one apartment. It was real nice. We had sixteen ashtrays. Had about four in every room. We had pictures on the walls. A picture of George Washington, and this one of a cocker spaniel dog standing on a red carpet. Then we had a couple a pictures of birds. I'm a nature freak. So's Nick. We're both nature freaks. We like animals, and the open sky.

It was real hard on Nick to be locked up. He don't like it when he's confined. When he had his surgery and he couldn't go outside—when you people wouldn't let him go out—that's when things was really rough. When they take yer kidney out,

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that's real painful. One of the most painful kinds of surgery, isn't that right? He had pain all the time he was in yer hospital. He just wanted to get out. That damn tube down his throat. The medicine you give that made his veins burn like fire. He didn't have a bath for three days and then I come up to the hospital and have to give hell to that one bitch nurse. When we left that night, we weren't ever comin' back.

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When I'd go visit Nick at Lansing they'd always be asking me for his number—his prisoner number. I'd say, "I'm here to see Nick Davidson." They'd say, "What's his number?" I'd say, "41756" Maybe you all should think about just giving yer patients numbers. Did you think a that? Might git things movin' 'round here, an' maybe you'd have time to give a man a bath, or help him outside for a smoke. Whatya think? My man, he's used ta being treated like a number. You all treat people like numbers, you just don't make effective use of 'em. Maybe you should think 'bout that.

I'm pretty sure some a you all been taking care a Nick. Maybe I don't know nothin'. I stayed in school thru the 10th grade—then, I don't know, I jus' kinda stopped goin'. Let's jus' say I needed to leave "home." I couldn't figure out no way to work and go to school at the same time. I didn't mind school that much. I even sang in the school chorus. Had a solo one time: "I know where I'm goin', an' I know who's goin' with me. I know who I love, and I know who I will marry." Well, I wuz better back then. Man I hope I sounded better back then. I liked singin' in that chorus. An' I was pretty good at math. Algebra. I got a 'A' in algebra as a matter a fact. How 'bout you? Did you take algebra in school? What'd you git? Did ya git a 'A'? Same as me. We're jus' the same.

Last week when Nick kept throwing up and was lookin' so gray-skinned, this guy Costello drove us to the VA. I begged him to come over an' help me with Nick. It's the only way I got him there. You think people want ta come? You think people like ta be treated like fucking cows? Tell 'em, "be at the clinic for a eight a.m. appointment," which means walkin' four blocks and takin' two buses, and then waitin', and waitin', and waitin'. I kin hardly git him to step foot on a bus. He's got so much pride, when he don't have a car that's runnin' he stays at

home. So Costello drove us up and helped me inside with him. Then a course, you told us ta wait. I sat there with him. He was sweating with fever, his color was bad. At first I kept trying to touch him, to pat his face and hand, to calm him down, an' keep him in his chair—but he didn't want to be touched. I went up ta the window. I said, "He's sick. An' we been waitin'." But you all, you didn't want ta hear that. *You don't wanna hear that.*

After somebody finally looked at him—and then sent him on ta the lab where he waited some more—at 'bout 1:00 in the afternoon he got ta his room. That nurse came in ta start his intravenous; if I hadn't been there ta hold him back, and ta say: "It's okay Nicky. I'm here with ya. It's okay,"—he woulda punched her. Hell I wanted ta punch her. He'd been there all day, jus' waitin' around. All of a sudden she's in a big fat hurry ta stick a needle in his arm. And now yer tellin' us he needs dialysis. First you take out one a his kidneys—now you say his other one's gone bad, and he may need dialysis fer the rest a his life? That he may need ta come ta the hospital two or three times a week fer the rest a his life? Come ta yer hospital fer the rest a his life?

I know what's goin' on. An' I know yer fuckin' with me. I know what is right, and I know why—I know why he suffers. . . .

If you knew him like I know him . . . you would see this won't work. This can't work. In the summertime we like ta take a few days and go out ta the lake. We sleep out there under the stars. We git away from the city, an' be in nature. Nick says it's whut keeps him goin', and I believe it. You can't make that man a invalid. He's a soldier. He needs ta be free.

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I know you don't like me. I don't look right ta you, I don't talk right. You think I don't know what I'm talking about. That I'm some cheap slut with an attitude. *Well let me tell ya somethin': when I get angry, it's not personal. This may be the only time you hear those words from someone like me. When we get mad, it's not personal. It's bigger than that. There prob'ly isn't a whole helluva lot you can do.*

He's damaged, I know that. It's not easy ta take care a him. Fer a good lookin' man he can be right ugly. I stay with him 'cause I love him, and I'm used ta takin' care a things. You all will get on bet-

ter with Nick if you explain things to him—'stead a jus' tellin' him to back up to the bars and git ready ta take his licks. You know what I mean? He's been screwed so much in his life—he's tired of it. I'll go now, I'm done.

[This story may not be used without the author's permission. Readers who want more information about Ms. Heide's work are invited to contact us at Midwest Bioethics Center.]

Stories Tell More Than They Say: Literature, Ethics and Health Care

by Alan S. Lubert

Literature reminds us that health and illness are surrounded by moral ambiguity. Fiction, drama and poetry approach health care by introducing characters who try to make sense of pain and mortality. The narrative unfolds in particular stories, we see how individuals cope with their fragility. We care about the characters, we want to understand their motivations and passions, we feel pain at their losses and rejoice in their triumphs. We see people wrestling to establish their identity, to protect their integrity, to cement important relationships. But an excellent novel or short story doesn't stop there. It fires our imagination so we can see beyond the local to the universal, we step outside the story's borders and look from a global perspective. By staying with the specific story, the narrative allows us to listen as characters answer the real challenges of illness: what does it mean to be human, how can we lead purposeful lives, what are friends for, where is our place in the community, how can we live with suffering, does God exist? Literature points beyond the immediate context and opens up the world in ways not otherwise possible. When we become angry or disappointed at what characters do, when we respect their ideals or doubt their values, we begin to know ourselves in new and unexpected ways. We read for enjoyment but often don't realize how we are transformed.

In health care today, we know how to do many interventions yet are not at all clear about why we should do them. Our technical skill outruns our moral wisdom, we can figure out *how* long before we understand *why*. People express a common fear that technology drives health care, that invasive procedures have replaced virtue and trust. Machines can be appropriate for analyzing and testing and probing, but they do not help us to understand suffering or mortality. Although as human beings our experience is embodied, we must be careful not to equate the physical body with personal identity.

Our bodies do break down, they are subject to disease; yet as self-conscious, purposeful agents we struggle to interpret our experience. Most important for moral reflection is the challenge to make sense of our suffering. We must distinguish the meaning of illness from the biology of disease. Illness disrupts our life story, it intrudes on relationships, it threatens to derail future plans. As patients we hope medical technology can solve the biological problems that have sidelined us, but as *persons* in search of meaningful lives we need moral insight into why this is happening. Unless we can share our mortality we will have difficulty connecting to one another. Illness threatens to cut us off from the community, to isolate us from human touch. This suggests that health care, when it focuses on technical intervention, is incomplete; it leaves out the uniquely human effort to make life intelligible and value-charged.

Narrative allows us to listen as characters answer the real challenges of illness.

To understand why we suffer or to grasp the importance of mortality, we must build them into the identity we are always constructing. When we picture life as a connected story from beginning through middle to end, individual actions are not torn out of context or abstracted from an ongoing history. Because illness fragments our sense that life is reasonably coherent, figuring out how to keep oneself intact presents a great challenge. Narrative

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