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In the Far Canada of a Hospital Room: The Loneliness of Dying

By Veronica Tomasic

> I'd never seen such rage in you before
> As when they wheeled you through the swinging door.
> For you knew, rightly, they conveyed you from
> Those normal pleasures of the sun's kingdom
> The hedonistic body basks within
> And takes for granted — summer on skin,
> Sleep without break, the moderate taste of tea
> In a dry mouth. You had gone on from me
> As if your body sought out martyrdom
> In the far Canada of a hospital room.
> —Thom Gunn, "Lament" (22-34)

As an attorney surrogate decision-maker, or conservator, as we are called in Connecticut, I visit clients who are dying in the intensive care units of our local hospitals. Advanced medical technology, for better or for worse, forecloses any possibility that these patients might consciously and serenely approach their final days and hours of life. It is anguishing for me to stand by the bed of a frail and helpless person who is unable to talk because of a breathing tube taped to her face and placed down her throat. Often these patients are attached to so many lines and machines that they can barely move or even turn over in their beds. They may be heavily medicated to control their pain, agitation, and anxiety. It is even worse to ponder how these experiences affect patients suffering from dementia. Do they understand what is happening to them? Are they confused or afraid? Can I say anything that would make sense and be a comfort to them?

It is an unfortunate but common result of increasingly sophisticated medical care that people die in lonely, alienated ways. "[D]rugged to oblivion" and "tethered to her pumps" as surgeon and author Atul Gawande (38) puts it, do they know they are dying? Is the agitation for which they are medicated a consequence of the helplessness they feel, bound as they are to their beds? If a patient is suffering from delusions, are they a product of the heavy medications he or she is taking, or is the hospital routine — lights always on, disrupted sleep patterns — the cause? If they are afraid, are they able to articulate their fears to anyone? How difficult it must be to die like this.

Modern medicine does wonders, but cutting-edge technology and pharmacology have their costs in human terms. In other eras people died at home, surrounded by family and friends, but perhaps needlessly or in unrelenting pain. Today a heavily medicated, technologically monitored, isolated ICU illness may characterize the final weeks and days of

many people's lives. A client of mine for whom I was a conservator, a young woman dying of AIDS, pleaded to be sent back to the nursing home where she had lived for two years, so she could die in her own bed and see for one last time her "family," other nursing home residents. Because she was subject to a complicated legal process she could not be quickly discharged from the hospital so she spent her last conscious hours of life in the ICU, tended to by strangers.

A patient need not be dying in an ICU, surrounded only by machines, to feel lonely at the end of life. Facing death transforms a dying patient's experience so that he or she will forever occupy a separate psychological reality from those who are not dying. This separate reality may be bridged somewhat by the presence in the hospital room of family and friends. Many hospitals have revised their visiting hours, allowing nearly unrestricted time for family members to sit by the bedside of dying loved ones. But even if your friends or family have spent the day with you, it must be very difficult when they leave, if you are remotely conscious or in some fashion aware of them. You may imagine that when they turn the corner down the hall their pace may pick up, they may start to think ahead to their afternoon or evening activities, and to the routine of daily life that they can take for granted and you cannot. Visitors have time at their disposal, which to them is easily expendable, but to you consists of precious moments you will not have for much longer. Being ill, when all around you are in health, brings with it a psychological exile from the "sun's kingdom," as Thom Gunn beautifully phrases it (25).

Johnny Gunther Jr.'s devoted parents were constantly by his side during the last fifteen months of his life. He suffered from a rare, aggressive and terminal brain tumor that doctors diagnosed when he was sixteen. In *Death Be Not Proud*, John Gunther's account of his son's last year of life, Gunther, a journalist, describes their family's relentless determination to find a cure for the tumor, and he portrays his son as contending with the illness bravely, unselfishly, and with equanimity.

But what a burden the illness must have been for the sixteen-year-old to bear. Despite his father's wrenching descriptions of how well Johnny was dealing with the circumstances of his life, rents appear in the narrative, revealing the boy's darker thoughts, the wistful, "'I have so much to do! And there's so little time!'" (Gunther 61). Or, "[I]t took a miserable lot out of him to pretend to ignore what he must have now known to be the truth, that he wasn't getting any better. The faraway look was in his eyes more often now" (Gunther 159).

For a patient adjusting to life with a prolonged illness, the hospital, inevitably, must undergo a subtle transformation. At first, hopeful, it is where you go to be cured. Then, gradually, the haunting familiarity of the walls, hallways, and rooms serve to remind you that you are not getting better. Gunther describes Johnny's return to the hospital after a brief reprieve for the Christmas holidays, which he had spent at home:

> I will never forget Johnny's calmness, covering over his heartbreak, as I drove him back and he limped down the long, empty corridor, and then hiked himself wearily into bed and drank some of his juices — so lonely, so alone, so unyielding, and with the hospital cold and stony and most of the nurses away for Christmas, after the warmth and lights and the presents under the tree at home. 'Well, Father,' he said at last, 'good night.' (Gunther 124)

Ideally, a hospital patient can form relationships with other patients. Such solidarity may help to ease the bitter effects of having to recognize and cope with the shadow terminal illness has cast on his or her life. In *At Night*, a Danish film, three girls in an oncology ward between the ages of eighteen and twenty bond together to try to stave off the fear, uncertainty, and loneliness they are experiencing because of their illnesses.

Stephanie has not been in contact with her parents for many years and is determined not to call to tell them she is in the hospital and very sick. Mette's parents stay with her when they can; when they are not there Mette desperately begs the staff to phone her parents to ask them to return. In response, the nurses, with a touch of exasperation, admonish her not to ring for them so often and they urge her to take tranquilizers, to help her relax and sleep. Sara, who has a brain tumor and must undergo a dangerous procedure on New Year's Day, has her father by her side, but he is grief-stricken because of her illness and seems unable to extend to her the warmth, physical closeness, and reassurance she craves. He talks to her but she wants to be held. They inhabit separate emotional worlds despite the fact they are father and daughter.

The medical staff is kind to the patients but distant. Doctors and nurses come and go in a near deserted ward, never actually talking to the girls but instead, issuing brief, declarative statements to them. The hospital walls are painted celestial blue, as if the filmmaker wanted to convey with this particular color choice the degree to which the girls are close to dying. They appear to inhabit their own world, the world of near-death. A nurse administers to one of the girls, briefly crossing over to her. She then returns to the nurse's station and settles-in with a popular magazine, back now in the world of health, of life.

The girls decide to celebrate New Year's Eve among themselves, a "VIP club . . . for people who have cancer," they decide. Their party is a brief, giddy, ecstatic, drunk-on-champagne respite from the pervasiveness of their fear and distance from others. Afterward, in the middle of the night, Mette wakes up and pleads with a nurse to call her parents, telling her that she feels "strange." Once again the nurse perfunctorily, and ever so slightly exasperatedly, urges her to take her pill. Stephanie and Sara sense, however, that something is very wrong with their friend—of course they would because they inhabit her world of near-death. They climb into bed with Mette, reassuring her that they are her mother who has come to be with her. Mette sighs with relief and falls asleep. As they all sleep holding one another, she peacefully passes away.

Wit also depicts a hospital's starkly divided reality. Vivian Bearing, an exacting, often intimidating professor of English literature, is dying of advanced ovarian cancer. Alone in her personal life, she is also very much alone in the hospital, her treating physicians enthusiastically viewing her more as a research subject than as a human being coping with a terminal illness. Despite knowing that she is a distinguished professor of literature, they talk at her, or over her to one another, as if she had a limited understanding of what they are saying to her. Ever patronizing, "in grand rounds, they read me like a book," she wryly observes.

The setting for *Wit* is a vast, efficient, cold and utterly antiseptic-looking hospital. At times Vivian's room is filmed as if natural light had never fallen within its walls; it is an anonymous space in the bowels of a building that is filled with machines and devoid of warmth and color. Busy nurses and doctors, like futuristic worker-bees, go about their work, oblivious to her. One exception is a nurse named Susie, who is capable of empathy and therefore recognizes that Vivian has feelings and emotional needs. Susie is able and willing to bridge the gap between the efficient but indifferent medical world of health and Vivian's world of illness,

fear, uncertainty, and isolation. She talks to Vivian and tries to find ways to cheer her up and to make her comfortable.

Throughout most of the film, Vivian manages to keep at bay any feelings she may have about her condition, cleverly deploying sharp-witted repartees in response to the petty humiliations and degradations the insensitive staff thoughtlessly inflict on her. But in due course, she starts to suffer the effects of the aggressive chemotherapy her treating physician has prescribed, and her use of her formidable intellect as a defense against her feelings begins to fail her. It is no accident that a framed reproduction of what appears to be Perugino's *St. Sebastian* (c. 1495), an image of a vigorous man, helpless, with hands bound behind him and punctured with arrows, is pointedly filmed on her nightstand.

Soon the pain and nausea are too much for her to bear and she becomes overwhelmed with fear and panic. Oblivious to her increasingly fragile emotional condition, her doctor, rather than acknowledging her psychological state, orders that she be given massive doses of morphine. He will not prescribe a PCA pump for her, a device which would enable her to control how much morphine she receives and when. Unable to manage the pain medication for herself, and too medicated to maintain awareness, she fades away in the face of this final aggressive treatment and never regains full consciousness.

But she is not completely alone in her final days. Evelyn Ashford, her former professor and mentor, comes to the hospital to visit her, dressed in colorful, free flowing clothes that defy the hygienic blandness of the hospital. Intuitively responding to Vivian's obvious misery — she is whimpering, bald, and breathing with difficulty — Ashford moves the rail aside on Vivian's bed and, instinctively, like the girls in *At Night*, climbs into bed with her former student. Professor Ashford, who had been as severe and exacting with Vivian as Vivian was with her students, now reads *Runaway Bunny* to her, the children's classic that is about human attachment and connection, in the tender singsong voice one associates with story-time. Comforted and at peace at last, Vivian curls up in her bed, transported to an infant-like state. Soon after, she passes away.

A hospital is like a fishbowl; it exaggerates and intensifies the differences between the healthy and the dying. With little to do but witness or be subject to illness and its repercussions, a patient is exposed, in an in-your-face way, to some of the most challenging experiences life offers: death, pain, and the terror of the unknown. But fear of death and the loneliness one experiences when ill and dying inpatient are no less relevant and difficult to cope with than when one is outpatient. Being the only one of your friends and family who can no longer take the future for granted creates psychological isolation; not only do you recognize in a very real, concrete way that your life is finite, you may also have to come to terms with the fact your family and friends will continue their lives without you in it.

In J. D. Salinger's novel *Catcher in the Rye*, Holden Caulfield's ruminations about his beloved deceased younger brother, the sensitive and brilliant Allie, form a subtext to the main narrative, which is ostensibly a tale of adolescent angst. Holden is deeply burdened by his brother's death, and his rebellious and ironic personality masks the profound depression that has followed from his traumatic loss. In what is arguably a climactic moment in the text, Holden thinks about his mother's reaction to his own death and then he goes on to imagine Allie in his grave:

> When the weather's nice, my parents go out quite frequently and stick a bunch of flowers on old Allie's grave. I went with them a couple of times, but I cut it out. In the

> first place, I certainly don't enjoy seeing him in that crazy cemetery. Surrounded by dead guys and tombstones and all. It wasn't too bad when the sun was out, but twice — *twice* — we were there when it started to rain. It was awful. It rained on his lousy tombstone, and it rained on the grass on his stomach. It rained all over the place. All the visitors that were visiting the cemetery started running like hell over to their cars. That's what nearly drove me crazy. All the visitors could get in their cars and turn on their radios and all and then go someplace nice for dinner — everybody except Allie. I couldn't stand it. (Salinger 201-02)

One can easily interpret Holden's fantasies about Allie as being like Freudian "screen fantasies," fantasies about someone else, which, in fact, reflect his own fears. In addition to being traumatized by Allie's death, Holden is worrying about his own death and its aftermath—the troubling ease with which people will go on with their lives after he dies, the ease with which people will transition from mourning and missing him to adjusting to living without him.

Family members, who are in various stages of coping with their own reaction to their loved one's illness, may inadvertently contribute to a patient's experience of psychological isolation from others. Some years ago, Dr. Janice Norton, a psychiatrist, published an account of her treatment of a woman during the last three months of her life, a rare account in psychiatric literature. Mrs. B was a thirty-two year old woman suffering from metastatic breast cancer. She had two sons, ages five and three. She wasn't sleeping well, was fatigued, had little appetite and was in substantial pain. Her sister had urged her to consult a psychiatrist because she was depressed and was considering suicide. Mrs. B, on the other hand, thought it was reasonable to commit suicide under the circumstances. She simply wanted to stop her suffering and to lessen the burden she thought she was imposing on her husband, parents, and children.

Mrs. B agreed to enter treatment. Dr. Norton recounts the loneliness Mrs. B described as she not only faced her impending death but also experienced her family members withdraw from her in their attempt to cope with the fact that she was dying. A pastor with whom she had become close withdrew from her emotionally after she confessed to him her attraction for him. Her doctors were frustrated that their treatments were not working and had become "hearty and hollow" (Norton 544). Talking with her family about her feelings about dying invoked in them intense feelings of grief they could not cope with. Her elderly parents hated to cry around her so they could not bring themselves to see her very often. Her husband buried himself in his work.

Dr. Norton was the only adult who did not withdraw from her; she was emotionally able to be with Mrs. B as she recounted her experiences. "I could listen and remain with her; she then allowed herself to grieve with me about the actual and potential losses she was facing—her husband, children, family, her health, and her future" (Norton 558). What emerged in the course of their sessions was mourning because of her separation from the people she loved and fear of others losing interest in her. She experienced moments of acute anxiety and terror at the thought of dying alone. Dr. Norton stayed with her, and in allaying her psychological anxieties may even have minimized the physical pain and sleeplessness Mrs. B would otherwise have felt (Norton 554). In her final days, with Dr. Norton by her bedside, Mrs. B gradually regressed to an infantile state, reassured by having her friend near her.

The distance between the world of the healthy and the world of the dying is a theme that Tolstoy also explores in *The Death of Ivan Ilyich*, one of his masterpieces. In *At Night* and

Wit, characters climb into bed with their dying friend, symbolically joining them in their world of illness. By contrast, Ilyich is ensconced in his sick room, and his family members, who occupy their own side of the house, only occasionally and reluctantly stop in to see him as they come and go to various social events. When visiting him they make awkward attempts to appear to sympathize with him, all the while being more intent on not letting his illness disturb their daily routine.

Tolstoy's descriptions of Ilyich's wife and children's near indifferent encounters with him are interspersed with descriptions of Ilyich as he wrestles with his increasing physical agony. But predominantly, he describes Ilyich's psychological torment as he comes to terms with the fact that he is dying and no one seems to care or even want to discuss that fact with him:

> The time for fooling himself was over: something new and dreadful was going on inside Ivan Ilyich, something significant, more significant than anything in his whole life. And he was the only one who knew it; the people around him didn't know, or didn't want to know —they thought that everything in the world was going on as before. This was what tormented Ivan Ilyich more than anything. He could see that his family—especially his wife and daughter, whose visiting season was in full swing—had no inkling; it annoyed them that he was not much fun and asked so much of them—as if he was to blame. Despite their best efforts to hide it, he could see that he was in their way. (Tolstoy 186-87)

The only exception to his psychological and physical isolation from others is a young servant named Gerasim, who comes into the sick room and tends to him, "wearing his thick boots and exuding both their nice tarry smell and that of the fresh winter air" (Tolstoy 197). Gerasim, like Susie and Dr. Norton, cares for and interacts with Ilyich in a meaningful way. He is able to transcend the psychological barrier that separates Ilyich from others and others from him. Immensely comforting, and comfortable with the manifestations of Ilyich's illness, the quality of Gerasim's interaction provides Ilyich with what he craves: genuine human sympathy and connection. Others are distanced from Ilyich by their inability to comprehend and empathize with the existential free-fall he is experiencing, not to mention the unrelenting pain, indignities, and life-interrupting fact of his serious illness. Gerasim, by contrast, is instinctively able to offer Ilyich something akin to Donald Winnicott's "holding environment." This concept refers to the emotional and physical environment created by a loving mother who is intuitively attuned to her infant's needs. Feeling "held" in this way, the child experiences being protected, understood, and nurtured. Gerasim's "holding environment" allows Ilyich, like Mette, Vivian, and Mrs. B, to regress to an infant-like state and to find some measure of peace before dying.

> There were some moments, after long periods of suffering, when what Ivan Ilyich wanted more than anything else — however embarrassed he would have been to admit it — what he wanted was for someone to take pity on him as if he were a sick child. He wanted to be kissed and cuddled and have a few tears shed over him in the way that children are cuddled and comforted . . . . And his relationship with Gerasim offered something close to this, which was why the relationship with Gerasim gave him comfort. (Tolstoy 200)

But many healthy people are not blessed with a natural ability to intuitively relate to a dying person, hampered as they are by a profound discomfort in the face of illness and death. They may be unable even to recognize and come to terms with their discomfort. Like Ilyich, a dying person is often relegated to a designated sick room and experiences an isolated psychological reality that few are able to share or even understand. He faces the end of his life coping not only with a repeated exposure to others' awkwardness as they relate to him, but also the awareness that others may be looking forward to his death. "[E]verybody knew that the only interesting thing about him now was whether it would take him a long time to give up his place, finally release the living from the oppression caused by his presence, and himself be released from his suffering" (Tolstoy 196).

Indeed, Tolstoy sets the tone for his story by describing the reactions of Ilyich's colleagues to the news of his death:

> Apart from the speculations aroused in each of them by this death, concerning the transfers and possible changes that this death might bring about, the very fact of the death of someone close to them aroused in all who heard about it, as always, a feeling of delight that he had died and they hadn't.
>
> 'There you have it. He's dead, and I'm not' was what everyone thought or felt. (Tolstoy 158)

Similarly, albeit less cynically, in Henry James's *The Portrait of a Lady*, Ralph Touchett, the character who sees and understands more than anyone in the novel, observes on his deathbed: "There is nothing makes us feel so much alive as to see others die. That's the sensation of life—the sense that we remain" (James 549).

As callous as Ralph's observation may sound, the idea that people are relieved when someone dies bears examination. The death of a friend, family member, or patient forces us to face our own mortality; relief at another's death may mask a deep reluctance to think about our own death. Writing after the outbreak of the First World War, Freud addresses this difficulty:

> To anyone who listened to us we were of course prepared to maintain that death was the necessary outcome of life, that everyone owes nature a death and must expect to pay the debt—in short, that death was natural, undeniable, and unavoidable. In reality, however, we were accustomed to behave as if it were otherwise. We showed an unmistakable tendency to put death on one side, to eliminate it from life. We tried to hush it up; . . . It is indeed impossible to imagine our own death; and whenever we attempt to do so we can perceive that we are in fact still present as spectators. Hence the psycho-analytic school could venture on the assertion that at bottom no one believes in his own death, or, to put the same thing in another way, that in the unconscious every one of us is convinced of his own immortality. (Freud 289)

Freud continues with another observation:

> It is an inevitable result of all this that we should seek in the world of fiction, in literature and in the theater compensation for what has been lost in life. . . . There

> alone too the condition can be fulfilled which makes it possible for us to reconcile ourselves with death: namely, that behind all the vicissitudes of life we should still be able to preserve a life intact. For it is really too sad that in life it should be as it is in chess, where one false move may force us to resign the game, but with the difference that we can start no second game, no return-match. In the realm of fiction we find the plurality of lives which we need. We die with the hero with whom we have identified ourselves; yet we survive him, and are ready to die again just as safely with another hero. (Freud 290-91)

In short, according to Freud, we do not really believe that we will die. But death occurs in life and on some level we must come to terms with it. Therefore, we find in the world of fiction, literature, and the theater a means to reconcile ourselves with death and loss. In our imagination we identify with the dying hero that we read about, but in our imagination we also safely survive him, leaving intact our unconscious confidence in our immortality.

Freud's insight suggests that psychological reasons lie behind the "self-distancing" we have seen in above examples, distancing that separates healthy people from dying patients. The grand self-deception regarding our mortality that he writes about may stem from a primal fear of our own final illness and death. Dread of what the future holds for us may be what prevents us from empathizing with people who are dying — we want to avoid them because they are a too stark reminder of what we, too, will one day experience. As a young, dying nurse writes: "[N]ow one is left in a lonely silent void. With the protective 'fine, fine' gone, the staff is left with only their own vulnerability and fear. The dying patient is not . . . seen as a person and thus cannot be communicated with as such. He is a symbol of what every human fears and what we each know, at least academically, that we too must someday face." (Anon 77)

In literature and the arts we find descriptions of experiences a dying person may have. Here we also find accounts of the particular isolation that knowing one is dying engenders, the separate psychological reality that few healthy people are willing to comprehend. In recognizing the challenge of coming to terms with our own mortality, we may be able to better bridge the distance between the world of the healthy and the world of the ill. Dying patients ought not to be symbols to us of our deepest fears, but rather, patients, friends, and family in need of our comfort, care, and concern.

Veronica Tomasic, PhD, JD, practices community law in the New Haven, CT area. She is a scholar of literature, painting, and psychoanalytic theory. Tomasic is a member of Yale University's Interdisciplinary Center for Bioethics and has published on end-of-life issues in the law and as they are represented in literature and painting.

Works Cited

At Night (Om natten). Dir. Christian E. Christiansen. Perf. Neel Ronholt, Laura Christensen. Zentropa Entertainment, 2007. Television.

Anon. In *American Journal of Nursing,* 1970. Reprinted in *The Oxford Book of Death*. Ed. D. J. Enright. Oxford: Oxford University Press, 1983. 77. Print.

Brown, Margaret Wise. *Runaway Bunny*. New York: Harper and Row, 1942. Print.

Freud, Sigmund. "Thoughts for the Times on War and Death." *Standard Edition of the Complete Psychological Works*. Ed. James Strachey. Trans. James Strachey. Vol. 14. London: The Hogarth Press, 1957. 273-300. Print.

Gawande, Atul. "Letting Go." *The New Yorker* 2 Aug. 2010: 36-49. Print.

Gunn, Thom. "Lament." In *The Man With Night Sweats*. New York: Farrar, Straus and Giroux, 1992. 61-64. Print.

Gunther, John. *Death Be Not Proud*. New York: Harper & Brothers, 1949. Print.

James, Henry. *The Portrait of a Lady*. New York: The Modern Library, 2002. Print.

Norton, Janice. "Treatment of a Dying Patient." *Psychoanalytic Study of the Child* 18 (1963): 541-60. Print.

Perugino, Pietro. *St. Sebastian*. Musée du Louvre, Paris.

Salinger, J. D. *The Catcher in the Rye*. New York: Little, Brown and Company, 2001. Print.

Tolstoy, Leo. "The Death of Ivan Ilyich." In *The Death of Ivan Ilyich and Other Stories*. Ed. Anthony Briggs, trans. Anthony Briggs, David McDuff and Ronald Wilks. London: Penguin Classics, 2008. 155-205. Print.

Winnicott, Donald W. "The Theory of the Parent-Infant Relationship." *International Journal of Psychoanalysis* 41 (1960): 585-595. Print.

Wit. HBO television. Directed by Mike Nichols. Perf. Emma Thompson. Based on the play by Margaret Edson. Pinewood Studios, 2001. Television.