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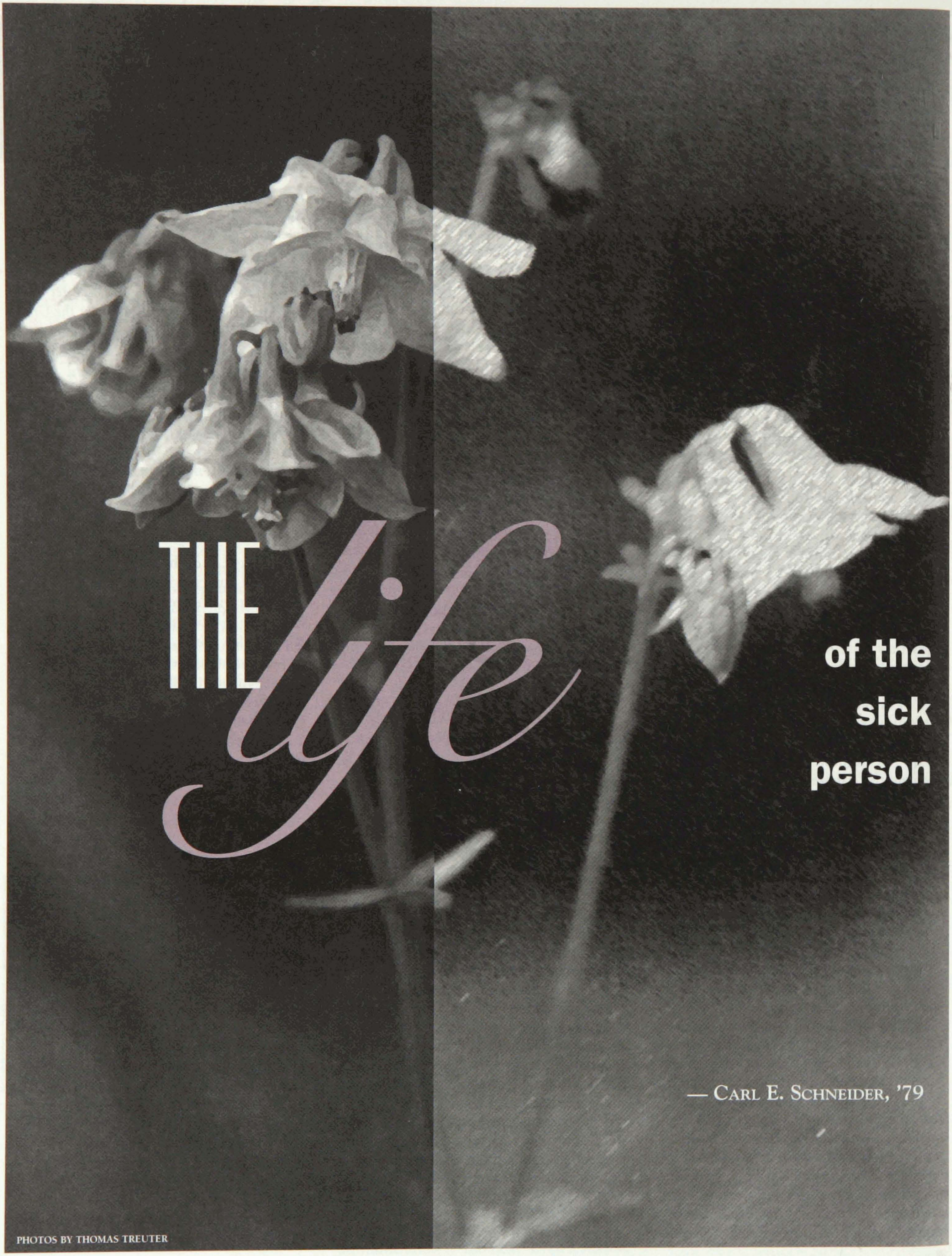


THE *life* of the sick person

— Carl E. Schneider, '79

PHOTOS BY THOMAS TREUTER

> *It takes time for an ill person to understand her needs. The caregiver cannot simply ask "What do you need?" and expect a coherent reply. A recently diagnosed person's life has already changed in more ways than she can grasp, and changes continue throughout critical illness. Part of what is "critical" is the persistence of change. Being critically ill means never being able to keep up with your own needs. Except for the need to hear that it is all a mistake — the lab results had the wrong name on them: I'm fine, really — the ill person does not know what she needs, though the needs are very real.*
>
> — Arthur W. Frank, *At the Will of the Body*

In The Practice of Autonomy: Patients, Doctors, and Medical Decisions *(Oxford University Press, 1998), Professor Carl E. Schneider, '79, examines the law of bioethics by looking at the lives of patients. He argues that bioethics has reached a point of paradox: Bioethicists increasingly seem to think patients have a duty to make their own medical decisions, but it is increasingly clear that many patients do not want to do so. The following excerpt, from the chapter "The Reluctant Patient," is part of Schneider's attempt to show why patients may be reluctant to seize the gift of autonomy that the law of bioethics seeks to offer them. This edited excerpt is printed with permission.*

To appreciate the force of the second reason patients might reject the leading role in their medical decisions, we should recall the syllogism that lies silent at the heart of the autonomist paradigm: People want to make all decisions that shape their lives. Few decisions matter more than medicine's life-or-death, sickness-or-health, fit-or-frail choices. Therefore patients want to make their own medical decisions. This syllogism is flawed because some patients conclude they will reach wiser decisions by deferring to the expertise and judgment of someone else. But the syllogism errs in other ways, ways suggested by what Talcott Parsons called the "sick role, with how people feel when they are ill." The autonomy paradigm rests on assumptions about the natural desire of all people to control themselves and their surroundings. These assumptions are overstated even for the population at large. But sick people differ from healthy people, for they often feel frightened, discouraged, dull-witted, abstracted, uninterested, and weary. These feelings, I will now suggest, may inhibit them from making medical decisions.

THE WORK OF THE SICK

We have just seen how arduous and distressing medical decisions can be. Even healthy people sometimes (indeed, regularly) cede control over decisions in the face of untoward demands on their energy, intelligence, interest, time, and attention. How much more, then, might sick people — even sick people who felt intellectually prepared — wish to escape so onerous and unpromising a burden? Oliver Sacks, surrounded by fellow patients, realized that "[w]e had all, in our ways, been undermined by sickness, had lost the careless boldness, the freedom, of the well." Thus some patients will accept that they lack — if only temporarily — the vigor, the persistence, the dispassion, the alertness, the concentration, the courage, the will — to resolve the riddles and face the bafflements of their medical distress. Such sick people may avoid all kinds of work, especially the fierce, foreign, and forbidding work of medical decisions. As one doctor-turned-patient observed, "Too sick at first to respond in any other than an automatic 'reflex' way, it was only now that I could bring out any new response which took into account the new facts. It was as though all before had been on a low level and only along lines ingrained from previous beliefs and behavior patterns. While words made sense, evaluations and thoughts did not. Nature seemed to reserve all energy for combating the disease. The transition of response was gradual and the evolution of critical appraisal and facing facts cannot be labeled as having occurred on any one day or in any one week."

And another observer, Reynolds Price, "was plunged into degrees of pain and realistic depression that produced a dangerously passive state. In that psychic bog of helplessness, like most trapped sufferers, I was transfixed by the main sight in view — my undiminished physical pain. And in such a trance state, for that's what a heavily drugged life is, any personal crusade for sane alternative therapies was literally unthinkable to me. It was all I could do to focus my scarce strength and clarity on one main aim beyond plain endurance."

Exhaustion dogs patients' lives. Their reserves of energy depleted, the severely ill barely stumble through the day. They lose the physical strength and emotional fortitude to keep their houses clean, their families cared for, and their friendships alive, much less to earn a living. They can hardly rise out of bed, brush their teeth, or make breakfast. One cancer patient was so weary he could not "read a newspaper for more than 15 minutes." Another said: "Weakness was the central experience — a bankruptcy of strength and energy. A few hours in the morning used it all up, and there was no reserve account on which to draw. I was overdrawn at the energy bank." In these straits, the labor of living preempts the work of medical decisions.

All these are calls on patients' reserves that are a normal part of life. But those reserves are also sapped by the special demands of illness. Patients must devote resources to recovering from their disease and coping with it physically, mentally, and spiritually. Some of this effort is tiring because it is hard physical work, like rehabilitation after a stroke. Some of it is psychologically wearing. As Herzlich and Pierret write, "Mentally, some persons find it very difficult to be responsible for their own treatment. . . . The young secretary acknowledged: 'Always, always having to pay attention, that . . . is something that people have trouble accepting. This is the thing that's hard to learn, because the shots. . . . I am always worried, but I do it. The analyses are not hard to do, but what is so constraining is that one has to pay attention at all times.' The older diabetic also said, 'That is why we who are sick are so tired, because we always have to gather up our will power to do the things that have to be done, and that one couldn't deal with if one let oneself go.'"

Many patients also must strive to manage their emotions, to sustain their spirits, to stop the slide into soul-sickening anger, frustration, and depression. As a doctor with cancer wrote, "I only know that during this time I felt blighted physically and overrun psychologically. I am sure that deep within me I was furious at the fates which had brought me to my knees in youth. Had I had the energy and a target or even a surrogate target, I imagine I would have broken out in rage. But I was past being angry. What I do remember feeling was despair." In addition, patients must work to adjust to the fact of their illness and their damaged future. Thus Michael Kelly says the decision to have surgery for colitis "is not about the absence or presence of particular information nor about its distortion, it is about the individuals changing their view of themselves so that they define themselves as sick. . . . The process is one of aligning the self with the public identity of prospective and actual surgical case."

These kinds of work can mount up to become all-demanding, so that medical decisions seem too expensive a distraction which can better be shuffled off onto intimates or experts. James Johnson, for example, had to decide about a skin graft after a long hospitalization for dire heart problems. He could hardly face even this relatively trivial decision, for he "suffered from battle fatigue. I'd had my fill of doctors and hospitals." So "[a]t this point, I knew I could not go on trying to figure it out." When considering whether she should make her own medical decisions, Joie McGrail concluded "it would be wasteful to use energy that would be desperately needed to fight my disease in simply asserting my personality, so I allowed myself to be trundled about, poked, prodded, kept waiting and rushed." Eileen Radziunas wrote sorrowfully that she "carried the burden of being the one to suggest ideas, ask about tests, and question possible diagnoses. I felt overwhelmed with all this responsibility, and I needed the *doctors* to take control so that I could use all my energy for recovering." Thus Kenneth Cohn found it "comforting to be treated by competent dedicated professionals. Their skill allowed me to eschew the medical literature on lymphoma and to focus on being a patient."

Agnes de Mille captures so many of the reactions of so many sick people to making medical decisions that she must be quoted at length. When she had a stroke, she was not young, but as a dancer, she had lived vigorously. As a choreographer she had bustled with energy until she was, literally and figuratively, stricken: "I was taken up with the minutiae of living. Everything was so extraordinarily difficult and so new to perform. Every single act became a contest of skill; and games can be tiring. I did not concern myself with the medical details. There are patients who do, and presume, after a short while, to advise the doctors and to interfere in their conferences. I wanted none of that. . . . I watched them at it and I was glad for their expertise, but I did not seek in any way to share it, and even when they tried to explain it to me I resisted. I was reluctant to learn because I didn't think the horrid details would help me to keep my energies where they belonged — on survival. The dreadful possibilities were entirely the doctor's business."

In sum, illness lays strength and stamina to waste. Thus the sick may decline to make their own medical decisions because they have too little vitality and too much to spend it on.

The Burdens of the Sick

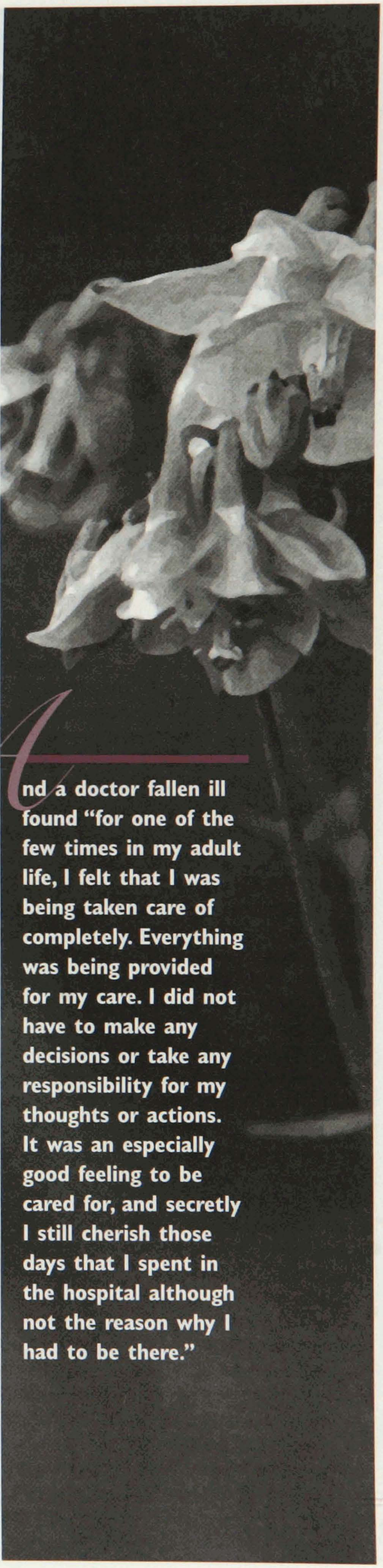
Recall what it is like to be sick: "[A] little cooling down of animal excitability and instinct, a little loss of animal toughness, a little irritable weakness and descent of the pain-threshold, will bring the worm at the core of all our usual springs of delight into full view, and turns us into melancholy metaphysicians." The only benefit, the only comfort, you may find in being sick is that other people will care for you, and you can let them, let them fix your meals, bring your pills, rub your back. May Sarton captures both these aspects of the sick person's life: "How I have enjoyed complete passivity! Being 'looked after' like a Paddington bear — listening to the bustle in the corridor as though from very far away so even the noisy voices didn't trouble my floating. But I still feel frightfully tired and so I dread going home." Even patients who always resented dependence may savor it when they are ill. Agnes de Mille reflects, "Up to May 15, as far as it was possible for a woman to be independent, I had been independent. Now, not so. I cared nothing. Let me lie still. Let me be. As far as I was concerned people could wait on me, serve me, help me in every way." And a doctor fallen ill found "for one of the few times in my adult life, I felt that I was being taken care of completely. Everything was being provided for my care. I did not have to make any decisions or take any responsibility for my thoughts or actions. It was an especially good feeling to be cared for, and secretly I still cherish those days that I spent in the hospital although not the reason why I had to be there."

As that doctor gratefully recognized, people may particularly spare you the travail of decisions. As another patient put it, "I allowed myself the forgotten luxury of childhood: other people were in charge." Jay Katz remorselessly disparages "the regression to more childlike functioning that can result from illness [and that] becomes augmented by a patient's wish for caretaking by a patient-physician who, as memory informs, will immediately alleviate all suffering." But I believe Sacks speaks with wiser tongue when he observes more sympathetically that, "though as a sick patient, in hospital, one was reduced to moral infancy, this was not a malicious degradation, but a biological and spiritual need of the hurt creature. One had to go back, one had to regress, for one might indeed be as helpless as a child, whether one liked it, or willed it, or not. In hospital, one became again a child with parents (parents who might be good or bad) and this might be felt as 'infantilizing' and degrading or as a sweet and sorely-needed nourishing." Such patients may accept the comfort of relief from the burdens of decision.

In addition, even more than most of us, the sick may wish to escape not just the wearisome labor of medical decisions, but also the responsibility for such savagely difficult choices, choices on which their own happiness and that of their friends and families may so much depend but which are so bewildering. When decisions go wrong, many patients blame themselves and feel blamed. Thus one study of kidney donors concludes, "[W]here the costs of failure on both sides are so great, our impression is that individuals frequently wish to absolve themselves of the responsibility of the decision. Deliberation and a conscious decision emphasize the freedom of one's choice and one's responsibility for the choice. To hold oneself responsible for a potentially disastrous outcome is painful, however."

Robert Murphy, an anthropologist dying of a spinal tumor, put this observation into more personal form. He acknowledged that "the patient is responsible for his own recovery, and this has many positive aspects." However, he learned it has its drawbacks too: "[I]f his efforts can yield improvement, then any failure to improve can be an indication that he isn't trying hard enough, that he is to blame for his own condition. This load of culpability is often added to a lingering suspicion among family and friends that the patient was responsible, somehow or other, for what happened to him. And the patient, too, is often beset with guilt over his plight — a seemingly illogical, but very common, by-product of disability."

The authors of a study comparing the desires of cancer patients and the general public for participation in medical decisions generalize this point: "The strong effect [on the desire to make decisions] of the presence or absence of cancer suggested that decision making preferences might be influenced by diagnosis of a life-threatening illness. In that context, being



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Medical decisions may repel patients for yet another reason. Such decisions cannot ordinarily be made well without acquiring thorough information about one's illness and analyzing it carefully. But not everyone finds that learning and thinking interesting, or pleasant, or even tolerable, particularly at the level of intensity and persistence needed to make complex and unfamiliar decisions.

freed of responsibility for making treatment decisions can produce an immense sense of relief, with treatment failures becoming the responsibility of the practitioner rather than the patient."

The problem is not just that a baneful sense of responsibility may impede decisions in the first place and make living with them tormenting. It is also that that sense warps decisions. Thus the study of kidney donation I quoted a moment ago found that people burdened with this sense "are motivated to regard the decision [to donate] as inevitable — as the only possible alternative, given the enormous moral obligation, or the social pressure, or the fact that another family member volunteered first, or the perception that this issue is not one's moral responsibility. Thus, while the outsider sees the potential donor as making a choice, the potential donor himself is likely to describe it as 'no decision at all'."

Medical decisions may repel patients for yet another reason. Such decisions cannot ordinarily be made well without acquiring thorough information about one's illness and analyzing it carefully. But not everyone finds that learning and thinking interesting, or pleasant, or even tolerable, particularly at the level of intensity and persistence needed to make complex and unfamiliar decisions. Some patients — like William Martin, the sociologist with prostate cancer — may "want to keep on looking stuff up and trying to make sense of it for as long as I can," and they may become "totally engrossed in trying to unravel the riddles of prostate cancer, sometimes almost to the point of forgetting just why I had developed such a keen interest in the subject." But other patients will not have made research their life's work, will not know how to do it, will not enjoy it, will not like learning a new vocabulary and thinking in foreign ways, and will find better things to do with their time. Indeed, some people find medicine, and even their own ailments and treatments, boring. Few subjects are universally fascinating, and medicine is not one of them. As Wilfrid Sheed writes, "I've never been the least interested in the nuts and bolts of sickness and health. In fact, even when I've been so ill myself that there's been no avoiding them, my position has always been 'just tell me what I'm supposed to do, and who do you like in the World Series?' or the Oscars, or any damn thing that doesn't require thermometers and blood tests every half hour."

Even people who once were fascinated by medical questions may see them pall after months of the tedium of patienthood. One couple put the point bluntly: *"We are both so weary of this medical junk."*

Furthermore, many patients — especially the gravely ill — will not relish having to think about the terrible and terrifying things that are happening to them, the cruel uncertainties they must endure, the wretched alternatives they confront, or the bitter prospects they face. For just such reasons many people resist buying life insurance, writing wills, preparing advance directives, signing organ-donor cards, seeing the doctor, and even visiting sick friends. In short, some patients will be disqualified from making decisions by their reluctance to learn enough about their illness. For Lance Morrow, "Having a heart attack and waiting for another at any moment results in an especially wearing and unlikable introspection. It is a physical introspection entirely, an in-peering anxiety, my focused self standing like a peasant outside the castle walls, awaiting the caprice of a lord who is given to drunken rages." Joseph Heller says wryly: "My attending doctors . . . had adopted the sensible approach of not giving me any distressing information about my illness unless they had to; and I had adopted the sensible defense of not seeking any." The mother of a child with cancer wrote that "the few articles and newspaper paragraphs I have read are certainly inadequate; yet I do not intend to become an authority on Carol's leukemia. Intuitively, I desire to keep all bitter informants at bay, to study no discouraging life expectancy charts or bleak percentages." Ernst Hirsch, a psychologist and a thoughtful man with multiple sclerosis, shunned the literature on his disease, since in it "the illness tends to be described in its most acute, extreme and often final form. Such an account naturally makes reading about the illness depressing, particularly to a patient who is afflicted with it." Reynolds Price, a writer with cancer of the spinal cord, reports, "From the start of the trouble, I made a conscious choice not to open my file and confront what doctors believed was the worst — I saw in their eyes that they had slim hope, and I knew I must defy them. On balance I think the choice of a high degree of ignorance proved good for me. All my life I've tended to try to meet people's hopes. Predict my death and I'm liable to oblige; keep me ignorant and I stand a chance of lasting." Finally, Molly Haskell reports that when a doctor told the mother of her desperately sick husband that he (the doctor) "couldn't promise he wouldn't have brain damage," Haskell was "stunned, outraged, first, that he should say such a thing to her, and second, because it was a possiblity I hadn't allowed myself to even think about. How dare he answer a question that nobody had asked! I told him from now on not to volunteer grim information unless we asked for it."

Such patients do not warmly welcome the practice of informed consent: "I signed everything without reading any of it, and tried not to listen while he told me in great detail what would happen later that morning. All I wanted to know was, would it hurt?" And: "I signed it quickly, not noticing too much of any of it. If it were going to happen, it would happen. But it was a bit frightening as I thought of that long list." Even less formal communications can be disturbing: "Another sort of drowning is inflicted on us patients by doctors who think out loud while they examine you. These physicians not only expose you to their full conclusions, they expose you to the full process by which they reach these conclusions. As your examination proceeds you hear all the malfunctions you might have, as well as those you do have, and you have twice as much to worry about." Thus one ill doctor "learned how simple words from a physician can strike absolute terror into the hearts of patients. A well-meaning internal medicine resident remarked, offhand, as he pushed on my belly, that my liver seemed 'a little enlarged.' The fear of metastatic malignancy nearly turned me to jelly."

As this last example suggests, even patients who are professionally equipped to understand their illness may not wish to know too much. One doctor afflicted with cancer wrote, "I am terrified at the thought of examining my own chart for fear that someone has recorded in it a poor prognosis. I know that's illogical and that I should look to see if there's an error that could be corrected. But I am no longer able to function as my own doctor. My confidence has been worn down — by my fears about my illness, of course, but also by something more subtle, something that's happened psychologically over these past months." Another doctor with cancer observed, "I knew as much as anyone about X-rays and easily could have examined my own on the way back to the clinic. I never did. The possibility that I would again discover trouble in my chest was so horrifying to me that it quenched my curiosity." Yet another doctor acquired an aversion "to learning anything new or even remotely pessimistic about my disease and its complications." He reasoned, "It is a doctor's job to search diligently for the worst. The patient hopes eternally for the best. When they are the same person, the conflict becomes extremely difficult (perhaps impossible) to reconcile."

But even if patients' curiosity is not quenched, even if they want information, the same fear that deters them from asking for it may keep them from assimilating it. When some of the colitis patients Michael Kelly studied were told they needed surgery, they "expressed great surprise when the operation was first mentioned to them, this in spite of the fact that several had been attending surgical outpatient clinics over many months." One such patient "tried not to think about it. 'I just blocked it out. I just didn't want to know. I just couldn't picture it at all. All I knew was that you have a bag. I just didn't want to know.'" Another patient "refused to acknowledge that she was a prospective surgical case, even after she had been admitted to hospital for the operation. . . . She claimed that she thought she was going into hospital for tests." And Gerda Lerner believed her husband "undoubtedly 'knew' before I told him of his brain tumor, and certainly many times refused to 'know' after I told him. He was already deeply caught up in the process of dying and conscious knowledge was only a minor aspect of it. Just so it is with me now: the fact of his death, his absence, is incontrovertible. I 'know' it in many different ways and with many different modes of perception. Yet, to this day, I still do not 'know' it the way I know other facts. It shifts; it wavers — sometimes it is as true as a rock; sometimes it is as true as a bad dream. I imagine it must be that way for the dying until that final stage when they really 'know' — then they let go."

To put the point somewhat differently, patients may prefer to "deny" their illness, avoid information about it, suppress thoughts of it, and try to go about their business as though they were well. Popular psychology has cursed "denial" with a bad name, perhaps with some cause. But denial has its uses, for happiness "has blindness and insensibility to opposing facts given it as its instinctive weapon for self-protection against disturbance." Paul Monette observes, "This force of life continuing is what they mean by 'positive denial'." Robert Murphy said he "once asked the neurologist how bad it could get, and, with a pained expression, he answered, 'Do you really want to know?' I didn't." Murphy commended the well-tuned repression mechanism, the ability to become detached from one's emotions, to benumb the inroads of fear." He acknowledged that "[t]his kind of repression is bought at considerable emotional cost, but it has its positive uses. Some fears and sentiments are better left unstated, and those that I harbored as I entered the hospital in 1976 were among them. What I refused to contemplate was the progressive and total destruction of my body, the reduction of all volition to quietude, the entombment of my mind in inert protoplasm." And a seriously ill doctor thought "psychiatrists only preach nonsense when they say: 'Adjust to reality.' We can only really endure life if we cherish healthy illusions, if we have faith no matter how fantastic, or the kind of healthy-mindedness that shakes off, as a dog shakes off water, the disagreeables of now and the future."

These opinions have even found scholarly defenders. Arthur Kleinman, for instance, writes, "[D]enial and illusion are ready at hand to assure that life events are not so threatening and supports seem more durable. . . . In short, self-deception makes chronic illness tolerable. Who can say that illusion and myth are not useful to maintain optimism, which itself may improve physiological performance. . . ?" And Kelly argues, "Rather than perceiving denial in these circumstances as evidence of a malformed psyche incapable of dealing with reality or as an automatic psychological defence, it is better to regard it a *realistic* response in the absence of the necessary skills to deal with the illness." Evidence that "denial" can sometimes be sensible also comes from empirical studies showing, for instance, that "[a]lthough some patients seek out information prior to surgery, such information does not always reduce their arousal levels or promote recuperation from surgery. . . . Indeed, information may actually increase arousal and retard recovery. . . " Thus, Miller and Mangan note that while laboratory studies show that most people want information about an aversive event, "in less artificial studies that mirror real life . . . , the preference reverses: The majority of individuals then prefer to distract themselves from threat-relevant information. . ."

Many memoirists put these opinions in terms of hope, "the only fuel that keeps them going." Natalie Spingarn writes: "I have found no skill more important (no matter how it is gained) than the ability to

The concerns I have been describing not only consume patients' time but are emotionally and intellectually draining. The sick will often prefer to treat their medical decisions as fixed points about which they need not worry and around which they can work.

believe in my survival, for at least a bit longer. For this, I am dependent on how my fellow human beings — doctors and nurses, family and friends — . . . reinforce the hope that sustains my life." She tried "to avoid the medical mighties who with their harsh 'honest' words — and I cannot say it often enough — deprive me of the hope that I can fend off my enemy, death." Their "blunt, tell-it-like-it-is" way of speaking may reflect "the common wisdom that *knowing all the news, whatever it may be, is 'good' for you,* conversely, [that] it is *'weak' to try to avoid even a single cancer statistic inferring bad news, even if it helps deprive you of hope.*" But Spingarn disapproved: "Hope, I repeat once again is the essential ingredient. Without it, we patients can find no reason for struggling to survive; without it, we find it easy to give up and stay in bed." Thus she remained "peeved at the physician who told me over the telephone when my second breast cancer was diagnosed, 'We have to stop talking in terms of cure and begin talking in terms of control — one year, maybe two.'" In sum, while some patients may cope with disease by visiting a medical library and tackling the relevant literature, others will be anxious to avoid learning about their illness, contemplating their perilous condition, acknowledging their grim choices, imagining their possible fates, or making medical decisions."

Many of my points about how being sick disinclines one to seize control of one's medical decisions are captured in a provocative article by Franz Ingelfinger, an editor of the *New England Journal of Medicine* stricken with the very illness he had specialized in as a physician. He "received from physician friends throughout the country a barrage of well-intentioned but contradictory advice. . . . As a result, not only I but my wife, my son and daughter-in-law (both doctors), and other family members became increasingly confused and emotionally distraught. Finally, when the pangs of indecision had become nearly intolerable, one wise physician friend said, 'What you need is a doctor.' He was telling me to forget the information I already had and the information I was receiving from many quarters, and to seek instead a person who would dominate, who would tell me what to do, who would in a paternalistic manner assume responsibility for my care. When that excellent advice was followed, my family and I sensed immediate and immense relief. The incapacity of enervating worry was dispelled, and I could return to my usual anxieties. . . ."

Ingelfinger is not alone. The editors of an anthology of doctors' accounts of illness report, "Autonomy may be lauded for modern patients, but it is not something sick physicians usually choose for themselves once they have found a doctor. Sick doctors want to be taken care of, even if they try to remain in control; we find the most relief when someone else takes over. Here we are, a group with special knowledge, and often trying to exert control beyond the bounds of reason, and yet almost to a man or woman sick doctors who express an opinion suggest that they want to be taken care of so that they can give up their lonely vigil. Most of them want to be cared for, have decisions made for them."

Perhaps doctors' testimony on this score should be doubted (although they seem especially suited to make their own medical decisions). But a similar reaction appears in the memoirs of lay patients. One wrote, "I think my husband helped me to transfer worry and responsibility to the doctors' shoulders instead of carrying the burdens myself. That was very important. It gave all of us something to lean on." A patient with infertility found "something reassuring in the order that [her doctor] imposed on the situation, the idea that there was a definite path to tread, and she'd take me by the hand. When I left the office, I was excited and relieved." Another kind of evidence comes from Ellen Annandale's study of a birth clinic which appealed to women who wished to be unchained from the bonds of medical authority. Even there, studying clients who were presumably vigorous, independent-minded, and healthy, Annandale witnessed the relief of abdicated autonomy: " 'I didn't need to worry about making decisions and could leave it all to [the midwives]. . . . I felt utterly relaxed being at home and having complete faith in those around me.' "

I have been suggesting reasons the sick may be in no mood to plunge into medical decisions. Let me close with one other. The standard argument is that patients should make their own decisions because those decisions so much affect them. By the same token, becoming immersed in your medical decisions means thinking intensively about yourself. Even in our psychologized, therapeutic society, not everyone believes this is a good idea. Some see a moral duty to temper their interest in themselves and invest it in their neighbors. Others are skeptical on prudential grounds. Sheed, for example, counsels against self-absorption. He admonishes advice columnists: "So tell your readers to go dancing, overeat at least once, or buy a book about Napoleon (*not* about self-help, or self-anything. Tell them to forget themselves for five minutes. The air outside is wonderful)." Sheed's attitude is so resonant that we have a word — valetudinarian — for people too fascinated by their illness and themselves.

CONCLUSION

The points I have made in this section may helpfully be seen in light of patient's memoirs. As I suggested earlier, often they are not primarily about making medical decisions, or even about patients' relationships with doctors. Rather, they are about what it means to be a person who is sick. They are about how illness ravages the body, staggers the rhythms of daily life, distorts personal relationships, and destroys the familiar. They are about how illness savages the mind and leaves it brooding and afraid. They are about how people struggle with pain and uncertainty. They are about how people labor to make sense of their pasts and their futures, their lives and their deaths. These memoirs suggest, then, that while medical decisions may have crucial consequences for patients, they will not always be most central, most pressing, or even most interesting to patients. To people "wrestling with the crises of their fate," medical decisions may seem a distraction, not a duty.

For many patients, medical decisions are both above and beneath their attention. Above, because patients are concentrated on day-to-day coping. They try to perdure with their lives despite their disease, to make it to work, to get a full night's sleep, to see their families, to get the laundry done and the lawn mowed, to pay the bills and call the plumber. They do not ignore their illness. But their attention is concerned with adapting to it, not treating it. They ask how they can learn to walk after a stroke, find a ride to dialysis sessions, avoid insulin shock, cope with incontinence, follow their diet, or manage their drugs and lives to reduce the risk of seizures.

On the other hand, medical decisions fall beneath patients' attention because illness urgently presents the largest kind of questions to them, questions about their religious faith, about whether their lives have been well led, about what a good life is. Patients ask why they became sick, whether they managed their careers well, whether they loved and were loved, whether they enjoyed their lives, whether lives were spiritually fulfilling, and, as to all these questions, how to do better in whatever future might remain. This leads some patients to become preoccupied with their emotional and spiritual development. For patients who have sought "alternative" therapies, the psychological, the spiritual, and the medical can become as one and become everything in their lives. Thus David Tate's experience with Hodgkin's disease (and later a heart attack) helped take him from Roman Catholicism and a career in the law and real estate to life as a psychotherapist and a New Age stand-up comic who found meaning in, among other things, Silva Mind Control, Edgar Cayce readings, acupuncture, psychic healing, Carlos Castaneda, Johnathan Livingston Seagull, Paramahansa Yogananda, spiritualism, Esalen, and transpersonal psychology, particularly psycho-synthesis.

Even if patients are not preoccupied with their spiritual situation, they may be absorbed by moral crisis. As Sheed writes, "The details of any illness are too tedious and repetitive to occupy you for more than part of the time and what you do with the rest is critically important in this case, as you bet your whole self against death." Thus "[t]he interesting part is all provided by you, an average citizen and image of God, finding out for probably the first time what's been in you all along." Here Sheed is reflecting on his three illnesses — the polio he endured as an adolescent, the depression and addiction he fought in middle age, and the cancer he suffered as he emerged from the depression and addiction. To Sheed, illness is crucially a battle of character and courage. The news he brings from the front is hopeful. He writes, for instance, "Numerous people who had had to care for critically injured patients have testified, as polio nurses once did, to how amazingly quickly the patient's spirit seems to take over and begin to pull *them* through, as if it were a new presence in the room, preternaturally strong and self-assured." Nevertheless, much of what absorbed his attention and energy in his illnesses was the moral problem of managing his response to the depredations of disease and the menace of death.

Now in principle, none of these concerns — whether quotidian or cosmic — has to preclude a patient from making medical decisions. But in practice, such concerns often divert patients' interest, attention, and energy away from the process of informed consent and the tasks of medical choice. The concerns I have been describing not only consume patients' time but are emotionally and intellectually draining. The sick will often prefer to treat their medical decisions as fixed points about which they need not worry and around which they can work.

Patients who cede authority to make medical decisions for the reasons I have examined in this section obviously run risks — the risks classically associated with paternalism. But the reason they run those risks differs from the usual justification for paternalism. These patients do not necessarily say someone else knows their situation and interests better than they. Rather, they say that, whoever might make the best choice, they do not wish to bear the weight of formulating a decision. Nor are these patients necessarily delegating decisions to the ordinary paternalists — their doctors. In my research, I have often encountered people who instead (or as well) ceded authority to their families, in whose concern, vigor, wisdom, and faithfulness they reposed their trust.

We may admire people who take on the burdens of illness, chart their own course, and, resolute, remain captains of their fates and masters of their souls. But surely we can understand sick people who shudder at the labors of analyzing their own medical problems, who ask to forget the terrors that assail them, who yearn to share the responsibilities that crowd upon them, who hope to husband their resources for other conflicts, who long for comfort and for care. For such patients, shrugging off the mantle of decision can be appealing, appropriate, and liberating.

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