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LET'S TALK ABOUT DYING



HEALTH

IN THE 1990s I was, for a few years, palliative care chaplain at a city hospice. One Sunday, while I was preparing for the Eucharist in the chapel, an elderly woman arrived, beautifully coiffed, dressed in twinset, pearls and a pleated woollen skirt. As she looked a picture of health, I wondered what she was doing at a hospice, so I probed, hopefully in a diplomatic way; was she visiting someone, I asked: a friend, a relative?

"No," she said, smiling. "I've just arrived from [country town]. I'm boarding here. Tomorrow I start six weeks of radiotherapy, for cervical cancer, at the hospital across the road." She was ninety-three, single, alone in the city, and had no close relatives.

Six weeks of radiotherapy at ninety-three. Hold on to that for a moment. Apparently, with advanced cervical cancer, a single or short course of radiotherapy can be palliative; however, as six weeks is neither single nor short, perhaps the medical profession was attempting a remission or cure. Or perhaps the medical profession had no idea what it was attempting.

As she didn't come to the Eucharist the following week, I visited her in her room; she was sitting in a chair reading a book, not quite as optimistic as before. At the end of the second week, I found her in bed looking tired and despondent; radiotherapy is stressful at any age, even though ninety-three is apparently the new sixty-one. At the end of the third week, she was in bed, looking like a dead sparrow, shrivelled, paralysed, mouth drooping and unable to shut, eyes open and unable to blink, one arm twisted and sticking out, her hand like a petrified claw shielding her face. Did she recognise me? Could she communicate? I couldn't tell. I wanted to stay and offer her support but I felt inadequate and my presence inappropriate. I went to the nursing station and asked what had happened. She's had a stroke, nurse said, they've stopped her radiotherapy. How good of them to work that much out, I thought, as I strode down the hall to the payphone, rang a friend, and sobbed uncontrollably into the receiver.

What did the hospice do? Put her into palliative care? Isn't that what it's for? No, it put her on a plane home. I rang the priest in [country town] to let him know she was on her way. She's already here, he said in a strained voice. She died on the tarmac while she was being taken off the plane. As there was nothing I could say—and I could tell he was angry—I got off the phone as quickly as I could.

Ethical and moral issues emerge from this story, at least for me. Some are timeless. Some are specific to our time.

SEVERAL YEARS LATER, I enrolled in Clinical Pastoral Education (CPE), a full-time, twelve-week, intensive hospital placement. Traditionally, CPE is a kind of boot camp for those in pastoral care, with challenging interpersonal dynamics that encourage us to change and grow, to recognise other points of view, to feel rather than think. Many *Quadrant* readers may be interested to know that religious language—or any philosophical or theological narrative—is discouraged in CPE, as such language is seen as counterproductive, as hindering an open pastoral encounter, as a denial of feelings; instead, the focus is on non-judgmental listening, on being patient-centred, which in this case means allowing the patient to be heard and not subjecting them to any value-laden script. The principal learning tool, apart from attempting to have open pastoral encounters in a confronting environment, is discussing verbatims of your individual encounters in peer groups and during one-on-one supervision. Perhaps unwisely, I took into supervision my earlier encounter at hospice, as I'd never got over it. Although this particular verbatim didn't fit the CPE mould—it was out of date and had lost its spontaneity—I wanted to discuss my unresolved issues around it.

The discussion didn't get far, as I took the view that—in this particular case—the woman's death was premature, her manner of death was problematic, and

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she had been deprived of quality of life in her final weeks or months. I questioned why the medical profession offered her six weeks of radiotherapy in the city; it should have considered—better than it did—her quality of life in relation to her age and prognosis; it should have undertaken to keep her comfortable and free from pain at home; that is, it should have offered her palliative care rather than attempt a remission or cure, or giving her treatments they must have known wouldn't work. Finally, since she had the stroke halfway through her treatment—a stroke that, I suspect, might not have otherwise occurred; a stroke that, I also suspect, left her unable to communicate—it shouldn't have discharged her from what was, after all, a hospice.

My supervisor, an ex-nun who understands boundaries and is in touch with her feelings, rightly pointed out that I didn't know enough about the circumstances to pass judgment on them with the benefit of hindsight. The woman may have insisted on treatment. The health profession may have advised her against it, or warned her about the potential consequences, and there must have been informed consent. As I didn't know the circumstances, and never will, I should stick to non-judgmental listening, and, generally speaking, she felt I was too rational and needed to do more work on getting in touch with my feelings. While there's some wisdom in this paradigm, which is part and parcel of the post-Enlightenment critique of reason, which is characterised by the clichés that dominated clinical and popular psychology for much of the twentieth century, I wonder whether—as far as treatment options for the elderly and end-of-life decisions are concerned—it's out of date and needs to be revised so it can participate in some kind of ethical framework or moral compass. The question for us, in our age of moral relativism, is: What ethical framework, what moral compass?

THIS ISN'T TO say a person who reaches a certain age shouldn't have access to invasive medical treatments; one size doesn't fit all; there are many examples where such treatments are warranted, if there's a good chance they'll enhance an older person's quality of life. Similarly, the issue isn't—or shouldn't be—the cost to society of medical care at the end of life. It's quality of life.

I know another woman who, when she was ninety-three, was told her coronary arteries were blocked and she needed a triple-bypass, which she had as soon as it could be arranged, from which she recovered extremely well. She's ninety-six, at the time of writing, sharp as a tack, and still does her own shopping, cooking and housework (including vacuuming). All things considered, her quality of life is still very good.

Here we have two examples, both women well into their nineties, one with advanced cervical cancer,

another with advanced coronary artery disease. Let's assume both were otherwise healthy for their age, the medical profession explained to each the pros and cons of their invasive treatment, and each understood what was happening to them, or likely to happen to them if they did or didn't have their invasive treatment. As far as these two women are concerned, I wonder whether, ethically or morally, the principle of informed consent makes their respective treatments a level playing field. If it doesn't, I wonder whether there's a difference in prognosis and risk between this individual cervical cancer and this individual coronary artery disease, whether the medical profession should be offering each woman any and all treatments—simply because it can and doesn't know how to do otherwise—or whether there's a point at which, perhaps in some cases more than others, we need to recognise that ninety-three isn't the new sixty-one, we are all going to die eventually, and quality of life should be our prime concern.

A FEW YEARS AGO I had a major operation. In the bed diagonally opposite mine was a frail, wizened, non-ambulatory old man who couldn't speak, who was extraordinarily docile, who didn't appear to have any needs, who couldn't communicate any needs he may have had. I knew nothing about him, except that he'd been brought to the city from [country town] for treatment. That didn't stop me from making assumptions about him which my CPE supervisor would no doubt say were unwarranted and unwise. He looked as if he was, or should be, a nursing home resident. He reminded me of some of my clients from my home care days in the 1980s; he presented like one of those single men who don't have many resources, who live in boarding houses, who spend a lot of time at the pub or club. I also guessed he'd once been a smoker. This is a demographic we don't hear much about but it exists and not only in my imagination.

After three days of watching the nurses either avoid him or make quarter-hearted attempts to communicate with him, of watching him not eat—special food would arrive, be placed out of his reach, and be taken away untouched—of watching him passively and resignedly trying to make sense of what was going on around him, he was visited by a doctor with a brusque manner who drew the curtain around his bed and spoke to him in an assertive voice that the whole room could hear. The gist of what I heard the doctor say was:

“I'm going to tell it to you straight. Your tests show you have throat cancer. If we don't operate, you'll die, and you don't want that do you?”

The old man made some raspy noises but no words came out.

“During the operation, we'll put a tube in the front of your throat and you'll need to learn how to

breathe and speak through that. Got it? Now, time is of the essence and I've been able to arrange theatre on Tuesday. Okay?"

The old man made a few more raspy wordless noises and the doctor left the room.

I'm not making this up. Even allowing that I knew nothing about this man's circumstances—he may have been a wealthy squattocrat with a masters degree in complementary farming; he may also have been a non-smoking teetotaller all his life—I was beside myself with anger. Given his age and prognosis, was this man being offered appropriate care? Even if he was, is this what negotiating informed consent looks like in public hospitals in twenty-first-century Australia?

But it's not all bad. Recently, a friend's mother, who'd been slowly weakening over time, was diagnosed with cancer at the age of ninety. She was given approximately eight weeks to live, assessed for palliative care, and her family kept her at home. She lost ground more quickly than expected; my friend felt the end would be closer to three weeks than eight. Her general practitioner worked opposite the house and called in every day, sometimes twice a day. Towards the end, the general practitioner gave the family firm instructions: If your mother has a turn in the evening, or during the night, just sit with her, give her adequate pain management, and make her as comfortable as you can; don't call an ambulance; don't take her to hospital; don't contact me until the next day. She died peacefully and with dignity. I find this story comforting, ethically and morally, because the medical profession and the family managed to get it right.

FOR AN EXAMPLE of the medical profession and the family getting it wrong, read "The Aquarium", by Aleksandar Hemon (*New Yorker*, June 13–20, 2011). Hemon normally writes fiction but this essay is a studied account of his infant daughter's final three and a half months of life. At nine months, Isabel had an ultrasound which found she was hydrocephalic and needed to present to emergency immediately. After an MRI, a surgeon said Isabel had a brain tumour the size of a golf ball; it looked like a teratoid but he couldn't confirm that until the tumour was removed and tested. Now he didn't tell Hemon about teratoids. Why not? Why let suspicions slip but not explain their consequences? Hemon did an internet search and eventually found an entry for teratoid rhabdoid, a highly malignant and exceedingly rare brain tumour, which occurs in 3 per cent of paediatric cancers of the central nervous system and has a sur-

vival rate of less than 10 per cent in children younger than three years. Recoiling from the screen, Hemon vowed to never again research Isabel's condition on the internet. In future he would only talk to and trust her doctors.

What follows is a broad and sanitised outline that doesn't go into the gruesome and horrific details of Isabel's assault and battery at the hands of the medical profession. If what happened to Isabel happened in any context other than medical care, it would be considered unethical, immoral and illegal.

The day after the MRI, a catheter was implanted in Isabel's head, to help drain and relieve the pressure from accumulated cerebrospinal fluid; however, her tumour expanded to fill the vacated space and its blood vessels began to burst. Immediate removal of the tumour was the only way to prevent her haemorrhag-

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ing to death. She survived the surgery and the surgeon believed he'd removed most of the tumour, which was now confirmed as a teratoid rhabdoid; however, after a few days, another tumour, inoperable, was discovered in her frontal lobe. In less than three weeks from her presentation at emergency, Isabel had undergone two brain resections, six additional surgeries to address the failure of the cerebrospinal fluid to drain, and a tube was inserted into her chest so chemotherapy drugs could be administered directly into her bloodstream. According to Hemon, the oncologists

didn't wish to discuss Isabel's prognosis at this stage and neither he nor his wife dared to press them. Hold on to that for a moment. What dynamics were operating here?

As teratoid rhabdoid tumours are so rare there are few drug protocols specifically designed for them. Isabel's oncologists decided on six cycles of chemotherapy of extremely high toxicity. To help her bone marrow recover, Isabel's blood cells needed to be extracted before each cycle, so they could be re-injected afterwards, in a process called stem cell recovery. I'll spare you the grisly and appalling details of Isabel's chemotherapy, apart from sharing Hemon's observation that an illness like his daughter's "causes a breakdown of all biological, emotional, and family order: nothing goes the way you expect, let alone want, it to". The problem wasn't communication; the oncologists did lots of communicating; however, Hemon says, "there were too many words, and they were far too heavy and too specific to be inflicted on others"; also, the oncologists, as professional and caring as they may have been or appeared to be, only spoke about treating Isabel. On top of that—and other unfortunate

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communications with friends and acquaintances who were in denial and wanted to avoid the difficult reality at hand—Hemon and his wife felt they were living in an aquarium. The walls of the aquarium were made of other people's words; there was no one on the inside with them: no one.

While Isabel was receiving the last drug of her third chemo cycle, her sodium levels dropped and she had a seizure. Breathing tubes were administered, along with heavy sedation to prevent her from removing the tubes. She had to stay in ICU until her sodium levels stabilised, and they never did. Her blood pressure dropped and drugs were pumped into her to keep it up. At that point, her oncologists sat the parents down and told them their daughter's state was dire. If Hemon is a reliable witness, this was apparently the first time he and his wife were asked to be responsible for the decision to continue: the doctors now made it clear the parents had to tell the medical profession when to stop.

Hemon's memory collapsed at this point. His wife was in the corner weeping ceaselessly and quietly; he says the terror in her face was literally unspeakable. Isabel's heart stopped beating. A resuscitation team did compressions and brought her back to life while Hemon wailed, "My baby! My baby! My baby!" Then Isabel's kidneys failed and she needed dialysis, which she may not have survived, but the medical profession offers it and the parents agreed to it. Then her heart stopped beating again and the resuscitation continued. The ward became the scene of a tragic opera, with unknown people in the hallway rooting for Isabel, some of them in tears, while Hemon kept howling, "My baby! My baby! My baby!" The compressions continued and Isabel's heart started again, after the doctor admitted she'd been clinically dead for twelve minutes. Then her heart stopped again. A young resident half-heartedly compressed Isabel's chest, waiting for the Hemons to tell her to stop. They finally told her to stop. She stopped. The nurses removed all the tubes and wires and everyone cleared out. The parents were finally left alone to hold the body of their bloated, battered, dead baby.

Hemon is clearly hostile towards religion, which he considers a soothing opiate. The hospital chaplain was ordered not to go anywhere near him or his wife throughout their ordeal, as they feared those who might offer the solace of platitudes. As Hemon puts it:

One of the most despicable religious fallacies is that suffering is ennobling—that it is a step on the path to some kind of enlightenment or salvation. Isabel's suffering and death did nothing for her, or us, or the world. We learned no lessons worth learning; we acquired no experience that could benefit anyone. And Isabel certainly did not earn

ascension to a better place, as there was no better place for her than at home with her family.

It would be insensitive to argue against these sentiments, which Hemon has every right to hold, apart from noticing that he's obviously never heard of CPE. He's putting hospital chaplains, which in this case are paediatric chaplains, in a false position; few would offer the solace of platitudes; most are more aware and better trained than that. Also, many readers of "The Aquarium" will believe that what happened to Isabel was far more despicable than any religious fallacy.

The following month, the magazine published two important letters about Hemon's essay, both written by women. Leah Rosenberg MD makes a significant point:

During the final medical crisis of Isabel's life, Hemon writes, the doctors "made it clear that we would have to be the ones to tell them when to stop trying." While I assume all present clinicians knew the likely outcome, there is a common belief among doctors that you bolster patient (or surrogate) autonomy through the "reasonable parent" standard. But this can go too far. As physicians, we need to remember that asking for reason as a child slips away is not only an impossible request but one lacking in empathy. We owe more to parents of children in medical crisis than a complicated menu of choices in the midst of a tragic situation.

Marilyn Mitchell expands this point and brings us closer to the ethical and moral issue:

Hemon characterizes the possibility that his daughter's suffering is ennobling as a "despicable religious" fallacy, yet it may be instrumental in sparking conversation about death in today's world. The doctors asked Isabel's family if they should do "everything they could to save her." But we cannot save anyone forever. Americans cling to a fantasy of fighting to the bitter end as a noble ideal. It's not. If the conversation had been about how the Hemon family would like to share Isabel's last moments, they might have had memories of her peaceful death. Instead, they held a body that had been battered by compressions. Until we adopt language that accepts the reality of death, our medical system will continue to practice an expensive and violent ritual that leaves everyone involved battered.

At what point should this conversation begin? If I'm hearing her correctly, Mitchell would have started it when Isabel's body began to shut down, at the end

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of her third cycle of chemotherapy, but I'm going to stick my neck out and suggest the conversation should have begun much earlier. Palliative care should have been discussed as an option—perhaps as the preferred option—before chemotherapy began, before all the unnecessary surgery and poisoning, before most of the avoidable assault and battery. Isabel's quality of life should have been the primary concern soon after her first surgery, once the diagnosis of teratoid rhabdoid was confirmed, once the surgeon admitted not all the golf-ball-sized tumour was removed, once another tumour, inoperable, was discovered.

The ethical and moral questions here are: How do we protect vulnerable human beings like Isabel who can't give informed consent? What are her rights? What are our responsibilities towards her? Who are her best advocates? Is she the property of her parents—to do with as they will in the name of love or some other difficult and complex emotion—or are they merely her custodians? The conversation about Isabel's quality of life should have been guided by the prognosis not by the medical profession and the parents colluding—albeit unconsciously—to deny the reality of the prognosis. The conversation may be difficult and fraught but it's necessary. My CPE supervisor would probably disagree and try to convince me I think too much and feel too little; however, that attitude all too easily elides into moral relativism.

FOR AN EXAMPLE of good work, read "Letting Go", by Atul Gawande (*New Yorker*, August 2, 2010), in which he shares what he's learned about the enormous value of palliative care.

Gawande once thought hospice was about providing "comfort care" for the terminally ill, sometimes in specialist facilities, though nowadays it's usually at home. In order for his patients to become eligible, he had to certify they had less than six months to live. Few of his patients chose it because they had to sign a form acknowledging their condition was incurable and they were giving up on medical attempts to cure it. His horizons began to expand, once he began accompanying a palliative care nurse, Sarah Creed, on her neighbourhood rounds. What Creed did confused him, as a lot of it seemed to be about extending her patients' lives. Wasn't the goal to let nature take its course?

"That's not the goal," Creed said. The difference between standard medical care and hospice care isn't between treating and doing nothing, it's in priorities. In ordinary medicine, the goal is to extend life: We'll sacrifice the quality of your existence now—by performing surgery, providing chemotherapy, putting you in intensive care—for the chance of gaining time later. Hospice care helps patients with terminal illness have the fullest possible lives right now. That means

focusing on objectives like freedom from pain and discomfort, maintaining mental awareness for as long as possible, or getting out with family once in a while. Hospice and palliative-care specialists aren't much concerned about whether that makes people's lives longer or shorter.

Like many people, Gawande once believed hospice care hastened death, because patients forgo hospital treatments and are allowed high-dose narcotics to combat pain, but studies suggest otherwise. In one, researchers in the United States followed 4493 Medicare patients with either terminal cancer or congestive heart failure. They found no difference in survival time between hospice and non-hospice patients with breast, prostate or colon cancer. However, hospice care seemed to extend survival for some patients; those with pancreatic cancers gained an average of three weeks, those with lung cancer gained six weeks, and those with congestive heart failure gained three months. The lesson seems almost Zen: you live longer only when you stop trying to live longer.

Creed enters people's lives at a strange moment; when they understand they have a fatal illness but haven't necessarily acknowledged they are dying. "I'd say only about a quarter have accepted their fate when they come into hospice [care]," she says. When she first encounters her patients, many feel they've been abandoned by their doctors. "Ninety-nine per cent understand they're dying, but one hundred per cent hope they're not," she says. "They still want to beat their disease." The initial visit is always tricky but she's found a way to smooth things over. "A nurse has five seconds to make a patient like you and trust you. It's the whole way you present yourself. I do not come in saying 'I'm so sorry.' Instead, it's 'I'm the hospice nurse, and here's what I have to offer you to make your life better. And I know we don't have a lot of time to waste.'"

Creed faces many challenges: assessing the family's ability to look after the patient at home; teaching the family how to care for the patient; ensuring that all the patient's treatment medications are being taken, that pain pumps are available and being used, that the patient or carer is trained to contact the hospice carer rather than calling 911 when an emergency arises. The last two challenges are particularly difficult: some patients are reluctant to take narcotics to relieve their pain because they don't want to need them, because they don't want to become a drug addict, because it feels like defeat; also, some patients never become reconciled to the incurability of their illness and prefer to go to ICU even though ICU rarely succeeds with terminal patients.

Palliative care has tried to offer a new deal for how we die. But doing so represents a struggle—not only against suffering but also against the seemingly unstop-

pable juggernaut of medical treatment. There are many reasons for the juggernaut.

First, doctors have unrealistic expectations about what they can achieve (a good outcome for them might be extending the quality of life by a year or two) and the expectations of patients are even more unrealistic (a good outcome for them might be extending the quality of life by a decade or two). One Harvard researcher asked the doctors of nearly 500 terminally ill patients to estimate how long they thought their patient would survive and then followed the patients. Sixty-three per cent of doctors over-estimated survival time, 17 per cent underestimated it, and the average estimate was 530 per cent too high; also, the better the doctors knew their patient, the more likely they were to err.

Second, we often avoid voicing these sentiments. Studies find that, although doctors usually tell patients when a cancer isn't curable, most are reluctant to give a specific prognosis, even when pressed. More than 40 per cent of oncologists reported offering treatments they believed were unlikely to work. In an era in which the relationship between doctor and patient is increasingly miscast in retail terms—the customer is always right—doctors are especially hesitant to trample on a patient's expectations. They worry far more about being overly pessimistic than they do about being overly optimistic, and talking about dying is enormously fraught. Gawande admits to having avoided these conversations himself. There have been times when he believed the best course with a terminally ill patient was to do nothing; however, explaining the reasoning for that meant confronting the patient with their mortality, something even Gawande has felt ill-prepared to do.

There's another problem here too. A doctor can present the odds to a patient, but who's to say they're zero? Take, for example, the experience of palaeontologist and writer Stephen Jay Gould, who published an extraordinary essay in 1985: "The Median Isn't the Message". Faced with a diagnosis of an incurable abdominal mesothelioma, he looked at the graphs of patient survival curves and saw a remarkable variation. Patients weren't clustered around the median survival but, instead, fanned out in both directions. Moreover, the curve was skewed to the right, with a long tail, however slender, of patients who lived many years longer than the eight-month median. This is where Gould found solace. He could imagine surviving far out in that long tail. And he did. Following surgery and experimental chemotherapy, he lived twenty more

years before dying in 2002 from a lung cancer unrelated to his original disease. While Gould accepted the wisdom of Ecclesiastes—there's a time to love and a time to die—for most situations he preferred to take the martial view that death is the ultimate enemy to be fought.

Gawande thinks of Gould's essay every time he has a patient with a terminal illness. There's almost always a long tail of possibility, however thin. What's wrong with looking for it? Nothing, of course, unless it means we've failed to prepare for the vastly more probable outcome. The trouble is we've built our medical system and culture around the long tail. We've created a vast edifice for dispensing the medical equivalent of lottery tickets and have only the rudiments of a system to prepare patients for the near-certainty those tickets won't win.

This is the modern tragedy replayed millions of times over. When there's no way of knowing exactly how long our skeins will run; when we imagine ourselves to have much more time than we do; our every impulse is to fight, to die with chemo in our veins, a tube in our throats, and fresh sutures in our flesh. The fact that we may be shortening or worsening the time we have left hardly registers. We imagine we can wait until the doctors tell us there's nothing more they can do, but they can always do more. They can give toxic drugs of unknown efficacy, operate to remove part of the tumour, put a feeding tube in a person who can't eat: there's always something. We want these choices. We don't want anyone—certainly not bureaucrats or the marketplace—to limit them.

Patients who had substantive discussions with their doctor about their end-of-life preferences were far more likely to die at peace and in control of their situation, and to spare their family anguish.

IS THERE A way out of this dilemma? Yes. In late 2004, executives at Aetna, an American insurance company, started an experiment. They knew only a small percentage of the terminally ill ever halted efforts at curative treatment and enrolled in hospice care, and when they did it wasn't until the very end. So Aetna decided to let a group of policy-holders, with a life expectancy of less than a year, receive hospice services *without* forgoing curative treatments. Patients could continue to try chemotherapy and radiation, and go to hospital when they wished—but also have a hospice team at home focusing on what was needed for the best possible life. A two-year study of this "concurrent care" program found that enrolled patients were much more likely to use hospice care: the figure leapt from 26 per cent to 70 per cent. That was no surprise, since they weren't forced to give up anything. The

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surprise was that they did give up things: they visited emergency almost half as often as the control patients; their use of hospitals and ICU dropped by more than two-thirds.

This and other evidence in favour of palliative care has grown in recent years. To take another example, two-thirds of terminally ill patients in the national 2008 Coping with Cancer Study in the United States reported having no discussion with their doctors about their goals for end-of-life care, despite being, on average, just four months from death, but the one-third who did were far less likely to undergo cardiopulmonary resuscitation, be put on a ventilator, or end up in ICU. Those who enrolled in hospice care suffered less, were physically more capable, and were better able, for a longer period, to interact with others. In other words, patients who had substantive discussions with their doctor about their end-of-life preferences were far more likely to die at peace and in control of their situation, and to spare their family anguish.

Can mere discussions really do so much? Yes they can, although the conversations are difficult and doctors are ill-prepared for them. Gawande spoke to Susan Block, a palliative-care specialist in his hospital system who's had thousands of these conversations and is a nationally recognised pioneer in training health professionals in managing end-of-life issues with patients and their families. "You have to understand," Block told him, "a family meeting is a procedure, and it requires no less skill than performing an operation."

One basic mistake is conceptual. For doctors, the primary purpose of a discussion about terminal illness is to determine what people want—whether they want chemo or not, whether they want to be resuscitated or not, whether they want hospice care or not. Doctors focus on laying out the facts and the options but that's a mistake, Block said, as a large part of the task is helping people negotiate the overwhelming anxiety about death, suffering, loved ones and finances. There are many worries and real terrors. No one conversation can address them all. Arriving at an acceptance of one's mortality, and a clear understanding of the limits and the possibilities of medicine, is a process, not an epiphany. There's no single way to take people through the process, but, according to Block, there are some rules. You sit down. You make time. You're not determining whether they want treatment X versus Y. You're trying to learn what's most important to them under the circumstances, so you can provide informa-

tion and advice on the approach that gives them the best chance of achieving it. This requires as much listening as talking. If you are talking more than half of the time, Block says, you're talking too much.

Also, the language the medical profession uses matters. For example, according to experts, you shouldn't say, "I'm sorry things turned out this way", as this can sound like pity. You should say, "I wish things were different." You don't ask, "What do you want when you are dying?" You ask: "If time becomes short, what is most important to you?" These are sometimes called "breakpoint discussions"; a systematic series of conversations to establish when to switch from fighting for time to fighting for the other things that patients value. Not enough doctors have these conversations and there's good reason to dread them. They can unleash difficult emotions. Patients can become angry or overwhelmed. Handled poorly, the conversations can cost a person's trust. Handled well, they still take time.

GIVEN HOW PROLONGED these conversations have to be, Gawande notes they revolve around a still unresolved argument: about what the function of medicine really is. The simple view is that medicine exists to fight death and disease; that is of course its most basic task. Death is the enemy. But the enemy has superior forces. Eventually it wins. And, in a war you can't win, you don't want a general who fights to the point of total annihilation; you want a general who knows how to fight for territory when he can and how to surrender when he can't; you want a general who understands that the damage is greatest if all you do is fight to the bitter end. More often, these days, medicine seems to supply neither kind of general. Doctors are increasingly generals who march the soldiers onwards, saying all the while: "You let me know when you want to stop." All-out treatment, doctors tell the terminally ill, is a train you can get off at any time: just say when.

For most patients and their families, this is asking too much. People only die once. They have no experience to draw upon. They need doctors and nurses who are willing to have the hard discussions, who'll help them prepare for what's to come and give them the opportunity to escape the fluorescent warehouse oblivion of death in an ICU which few really want.

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