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Red Towels: Maximizing the Care of Patients Who Are Dying

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In this issue of *The Journal of Clinical Ethics*, in “Last Hours of Life: Encouraging End-of-Life Conversations,” Benjamin F. Stump, Craig M. Klugman, and Barbara Thornton report findings on what people said they most wanted in their last hours. Some of what they wanted wasn’t surprising. Those surveyed particularly wanted to be with their family and loved ones, and wanted them to do well later. (“Families and loved ones” will be referred to as “families” for the remainder of this discussion.) People also wanted to be with their pets. Other wants were surprising, for instance, a particular aroma or being outside. An unexpected and even disturbing finding was that people may *not* want to be with careproviders, which may have significant implications for careproviders.

Based on these findings, how can careproviders help patients to the greatest extent possible during their last hours? Since patients’ last hours may be profoundly affected by their prior experiences, how can careproviders best care for patients during the weeks and months prior to their death?

The best approaches may not be as well known as they could be. For instance, during a meeting that I attended not long ago, a careprovider asked if anyone present knew of a local careprovider who was especially skilled in treating patients who were imminently dying, because he was seeing a patient who desperately needed this care. (Patients who are “imminently dying” will be referred to as “dying” throughout the remainder of this discussion.) More than 100 local careproviders were there, but not one knew a single careprovider who fit this bill.

Given this, I will discuss here what careproviders can best do for dying patients, beginning many months before their lives most likely will end. In this issue of *JCE*, Stump, Klugman, and Thornton provide a worksheet of important questions that careproviders can ask patients. As a supplement to this, I will add some other things that careproviders should know. I will not review much of what is well-known, such as the importance of listening to patients.¹ Rather, I will focus on less well-known interventions — for instance, that family members of patients who are dying at home from some kinds of head or neck cancers may want to buy red or black towels. On rare occasions patients may suddenly start “bleeding out” if their cancer involves their carotid artery and the skin of the neck. Dark-colored towels may reduce the horror that patients and their family members experience, and buying towels to prepare for this possibility may at least help them feel more prepared.² This one example represents many others that are not common knowledge, and so I include it in the title of this article.

MEETING PATIENTS' NEEDS AS INDIVIDUALS

Careproviders should attend to patients' most urgent needs first, *as they are determined by the patients*. A common, most important example, and the one I will discuss as a paradigm, is relieving patients' pain — and ensuring that patients know their pain will be relieved.

Relieving Physical and Emotional Pain

When patients have physical pain, careproviders should know the best current approaches to safely give them optimal relief, for example: how to give the fastest pain relief possible; how to give *different* pain meds, because one may be successful when another isn't; and how to relieve side-effects such as constipation, which may be persistent.³ If careproviders lack this expertise, they should refer their patients or consult. Patients may have excruciating emotional pain, and how to best treat that is more ethically controversial. Standard treatments such as antidepressants and anti-anxiety meds may be most helpful, but even these meds may not substantially reduce the greatest source of pain: the anguish that one is dying.

When patients have profound and unremitting physical *or* psychological pain, regardless of the source, they may benefit greatly from knowing in advance that if their pain stays as bad or gets worse, their careprovider will do *whatever is necessary* to make it bearable.⁴ Patients may be afraid to ask whether their careprovider will do this and feel "petrified" that their careprovider will abandon them. Careproviders who will provide relief when needed should take the initiative to tell patients this. In extreme cases, it might mean giving patients adequate sedation, at least temporarily.⁵

It may be possible to heavily sedate patients for only a short time, such as a few days, and then see if they continue to request the same level of relief. Some patients may change their minds. One fear careproviders may have is if they take the initiative to make such a promise to patients in advance, it may be seen as suggesting the option, and, as a result, the suggestion may become a self-fulfilling prophecy. Patients could, for example, from the first time their careprovider mentions this level of relief, want it, and then they may never have the opportunity to have positive experiences such as finding meaning and joy in their last days, as otherwise might be possible and more beneficial for them. This could happen. Conversely, taking this initiative might have a paradoxical effect: it may *decrease* the likelihood of patients' ending their lives. Patients' anguish, physical or emotional, may decrease when they know that they *could* have relief should they need it. Patients may experience relief because they can see this light, at least, at the end of the tunnel.

A related controversial question is whether careproviders should try to relieve incompetent patients' pain in the same way. Compassion and justice might "argue" that careproviders should give incompetent patients equivalent relief. Readers who want to consider a case in which careproviders gave an incompetent patient such relief may review several articles published in a previous issue of *JCE*.⁶ Incompetent patients may be much less able to find meaning that helps them compensate for the pain they have in their lives. Current practice may favor giving only competent patients a greater degree of pain relief; it might be, however, that the "threshold" for giving incompetent patients adequate pain relief should be lower. They can't request pain relief; if, due to pain, the quality of incompetent patients' lives is wholly negative, it is open to question (if they could express themselves) whether they would want to stay alive under these conditions.

Optimal Interventions

Careproviders should attend to patients' physical and emotional pain, and they should also ask patients about their other needs — things that are very important to them but are less obvious to others. Careproviders might then ask themselves whether a patient is in denial about dying, and, if this seems to be the case, the degree to which this should be respected. When patients aren't in denial, careproviders can concentrate on giving them the information they need, doing it in a way that allows patients to retain hope. If patients are given too much information or are given it too early, it may break through their denial and harm them.

When patients do not want information because they are denying they are dying, they may indicate this explicitly or suggest it with nonverbal behavior, such as avoiding the topic or showing great anxiety during

discussions about it. Careproviders may believe that they should always confront denial, or at least try to nudge patients so that they increasingly accept the reality that they are dying, over time. Careproviders have good reasons for wanting to nudge. Without denial, patients can try to get their affairs in order and, more importantly, be able to find meaning and even joy with loved ones during the time they still have together. Patients can also participate in and make medical decisions. When patients can participate, it is much easier for careproviders. Such increased ease cannot, however, be used as grounds for careproviders to break through a patient's denial.

Instead, careproviders should know that patients and families may be unable to overcome their denial at any given point in time. One careprovider who works extensively with dying patients reports that, with one patient, he was "reduced to" either supporting her denial or "alienating her completely."⁷ Some patients may do better if their careproviders do not confront their denial,⁸ because they need to accept dying at their own pace — if at all. This possibility is suggested by a recent study conducted in Japan. All of the patients in the study were inpatients on the same ward and were dying of liver cancer, but their careproviders didn't tell them they were dying. The patients accepted death at a pace that was acceptable to them. The authors claim that although there was no control group, based on the responses of equivalent patients who had been told they were dying, the patients who were not told died much more peacefully.⁹ A wish to remain in denial may vary by culture. Patients from some cultures will want all information to be given to their families.¹⁰

Still, careproviders should be careful not to stereotype patients on the basis of their culture. They should not presume that patients share the beliefs attributed to a majority in their culture. Next-door neighbors may have radically different beliefs. I recall a patient's wife who shouted out to him with each breath to fight on so that he could get well, even as he died. This was her way to be with him as he died. Perhaps it was his way as well. I have seen her many times since and she has done well.

Careproviders should generally *not* try to break through denial, since it most likely will be futile and may make the denial worse.¹¹ When possible, careproviders should ask patients in advance what they would want. They might ask, "If you were dying, whom would you want me to tell?" If patients say that they don't know what they want, or say that they wouldn't want to know, careproviders can ask whether they would want to discuss "just the pros and cons" of knowing or not knowing another time, possibly later. Careproviders can say that the patients might be better able to decide at a later time, when (if ever) they might want to know more.¹²

This uses an approach called motivational interviewing, which presupposes that people change mostly in stages, and that careproviders can most help a patient by responding only to the stage that the patient is in. Some patients who are dying may believe that the gains of not knowing surpass those of knowing. The goal is not to oppose this position, but rather to reframe it or even side with it, "so that it becomes the patient who is the one arguing for change."¹³ Asking a patient whether she or he would want to discuss the pros and cons of knowing may support the patient's denial, rather than cause the patient to feel pressured. This should enhance the likelihood that the patient will give up denial, if she or he can. If a patient doesn't want to discuss the pros and cons, careproviders might say, "We can always discuss the pros and cons together later. But if we do it later, it could be more difficult. Then we may know more about your illness, and we may lose the opportunity for you to decide, in advance, that you do not want to know that you have an illness that could end your life. But even considering this may be too stressful. Should we go on to discuss other things?"

It might seem that this tack might increase patients' stress, leading to increased denial. In this instance it may be ethically warranted for careproviders to take that risk. When patients are rapidly dying, it may be preferable not to even ask if they want to discuss the pros and cons, as it might cause patients to feel more fearful, and make it more unlikely that they can accept that they are dying.¹⁴

The risk that patients will respond negatively may be reduced by acknowledging the responses they might have before they speak. Ngo-Metzger, Legedza, and Phillips offer a superb example when they discuss how careproviders should decide whether to counsel patients directly: on the one hand, if careproviders directly counsel when patients prefer nondirective counseling, patients can see this as "a lack of collaboration"; on the other hand, if careproviders are nondirective when patients would prefer them to be directive,

patients may "lose confidence" in their careprovider.¹⁵ The authors suggest that careproviders ask patients whether they want only to be given options, or to know what the careprovider thinks they should do. The authors recognize a particularly subtle reality, that careproviders risk unduly harming patients if they give only one of the options explicitly, rather than both, even though the meaning of only giving one option is just the same.

Patients may prefer receiving bad news to receiving no news, because even bad news may be less painful than uncertainty. Consequently, careproviders who see dying patients should ask patients repeatedly whether they want more information. Ideally careproviders might say that there are no dumb questions, but rather only questions that patients don't ask.¹⁶ Patients may need additional encouragement to ask the questions that are most important to them. Careproviders should go beyond this and anticipate what patients might want to know; they might want to know, for example, the most likely clinical course, and — but only if they say they want to know — the worst outcomes they could expect.¹⁷ Patients with certain kinds of cancer may, for example, be more likely to have a rapid downhill course; those with heart and lung disease may die abruptly or wax and wane for some time; those with dementia may go more steadily downhill.¹⁸

Patients with chronic obstructive pulmonary disease (COPD) are a good example of a group who may want to know how they will probably die — or, rather, how they will not die, due to their careproviders' interventions.¹⁹ Their concerns may be greater than that of other patients, because they may fear (rightfully) that they may die with feelings of suffocation. Giving dying patients the information they desire respects their autonomy to the utmost degree. It may also help them decide what they want to do to make their remaining time most meaningful.²⁰

This is crucially important when patients have little time. Some careproviders say that when patients want this information, they should be told, even that they have only "minutes to hours," although it must always be acknowledged that exceptions are possible in either direction.²¹ Often patients find it very meaningful to tell their families how much they love them, to express their gratitude to them, to ask for forgiveness, and to give forgiveness in return.²² Many find it meaningful to recall with their families the times they have shared, and sometimes to say their last goodbyes.

Some patients and families will not share in these ways for various reasons; for instance, it may not even occur to them to try. Or they may be afraid it would cause too much pain for them or family members. Careproviders can help patients and families by taking the initiative to say that when patients are dying, many patients and families find this kind of sharing deeply meaningful and emotionally rewarding.

When careproviders share the likely course of an illness with patients — for example, how much time they have left — they should also acknowledge their uncertainty.²³ This respects and benefits patients because it increases their knowledge, and such uncertainty may provide a needed source of hope for some patients. Careproviders may want to meet this need, although it may be essentially irrational. Careproviders can also acknowledge the frustration that *they* feel as a result of this uncertainty.²⁴ This may model for patients how they can share painful feelings, and it may help them to feel less alone.

Are there limits to how far careproviders should go in anticipating information that patients might want to know? A test example might be careproviders who tell patients on a respirator that they may have a "window of opportunity" during which they may be able to die suddenly, rather than taking a longer time. That is, in some circumstances a patient can't breathe without assistance because of damage to the brain. Brain function may improve over time, so the patient might die if the careprovider discontinues the respirator *early on*, but the patient might not die if the respirator is discontinued later. If the patient — and, thus, the careprovider — waits too long to decide, the brain may recover enough that if the respirator is withdrawn, the patient will be able to breathe without assistance, and if the patient still wishes to die, he or she may only be able to die in another way, such as by not taking food and water.

Should careproviders tell patients who may be in this situation that they may have only a limited time during which they could die quickly by discontinuing the respirator? Some careproviders may believe that they should never give patients this much information. Their rationale may be somewhat like the concern discussed earlier, that informing patients about temporary sedation could result in this becoming a self-

fulfilling prophecy. Even if this should happen, however, it may still be ethically preferable for careproviders to share such information, because it enhances patients' autonomy. Having greater autonomy is particularly important here, because the stakes are as high as they can possibly be — life or death.

This may provide emotional benefit for some patients. They may feel that they have greater control, and this is a time, surely, that patients most need this. Finally, this is an intervention that careproviders can do early on, before patients are dying, that may profoundly affect patients' experience of dying later. Why? Because patients may know, rather than hope, that their careprovider will provide what they need in the future. Patients will trust their careprovider, and this itself may give patients great relief.

People often need, or at least want to continue to have, hope, even when their reasons for hope are almost completely irrational. Patients who know that they are dying may greatly need and want information, but receiving this information may quash their hopes. What should careproviders do? Some careproviders who specialize in working with dying patients urge patients to try to adopt new hopes for different outcomes, other than continued survival. An example is the hope to die in a way that will enable family members to remember them well. This may be preferable by far for patients, because such hope is based in reality. There is a great deal of evidence that people *can* find new reasons for hope. Parents who have children who are born with the most profound special needs must give up their old hopes and replace them with hopes that are new; they must find what some refer to as "a new normal" life. Many are able to do this. Many find a life that is as rich or richer than usual, finding meaning and joy in sharing their lives with their children. People who are dying, or who are with people who are dying, can find "a new normal" life that is rich. A paradigmatic example is patients who have Alzheimer's disease. Abigail Thomas, the wife of a man who has Alzheimer's disease, writes, "Rich and I sit together, we hold hands . . . that's all the communication we need."²⁵

Sometimes it isn't possible for patients to find meaning or to experience hope in a different "new normal," possibly because time is too limited time, or because it seems as though time is too limited. Careproviders have no choice but to tailor the care they provide to the needs of each patient. It may be possible to let patients retain some hope while still telling them the truth. Ngo-Metzger, Legedza, and Phillips suggest several possibilities. Careproviders may suggest that patients hope for the best while expecting the worst. Careproviders can discuss much of what patients will experience and what patients might want their careprovider to do in the "worst-case scenario," while at the same time not "taking away" the "possibility of the best-case scenario."²⁶ Another approach suggested is "sequential treatment." In this approach, careproviders support patients, but also discuss what the next step will be *if* the initial treatment isn't successful. This approach sets "practical parameters and allows discussion of alternatives if the initial treatment is unsuccessful."²⁷ They also suggest that careproviders can refer patients to a Phase 1 clinical protocol; indeed, some believe that careproviders have an ethical duty to make patients aware of such research opportunities when they are available.

There are other options. Careproviders may be able to tell patients truthfully that while statistically they are likely to die soon, there may be exceptions. They can also tell patients truthfully when there is no medically certain reason that they can't recover. I think of a patient whose liver failed, and then his kidneys. Each day his lab values got worse, and all of his doctors believed that he would die, except me. No one knew why his organ systems were failing or why they continued to do worse. I didn't know that the patient would do better, but, on the basis of medical uncertainty, I did know that his dying wasn't inevitable. I told him that, and with his permission also told his wife. Days later when I arrived on the ward and checked the lab reports from the previous evening, I couldn't believe my eyes: the lab results weren't worse, in fact they got better, and so did the patient. It's noteworthy how the patient and his wife responded when I indicated that I had some hope. Their relationship totally changed. He had been silent and forlorn; she, irrational and demanding. Their relationship was emotionless and distant, but with some hope, he could smile, as could she. Their relationship became virtually ceaselessly intimate and, indeed, overtly passionate.²⁸

Patients may respond differently. They may feel rage. They may "expend their waning energies," as one careprovider put it, "lashing out at the Grim Reaper."²⁹ If this happens, careproviders shouldn't imply that somehow patients should die a "better" death. They should validate patients' feelings and be present so they

don't feel so alone.³⁰ To confirm that such feelings are valid may have a paradoxical effect: patients may feel more positive because they feel validated and because they feel less alone.

I recall a patient who had been caring for his wife constantly since she was bedridden. He developed cancer and knew he would be the first to die. "I planned to continue to care for her, and for her to die first!" he shouted from his hospital bed. He convinced his best friend to bring to him a knife, but it was spotted before he could use it. I said, "All you wanted, you lost. I can't imagine how devastating this is." He responded wordlessly, indicating, "Yes, this is life." But he didn't try to take his life again.

Some careproviders might ask whether there are any limits — are there some times that careproviders should *not* validate how patients feel? I know of none, but I believe in expressing that there always may be some ground for hope, even when it can't be seen. For example, in even the worst-case scenario of patients who want temporary sedation, the patients may, on waking up, for unknown reason, feel better. The reason this happens, I might say to patients, may remain unknown, not only to me, but to them.

Helping Patients Who Aren't Dying

Careproviders can take these initiatives with patients who aren't dying, but who may have a limited amount of time to interact meaningfully with their family members. One example is patients with progressive dementia, whose illness will rob them of their capacity for cognition. Once they lose this capacity they may live on for several years. Further, they may not live on like Abigail Thomas and her husband, mentioned above. Patients with dementia may become much worse, and for them and their families it may be equivalent to death.

I think of a woman whose husband had Alzheimer's. He lived at a nursing home, and when she went to enjoy a concert with him, he sat with one arm around her on one side, and one arm around his "new girlfriend" on the other. He apparently still had a warm feeling toward his wife of 52 years, although probably undefined, but otherwise he had no idea who she was. Thus, careproviders should ask patients as early as possible if they want to discuss things with their loved ones while they still can. If patients don't want to do this, careproviders can ask whether they want to discuss even just the pros and cons, as described above. Also, as above, careproviders can point out that it might be more difficult to discuss the same issues later, that they know this might be very stressful, and so it might be too much to discuss, ever.

For patients who have Alzheimer's disease, such discussions will not be more difficult later because they will be near death; they will be more difficult later because the patients will be less likely to understand or respond. I had a patient who had very advanced Alzheimer's. I asked her if she wanted me to try to help her reconnect with her son, whom she hadn't seen in decades. She said "yes," so I did. When she saw him, she recognized him and they were able to talk. Soon after this meeting, she lost the capacity to recognize loved ones and the capacity to talk. There is no way for us to know how important meeting her son was for her, but from what happened after they finished talking that afternoon, it might be inferred. The patient's husband had driven her to where we all met in his pickup truck. I had come in my own car, but the patient didn't seem to realize that. After she had finished talking with her son, as she and her husband were leaving, she walked to the back of the truck and climbed up over the rear bumper into the open truck bed. "She's never done *that* before," her husband remarked. She seemed to want to express her gratitude to me by giving me the seat by her husband, in front.

HELPING PATIENTS BE WITH FAMILY

The best thing careproviders can do to help dying patients is probably to help them be with family and to help maximize their time together. Careproviders can help in many ways; for example, they can help family stay with patients in their hospital rooms. Ideally, careproviders may be able to help patients and family find a room where they can be together without the usual hospital noise, turmoil, and interruptions.

It may seem implausible, but with careproviders' support (and perhaps "a little pressure"), wards may allow this and other exceptions. Ann Berger, a nurse and internist who specializes in palliative care at the

National Institutes of Health, for instance, helped a dying patient have her small dog with her in the ICU.³¹ Some may believe that patients' feelings for their pets shouldn't be given the same respect and effort as feelings for family members. But, in general, patients should be allowed to define their own needs. Berger reports that arrangements were made for one patient to speak regularly with her dog over the phone. The dog would bark in response to hearing her voice!³² A question this raises is whether dying patients should have visits from young children.³³ This may be open to different views, based on what is or isn't best for the children. If the child's best interest isn't affected, this may be a situation in which wards may be willing to make an exception.

One very important intervention that careproviders can provide is to help estranged families reunite, as noted above. Here is the approach I have used. When I talk with patients, I listen for any ambivalence they have regarding family members they no longer see. If I hear this I make an offer: "It sounds as though you had *some* positive things together. I find that many patients gain greatly from being able to reunite with family members, even when they haven't seen each other for years. I would like to tell you how I do this. Is this okay?" If they say it is okay, I tell them that I contact the family member and say why I'm calling. I tell patients that, as their doctor, I will call their family member and ask for help, because that person can do something that I can't. I will ask the family member to come on the phone and talk with the patient and me, or come to be with us in person, even if for a minute. If the person wants to hang up or leave, even after only a minute, this is fine. I would feel only great appreciation. There would be one hitch: since I would be so grateful, I would want to insist on being able to end the phone call or meeting myself, if I thought that the family member was being harmed or even at risk of being harmed. I say that I am concerned that old patterns of behavior might repeat themselves, and I would want to be able to end the discussion, rather than allow any risk of harm. This has never yet been unsuccessful.

Should patients ever *not* reunite and forgive? Opinions differ. Years ago, Cornelia Wilbur, a psychiatrist, shared with me an argument against reuniting and forgiving. Wilbur treated a well-known patient called Sybil, who had multiple personalities, and whose life and therapy were depicted in a book and in films.³⁴ Sybil's mother did horrible things to her when she was a child. Wilbur asked me if I were treating Sybil whether my goal would be to try to help her to forgive her mother. I said yes; Wilbur said no. It would be bad for Sybil to forgive her mother, Wilbur explained, because her mother had done her such harm. The only "healthy" emotional response for Sybil, Wilbur maintained, would be for Sybil to sever ties completely and neither see nor forgive such a parent, forever. But I'm not sure that I can agree.

Maximizing Communication

If family members can be present, patients often find it very meaningful to share together what it means to each person that the patient will die. Some patients may deny that they are dying, but may know that they are dying and not want to tell their family. Hospital wards can establish practices to ensure that family members know that if a patient is dying, he or she can choose to keep this information confidential.³⁵ Patients may realize that it is more likely that family members may suspect that they are dying, even if the patients don't tell them. Patients and family members may not want to share their feelings with each other openly. This may be for any number of reasons, such as being afraid it would be too painful. Careproviders may help by taking the initiative to tell patients and their families that, despite their concerns, most patients and families greatly benefit from such discussions. One careprovider who specializes in this area tells patients and their families about this in a way that may allow them to maintain hope. He says, "Are there things you would want to say . . . just in case?"³⁶ When families do this, they are thankful later, because "They have made allowance in their calculations for their loved one's demise. . . ."³⁷

Careproviders should prepare patients that they might have negative interactions with family, to reduce the chance of harm. Family may respond in negative ways to physical changes in dying patients. We often see ourselves not as we are but as we imagine others see us, and as patients become increasingly ill, they may become particularly vulnerable to this. They may regress emotionally as they feel more helpless and become more dependent on how others see them, as small children do. When patients undergo changes such as losing

hair, some family members may shrink back and respond in negative ways, even if they try not to. Or family may respond to what patients do or say; as one careprovider notes, patients say "fearful things and wear . . . pained expressions that make their loved ones uncomfortable."³⁸ Changes may be profound, as when patients have cancer of the face or neck.³⁹ Family members may no longer want to go out with them to dinner, and the patients may feel guilty about it.⁴⁰

Careproviders should try to anticipate such outcomes when they can and discuss them with patients before they occur, so patients can be better prepared. Patients may find such experiences traumatic because they want their families to remember them in a positive way. Many dying patients focus on leaving their family the best memories of them they can, and as a result, may not want to others to see them, even people they love. They worry that being seen in a discrepant and debilitated state may affect how their family will remember them. For instance, when I was younger, my mental image of my father was as a grandfather to my two older children, with a bright twinkle in his eyes, pushing them on swings from the front, pushing them by their feet. Swinging toward him, their feet would push into him, smack into his belly. To the children's great delight, he would make a show of falling over backward, his white hair flying. Later he had a stroke and died after three months in a persistent vegetative state. Now my memory of him is not of his twinkling eyes, but of his eyes staring vacantly into space.

Careproviders should support patients who wish to be remembered well, even when it causes them to avoid those dearest to them. Careproviders should try to discuss this possibility with patients and family members ahead of time. Dying patients who refuse to see family members will probably need support from their careproviders, because the pressure from their families to see them may become very great.

Helping Families Afterwards

As Stump, Klugman, and Thornton report, dying patients' greatest concern often is not for themselves but for their family. Careproviders can help in various ways, from asking a patient if he or she would want to consider family members' emotional and financial needs when discussing advance directives, to telling a patient how they will try to help the patient's family before and after the patient dies. Careproviders rightfully focus on the care of the patient, but families may also feel devastated. Before a patient dies, careproviders can tell family members what they can probably expect.⁴¹ This may include physical changes in the patient and the negative responses that family members may have despite their best efforts. In this way careproviders can help patients and families deal with feelings such as shame and guilt. Careproviders can also anticipate and recommend practical measures such as buying red or black towels for patients with head or neck cancer, mentioned above.

If a patient is dying at home, it is important for families to have a number they can call to get help 24 hours a day.⁴² Families tend to fear sudden medical "disasters" that they don't know how to handle, and having a number can quell their fears, whether or not it's ever used. After the patient dies, careproviders can help families by giving them sound information regarding the process of bereavement.

Many people incorrectly believe, for example, that there is only one "right way" to grieve, and that if family members don't cry or at least grieve painfully in an obvious way, they didn't care. Ideally, careproviders can tell patients and family members together that there is no right way to grieve, and that if they don't grieve, they may be fortunate because that involves less pain, and it may indicate that they have especially good emotional health.⁴³ Careproviders should strongly consider calling the family after a patient dies to inquire how they are doing, to go to a patient's funeral (when possible), and to even write the family a note on the anniversary of the patient's death.⁴⁴ In considering any of these interventions, careproviders should consider that, to the family, they *and they alone* shared, and continue to be, a precious and unique part of their past. When careproviders decide they would like to do any of these things, it will benefit the patient to tell him or her about it as early as possible. The beneficial effect may be disproportionately great.

CAREPROVIDERS

For many, the worst aspect of dying is the fear of dying alone. Dying patients may benefit from doing these four things: saying "I love you," expressing thanks, forgiving, and asking for forgiveness. Obviously all of these are interpersonal. When patients don't have family members who are present, their careprovider may be all that they have. Stump, Klugman, and Thornton indicate that dying patients may *not* want a careprovider by their deathbed; it may be not because careproviders *can't* be immensely meaningful to patients at this time; it may be simply because they currently are *not*.

Ernest Becker, in his Pulitzer Prize winning book *The Denial of Death*, suggests that although people greatly fear death, one way to reduce this fear is to place childlike faith in another.⁴⁵ Such faith is largely irrational, since others can't forestall or prevent death — still, the effect of this faith, like religious faith, can be immense. Patients become more dependent and tend to regress when they become fatally ill, and become more like they were as children; thus careproviders should try to help patients, particularly when they have no one else, if they can.

Helping Patients as Much as Possible

There are guidelines that can help careproviders to maximize the time they can have with a patient, as brief as their time together may be. When careproviders come to see a patient, they should sit down as far from the door as they can. They should turn off their cell phone or beeper or leave them with someone outside the room who will answer it for them. They should listen attentively to the patient and, unless there is a cultural or psychological contraindication, communicate that they are fully attentive by looking the patient in the eye. Careproviders may feel nervous if they don't know what to say; they may fear that to talk about everyday things, such as sports or art, may risk trivializing that the patient is dying. They may fear that if they take the initiative to talk with the patient about death, it may be an unwanted downer.

I recall laughing together with a patient for hours, even though we both knew that he would soon die. I felt anxious because we were laughing, and I feared that I was being phony. But feeling either that one may be too light, on one hand, or too heavy on the other, may be right. St. Augustine wrote that he made jokes with his friend as his friend died, and his friend "shrunk back" as though St. Augustine was his "enemy."⁴⁶ But asking dying patients about their feelings may be the last thing that they want to hear. For example, one patient told his psychologist, "Barry, cut the psychological crap."⁴⁷

Many dying patients delight in laughing and interacting with others as though they aren't dying, maybe because it is distracting and gives needed relief. Such interactions create moments when patients are just people, rather than people who are dying. Actress Gilda Radner, who died of ovarian cancer, describes how careproviders came to her home and gave her chemotherapy: "They called it 'the chemo party' . . . Those nurses would make me laugh, or they'd dance around the bed and entertain me. . . . The chemo parties were like the scene in *Cinderella* when the little birds and mice come to wake up Cinderella in the morning. One minute you think her life's so bad, but then she has all these little friends. That's what I felt like."⁴⁸

When careproviders feel they have to choose between trivializing dying on the one hand, and being too serious on the other, I suggest they share their dilemma with the patient and ask the patient what she or he prefers. It might cause the patient some pain, but it avoids hiding or trying to repress feelings, and engages the patient as an equal. Asking helps a patient to say what she or he wants. As Callahan and Kelley note, "Don't push. Let the dying control the breadth and depth of the conversation." They add: "If you don't know what to say, don't say anything. . . . Sometimes the best response is simply to touch. . . . Touching gives the very important message, 'I'm with you'."⁴⁹

Dealing with Feelings

What should be done in response to exceptionally strong or even overwhelming feelings, for example, wanting to cry? You should.⁵⁰ This may be more meaningful to a patient than anything else that a careprovider does. On the other hand, careproviders may be especially vulnerable to denying feelings and then acting

them out. Careproviders have power and mixed responsibilities, and so may be prone to becoming exceptionally rigid. For instance, they may force an unnecessary "stand-off" between themselves and patients or families about whether patients should have cardiopulmonary resuscitation (CPR). Patients or families may change their view and accept a do-not-resuscitate (DNR) order if given more time. When careproviders feel unusually moved to oppose patients and families, they should make a habit to check their own views with others. They should do this routinely to help ensure that the position they take makes as much sense to them as it first seems, or that they are not "acting out" in response to exceptional pain and grief they feel due to a patient's dying.

Patients and families have exceptionally strong emotions in these circumstances, and may make requests that are not rationally based. Ambulance drivers report, for instance, that some families want them to perform CPR even hours after a patient has died. Some comply. They perform CPR to meet families' requests, although they may think this might be ethically wrong, since it would be like doing a "slow code." But some report that doing CPR, even if only for a few (token) minutes, almost miraculously gives some families immediate and profound emotional relief. It is as if they required ambulance personnel to make an attempt for them to have emotional closure.

CONCLUSION

Because the extent to which careproviders can cure is always limited, I have described some lesser known initiatives that careproviders may be able to use to help dying patients and their families.

NOTES

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2. N.E. Goldstein, E. Genden, and R.S. Morrison, "Palliative Care for Patients With Head and Neck Cancer," *Journal of the American Medical Association* 299, no. 15 (16 April 2008): 1818-25, p. 1824.

3. S.D. Block, "Psychological Considerations, Growth, and Transcendence at the End of Life: The Art of the Possible," *Journal of the American Medical Association* 285, no. 22 (June 2001): 2898-905, p. 2901.

4. J.R. Curtis et al., "Patients' Perspectives on Physician Skill in End-of-Life Care," *Chest* 122 (2002): 356-62, p. 359.

5. N. Modyl, N. Coyle, and K.M. Foley, "Managing an Acute Pain Crisis in a Patient With Advanced Cancer: 'This Is as Much of a Crisis as a Code'," *Journal of the American Medical Association* 299, no. 12 (26 March 2008): 1457-67, p. 1461.

6. Much of *JCE*, 17, no. 4 (Winter 2006) is devoted to the discussion of this question as it arose with Margaret, a 54-year-old woman with severe Alzheimer's disease.

7. B. Jacobs, "Reliable Witness: What It Takes to Be With Your Clients to the End," *Psychotherapy Networker* 31, no. 5 (2007): 35-9.

8. See note 3 above, pp. 2899-900.

9. Y. Maeda, "Psychological Process from Hospitalization to Death among Uniformed Terminal Liver Cancer Patients in Japan," *BMC Palliative Care* 5 (4 September 2006): 1-12, www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1574288, accessed 16 May 2008.

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11. See, e.g., Z. Tormala and R.E. Petty, "What Doesn't Kill Me Makes Me Stronger: The Effects of Resisting Persuasion on Attitude Certainty," *Journal of Personality and Social Psychology* 83, no. 6 (December 2002): 1298-313.

12. See note 3 above, p. 2900.
13. L.J. Griffith, "The Psychiatrist's Guide to Motivational Interviewing," *Psychiatry* 2008 5, no. 4 (April 2008): 42-7, p. 47. See, generally, W. Miller and S. Rollnick, *Motivational Interviewing, Second Edition: Preparing People for Change* (New York: Guilford Press, 2002).
14. See note 3 above, p. 2900.
15. Q. Ngo-Metzger, A. Legedza, and S. Phillips, "End-of-Life Care: Guidelines for Patient-Centered Communication," *American Family Physician* 77, no. 2 (2008): 167-74, p. 173.
16. J.J. Fins, *A Palliative Ethic of Care* (Boston: Jones and Bartlett, 2006), 197.
17. K.A. Lorenz et al., "Evidence for Improving Palliative Care at the End of Life: A Systemic Review," *Annals of Internal Medicine* 148 (2008): 147-59.
18. Ibid.
19. S. Wingate and D.L. Wiegand, "End-of-Life Care in the Critical Care Unit for Patients with Heart Failure," *Critical Care Nurse* 28, no. 2 (April 2008): 84-95.
20. T.E. Quill, "Initiating End-of-Life Discussions With Seriously Ill Patients: Addressing the 'Elephant in the Room'," *Journal of the American Medical Association* 284, no. 19 (2000): 2502-7.
21. Ibid., 2506.
22. M.J. Penta, "Ethics at the End of Life," presentation at the *NNMC Bioethics Symposium/ Ethical Issues at the End of Life*, Bethesda, Md., 22 April 2008.
23. See note 20 above, p. 2507.
24. Ibid., 2506.
25. A. Thomas, *A Three Dog Life* (New York: Harcourt, 2006), 162.
26. See note 15 above, p. 170.
27. Ibid.
28. S.C. Segerstrom, "Optimism and Resources: Effects on Each Other and on Health over 10 Years," *Journal of Research in Personality* 41, no. 4 (August 2007): 772-86; G. Von Ah, D.H. Kang, and J.S. Carpenter, "Stress, Optimism, and Social Support: Impact on Immune Responses in Breast Cancer," *Research in Nursing & Health* 30, no. 1 (2007): 72-83.
29. See note 7 above, p. 39.
30. See note 3 above, p. 2900.
31. A. Berger, "Challenges to Blending Palliative Care and Curative Therapy," presentation at the *NNMC Bioethics Symposium: Ethical Issues at the End of Life*, Bethesda, Md., 22 April 2008.
32. Ibid.
33. Ibid.; see also note 1 above, p. 1575.
34. F.R. Schrieber, *Sybil* (New York: Warner Books, 1973); *Sybil*, Lorimar Productions, 1976; *Sybil*, Norman Stephens Productions, 2007.
35. HIPAA regulations may allow careproviders to share information with families if patients haven't specifically told them not to. See note 10 above, p. 486.
36. See note 7 above, p. 39.
37. Ibid.
38. Ibid.
39. See note 2 above.
40. See note 3 above, p. 2902.
41. See note 10 above, p. 489.
42. Ibid., 488.
43. F.D. Ferris, "Basic Concepts in Palliative Care for Psychiatrists," presented at the 160th Annual Meeting of the American Psychiatric Association, San Diego, Ca., 22 May 2007.
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45. E. Becker, *The Denial of Death* (New York: Free Press: 1973), 148.

46. St. Augustine, *The Confessions of St. Augustine*, trans. R. Warnter (New York: New American Library, 1963), 74.

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49. M. Callahan and P. Kelley, *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying* (New York: Simon & Schuster, 1992), 227.

50. See note 7 above, p. 37.