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At the Bedside

Sweetening the "Sweet Spot" of Dementia

Edmund G. Howe

ABSTRACT

Alzheimer's disease is singularly tragic in that it may rob patients of much or all of their personal identity. Some persons fear this outcome so much that they talk of wanting to find the "sweet spot," a time midway in the course of ever-increasing dementia, during which they are able to foresee a possible loss of identity in sufficient time to end their life before they lose the capacity to choose to do so, and before further devastation occurs. This article presents the belief of some experts that patients always retain a basic, core underlying awareness. Practical approaches that careproviders and caregivers can take to maximize patients' quality of life are discussed. The possibility that patients and loved ones can find meaning in last months and years of life is emphasized.

It is a sad truth that we sometimes need a terrible shake-up such as COVID-19 to move us to pursue needs we have neglected. This includes our need to be as prepared as possible

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for the next pandemic, to be able to help other nations, and to care for our climate.¹ In this issue of *The Journal of Clinical Ethics (JCE)*, Megan E. Bunnell, Sarah M. Baranes, Colin H. McLeish, Charlotte E. Berry, and Robert B. Santulli discuss an innovation in which researchers had such foresight.² In "The Dartmouth Dementia Directive: Experience with a Community-Based Workshop Pilot of a Novel Dementia-Specific Advance Directive," they present a new approach for patients with dementia that provides patients different advance directives to fill out at different stages of illness. Patients can tailor these directives to their idiosyncratic needs.

This gain is significant because patients with mild dementia may dread the future when they may become more severely demented, and they will then have no control over what happens to them. For example, patients may lose the capacity to recognize a loved one they have lived with for decades and become attracted to a nursing home resident they hardly know.³ Or they may physically attack a loved one. Due to these kinds of fears, some patients with mild dementia look for the "sweet spot," a time when they are able to enjoy life despite encroaching dementia, are still able to anticipate what they will lose when they become severely demented, and are able to choose when to end their life.

In this article I seek to build on the gains that Bunnell and colleagues relate as a result of

graded advance directives. I discuss ways that careproviders may better help patients. (In this article I use “careproviders” to refer to clinicians, and “caregivers” to refer to family members and other nonclinicians.) Some of the ways that careproviders may help patients are uncommon, and a few clash with usual professional standards. But they may be optimal, because the outcomes of dementia can be so singularly negative.

In the first section of this article I present an overall view that experts in the area believe is critical for careproviders to know. In the second section I discuss the darker side of dementia. In the third section I suggest guidelines for practice. The first of the guidelines will describe exceptional interventions that careproviders may make before patients know they have dementia, and interventions that may be made when patients first learn they have dementia. The next three guidelines involve the early stage of dementia, the middle stage, and later cognitive decline. The last guideline addresses when patients are at the end of life. I discuss the ethical issues that arise for each guideline.

My overall goal echoes the purpose of Bunnell and colleagues: I wish to further the extent to which careproviders can help patients gain maximum joy and meaning in life. As I hope becomes clear, this is possible for many patients up until the very end of life.⁴

PATIENTS RETAIN THEIR CORE IDENTITY

Tom Kitwood, Naomi Feil, and Stephen G. Post are three experts on dementia who share the view that patients remain aware of who they have been and still are, even when they may not seem to show it.⁵ Further, based on this view, each expert makes practical recommendations careproviders can follow. The experts hold that patients may retain an underlying, remaining awareness, even if they do not respond as though they do. It is hopeful to regard patients in this more positive way, and this assumption regarding patients’ underlying awareness may lessen the despair that dementia can otherwise bring about. Kitwood, Feil, and Post may see what others don’t because they are more skilled in eliciting meaningful responses from patients. I discuss their approaches subsequently.

These approaches as described as “person-centered care.” Kitwood introduced this phrase in 1988 to distinguish his view from what he saw as the standard medical approach. He saw the standard approach as rigidly treating patients

as if they were all the same, and worse, as tending to dismiss patients as almost “non-people,” since it was presumed that they lacked awareness.⁶ Kitwood’s approach focused on optimizing patients’ interpersonal relationships and rested on an assumption that patients retained both past and present awareness within themselves. All three experts urge careproviders, as well as patients’ family members and loved ones, to connect emotionally with patients however they can. It may be possible, they maintain, even when patients lose all capacity for cognition.

We can, for example, reassure and provide comfort to patients by touching them, massaging their hands or feet, or even just brushing a flower gently against their cheek.⁷ These non-verbal ways to connect with patients may increasingly benefit them as their capacity to communicate verbally wanes. (On the other hand, it is possible that a loved one believes a patient retains basic awareness because the loved one wants to see the patient as they remember him or her. This could be harmful to the patient who wants to find the sweet spot, because it may encourage the loved one to try to extend the patient’s life, a violation of the patient’s dignity and prior autonomy.)

In any case, Post states, building on Kitwood, “our task is to preserve identity, rather than deny it. It is for this reason that many units for the deeply forgetful in nursing homes will post biographical sketches on the doors of residents, or family members will remind a loved one of events and people who have been meaningful along life’s journey.”⁸ Post says Kitwood believed that patients’ main psychological needs are care and love. What patients most want, Post says, is “generous, forgiving and unconditional acceptance, a wholehearted emotional giving, without any expectation of direct reward.”⁹ This is also what patients’ loved ones want.

Caregivers Are All Important

As these views suggest, how patients are cared for is all important.¹⁰ It may determine how patients continue to regard themselves.¹¹ Caregivers can convey to patients, as no one else can, that they are still loved and lovable.¹² This is a first key instruction for treating patients. Careproviders should attend to the needs of caregivers as much or even more than they do to the needs of patients, since caregivers are with patients as much as 24 hours a day. By directly benefiting caregivers, careproviders can indirectly benefit patients. Careproviders may in-

quire how caregivers are doing, or help them find a support group, or encourage them to create times of respite in their schedule so that they can find some of the relief that they need.

Further, careproviders should attend to what caregivers feel after a patient dies. A paradigmatic example is for careproviders to anticipate and help caregivers not feel guilt after a patient's death. Caregivers may feel guilt if they play a role in deciding when a patient will or will not die. Caregivers may feel guilty regardless of what they do, since choosing that the patient lives longer may increase the patient's suffering, but the other choice is death. Caregivers may feel guilty if, after the patient dies, they feel "nothing." This may be because they have already felt ever increasing increments of grief with each new symptom of the patient's dementia. Forewarning caregivers of these possibilities may help prevent such feelings.¹³

Notwithstanding this goal, careproviders should go out of their way to try to give patients the loving care they need. Careproviders should, for example, take special care to address patients by their name, and always talk first with them, rather than with caregivers. Careproviders may speak mostly or exclusively with caregivers who bring patients to appointments, and sometimes not even look at patients, as if, as Kitwood said, they aren't even there. But patients notice this, and it may hurt them deeply. In response, they may be silent during future visits, making careproviders' view that patients have nothing to say a self-fulfilling prophecy. This is what Kitwood noticed. Caregivers may notice that a careprovider does not attend to the patient, and may come to view the careprovider negatively, even though, by allowing the careprovider to ignore the patient, they have been complicit.

Accordingly, I make it a practice to speak with the patient first, and ask if it is okay to talk with the caregiver. I do this even if I am not sure that the patient will thoroughly understand me. I trust, though, that when I do this, my eye contact, attentive body posture, and soft tone of voice will convey to the patient the continuing respect and regard I want the patient to experience from being with me. The effects of nonverbal communication tend to outweigh those of verbal content for all of us.¹⁴ This propensity among patients, although greater in degree, is not different. Their response to nonverbal intervention is, however, more pronounced. The degree to which they respond to nonverbal cues will continue to increase relative to their capac-

ity to respond to cognitive input as their cognitive capacity decreases.

Finding and Reaching What Is Hidden

Here are two real examples of how careproviders reach patients who have dementia. One careprovider sought and successfully reached a patient through music. She learned from the patient's same-aged relative that the patient had loved a specific song in his youth. The careprovider found this song and played it for him. Although the patient had not spoken to other residents in the nursing home where he had lived for years, he burst into song. More surprising, after this he spoke to other residents at the nursing home, as if his singing had unlocked a capacity to talk from within him.

Stephen Post says in this regard, "In my years of interactions with the deeply forgetful at all stages of decline I have never met an individual who did not surprise me with some sporadic expression of continuing personal identity."¹⁵ In regard specifically to music, Post states, "It is a good idea to sing little tunes like 'You Are My Sunshine' or 'Take Me Out to the Ball Game.' For folks with a religious history, try a hymn." He writes, "Enter into this world, because I have found that there is some way to connect a bit with pretty much everyone, however limited. Small gratifications," he adds, "go a long way."¹⁶ This inference is hopeful and not possible to validate. Even so, knowing this, we may, like Post, keep trying and hoping.

Still more remarkable for me is a similar example that involves a careprovider who sought to reach a woman who had not spoken to others for years. This careprovider learned from the patient's relative that the patient, in her youth, had loved horseback riding. The careprovider arranged to take the patient and a few residents who often sat with her at the nursing home by bus to a farm where, by pre-arrangement, they had a pony saddled for her. Once there, the careprovider and other helpers put her on the pony. As she rode, the blank expression she had shown for years softened. In a period of minutes, she began to smile. She then began relate to her fellow residents as if a spell that she had been under had been broken.

DARKER MOMENTS OF DEMENTIA

The three experts mentioned above speak with passion. Dementia has, though, a much darker side. It may affect careproviders' deci-

sions, and be a source of dread that some patients feel and express early in their illness. They may be the ones who hope to find the sweet spot. Patients may have negative behavioral and psychiatric symptoms¹⁷ including inappropriate disrobing, exit seeking, hiding things, hoarding, pacing, repetitious mannerisms, and restlessness. They may be physically aggressive and bite, hit, kick, make unwanted sexual advances, spit, scream, and curse.¹⁸ In addition to forgetting loved ones, they may forget how to have sex and even how to eat. They may forget that they have to swallow, and this may pose a risk that they will aspirate liquids and solids.

I close this section with a specific example. A man who acquired dementia was an artist. He increasingly lost his judgement in social settings. He would walk up to people who were African American, for instance, and ask them if they were Michelle or Barack Obama. As his dementia became worse, his wife could not trust him. Without help, sometimes she could not get him in and out of the car to go for a treatment. Once this involved treatment for a partial bowel obstruction. Once when she had to push him out of the car with her feet, a neighbor saw this and called Adult Protective Services.¹⁹ Thus, some patients may be soothed by the touch of a feather, or go this other way. What can we do for them?

INTERVENTIONS THAT MAY HELP

I present guidelines in this section in three parts. First I describe interventions that may help patients indirectly: (1) how careproviders may best respond to patients before it is known whether they have dementia, and (2) how careproviders may help patients reconnect with loved ones. The goal is to reconnect patients with loved ones while patients can still remember and meaningfully communicate with “lost” loved ones. Second I describe approaches to use with patients who have mild, moderate, and severe cognitive deficits. These categories are roughly defined and are not used by careproviders in medical contexts. I use these categories because they best determine how careproviders may optimally intervene. Third I address decision making at the end of life.

How to Best Help Patients Indirectly

“Do You Want to Know If You Have Dementia?”

Older patients who come for an annual medical visit may report increased problems

with memory. They may, for example, have trouble finding words. This may occur with most people as they age,²⁰ and so it may or may not be an early sign of dementia. Such forgetfulness may have been discerned by another.

In general, careproviders hold that they should diagnose before they treat. But this may be an instance when they make an exception: that is, when aged patients report some small memory loss, careproviders may respond in either of two ways. One response is to do a very brief memory test: for example, give patients three paired objects—I use flower: rose, street: Broadway, and number: seven—and ask them to recall the pairs of objects five minutes later. In just five minutes this test can indicate whether there may be a pre- or early dementia problem.

A second response is to tell patients, prior to any memory testing, that difficulty finding words may occur normally as we age. Careproviders can ask patients whether this difficulty with memory has a negative effect on their life. If it doesn't, depending on what patients say they want, careproviders may opt not to test.

If careproviders choose not to tell patients that some forgetfulness can be a normal part of aging, and go right to testing and a diagnosis of possible dementia, the diagnosis may irretrievably, negatively affect patients from that moment on. To avoid this risk, before testing and diagnosis, careproviders can advise patients that they may choose not to be tested. Careproviders can explain that if patients choose not to be tested and their memory gets worse, they can always come back in to be tested at that point. Careproviders can ask patients who are worried if they have ever effectively used the psychological defense of denial. That is, careproviders can ask them whether, in the past, they were able to successfully ward off real worries to the extent that they could continue to enjoy life, or if putting off worries has generally been impossible for them. Do patients instead, for example, track down every possible worst-case scenario in order to feel some relief from worry?

If patients say they have been able to put off their worries in the past, then it may be more likely that they can go on without being tested and can completely enjoy their life, even though they may later be found to have dementia. I have used this approach with some of my own patients. Some say, emphatically, “No! Don't test.” One said she spoke four languages and would take her chances. Another said “of course” he wanted to be tested.

This last patient's history may, however, be noteworthy. Not long before we discussed testing, his wife had died, and he had deep regrets about some of his actions toward her. After a test for dementia, which indicated that his memory was fine, he acquired cancer. He declined treatments that might have prolonged his life. His choice to be tested might have reflected that he did not care, to a degree, what the test would indicate. This suggests a practical intervention for careproviders who choose to ask patients whether they want to be tested. If patients say they do want to be tested, careproviders might ask them, before testing, their reasons. Patients may disclose some kind of underlying despair. After sharing this with their careprovider, they may make a different choice.

"Do You Want to Locate a Lost Loved One?"

Some patients reach a stage when they cannot recognize loved ones. Long before this happens, careproviders should consider another uncommon intervention: ask older patients if there is anyone they would like to see again, that they haven't seen in decades or years. Alternatively, it may be inferred that there may be a "lost" loved one when patients talk about happy times they had in the past. Perhaps a conflict ended their closeness. If there appears to be a broken relationship from the past, careproviders could ask patients whether they might like help in reuniting with their loved one, either in person or on the phone.

The patients I've asked about this have always said "yes" (although sometimes reluctantly). When patients have said "yes," I have called the loved ones, explained who I am, and said that they can do much more for the patients than I could ever do. Which is true. I also say, however, that if they come in person or are willing to be in touch on the phone, I want them to be aware of only one condition: that I would personally be so grateful to them, that the last thing I would want is for a past conflict to re-emerge and for either party to be harmed by it. If this were to happen, I would leave the room or phone conversation, so that my continuing to be present would not extend the interaction. On the other hand, if both parties want, I could stay to help them resolve any conflict that has re-arisen.

No lost loved one has turned me down yet, although in one case it did take some discussion. I should acknowledge that saying I would leave the room or get off the phone is, in one

way, manipulative. Because it is likely or even inevitable that saying this will trigger, to some degree, an oppositional response in the lost loved one. That is, my saying this to the loved one will probably evoke an automatic response to oppose me, which in this case could take the form of the loved one saying to him- or herself, "I will come," but also, "I will stay and not be affected by whatever you will do." Some might see it as unethical that I do something I know may be unethical. They may be right. Feil, one of the three experts mentioned above, may be among these. Unlike some other careproviders (including ethicists), Feil believes in always responding to patients truthfully, as she believes it to be most beneficial. I place dispositive weight on beneficence when I take the initiatives noted above, although my view that the parties involved—particularly the patients—will benefit may be wrong. I believe both parties likely want to be reunited and will benefit.

This intervention is still more manipulative because I use my relative position of power as the patients' physician, and exploit patients' and loved ones' vulnerability to try to bring about this end. I am implicitly manipulative in just contacting loved ones. If they will not participate, my invitation may convey an irreversible guilt trip, exacerbated by my saying how grateful I will be to them if they come.

Interventions at Different Stages of Impairment

I now discuss optimal interventions that careproviders might consider at three different stages of lost cognition: mild, moderate, and severe. I begin the discussion in each stage with a description of a real patient, to make it clearer what kind of patient I have in mind.

Mild Dementia

Case example: Dr. Jones. Dr. Jones was a crackerjack psychologist who instructed me and others during my training. He was my mentor. Decades later, when I was teaching a course in which he participated by leading small group discussions, he called me out of the blue one day to tell me that he could no longer teach. He had, he said, early dementia. He and I had spoken at some length not long before that. Based on this discussion, I said that I believed his wisdom was so exceptional that it would more than amply compensate for any deficit he noticed that I hadn't noticed. When I was just talking with him, I said, I had noticed none. This time, the denial was mine. But he still declined.

In retrospect, responding as I did was insensitive. He knew what deficits he had experienced and I did not. More importantly, he knew how he would feel teaching students, and I didn't. A guideline that stems from this is that careproviders should generally, throughout the disease process, accept what patients say they want and defer to them. This guideline should apply particularly when, legally, patients are no longer fully competent. At that point, although they are cognitively more limited, they may still know what they want. We might regard patients' autonomy much like we regard children who give assent to participate in research. Unless they assent, it may be that research that involves them can't be done.

In her article in this issue of *JCE*, "Financial Decision-Making Capacity and Patient-Centered Discharge," Annette Mendola writes, "Decisionally capacitated people can be wrong about what is best for them. But, all things considered, they will get it right most of the time. And even when they get it wrong, they retain the experience of being in charge of their life."²¹ The context of Mendola's article is somewhat different than our context here, but her statement holds true for patients with dementia.

The next time I met with my former mentor, we had lunch. The sandwich he was eating fell apart and he couldn't put it back together. This memory still makes me sad. My sadness mirrors, to a much lesser extent, the sadness and grief that loved ones feel as they see patients' capacity diminish. Patients may feel this sadness, too. All of us have experienced such a feeling with a loved one. We can consciously seek to recall this sadness and grief when we see patients, so that we do not unconsciously distance ourselves from them to protect ourselves from sadness, as Kitwood, one of the three experts mentioned above, feared.

My mentor later entered a nursing home and died there. Since I knew his family, we talked, and they told me that up until his death, he said he relished their frequent visits and told them each time how much he couldn't wait until he saw them again. This is an actual instance that indicates how patients can still find their life to be meaningful up until they die. Later I discuss how some patients continue to have this mutual meaningfulness with family members, and so remain candidates for a percutaneous endoscopic gastrostomy (PEG) feeding tube, a tube surgically placed into the abdomen that allows patients to be fed when they can't be fed other-

wise. This highly controversial intervention is considered at the end of this article.

Patients and their loved ones may continue to find meaning when patients near the end of life, and may, counter intuitively perhaps, experience even greater meaning than they have experienced previously. One caregiver describes her mother's "final gift" to her in this way: "It seems incredible that caregiving can be so satisfying. I look into her bedroom now and I can feel her presence . . . and I am thankful for the final gift she gave me. . . . I remember when she was in control, and when I needed her—and she was always there for me. As her memory worsened, I began to appreciate my mother in a way I never knew possible."²²

Guidelines for mild dementia. My mentor's loved ones helped to give him meaning in his life by allowing him to make every choice he could. Doing this in every context may require us to go beyond what we might usually do. In nursing homes, for instance, staff might be willing to allow patients to eat what and when they want. Some already allow patients who can't sleep and/or like to stay up at night to meet in a separate room during the wee hours to watch favorite old films. This may take additional time and effort, so that even if staff are willing to provide residents greater control, their managers may not permit it.

Loved ones who care for patients at home can do this too, and careproviders should urge them to do so. One example is to buy patients pants that fasten with an elastic tie when they are no longer able to buckle a belt. Another example is to tape luminescent arrows on the hall floor that point from the patients' bedroom to the bathroom, so they can find the way to bathroom in the middle of the night.

Some problems that arise at home may be very exacting for caregivers. One example is when an adult child of the opposite sex cares for a parent in the same home. If the parent loses bowel control, the adult child may have to clean the parent. The child may find this difficult, and the parent even more so. Doing this may be necessary to enable patients to stay in their home.²³ It may evoke shame.

Patients who can't find the bathroom or lose control of their urine or bowels may, as anyone would, feel shame. Careproviders can take the initiative to convey to patients, well in advance, that whatever may happen to them does not define who they are. We should share this with all patients who feel shame. We should add,

when we do, a most important concept that is often overlooked: that is, that we may do things not only unintentionally but intentionally that we later regret. Not finding a bathroom in time or losing bowel control are unintentional. But we may regret much more what we do intentionally. Careproviders should especially stress, then, with all patients, that while we may feel greater shame about what we have done intentionally, these acts should not define us either. What this does mean is that we are human. Patients with dementia need to know this. They may be more sensitive to temperature, as when they are taking a bath; to light; and to noise; and, when they are upset, they may strike out at others. They may see this something they intended to do, and so they should be told before they begin to have dementia, and after, that these actions are not, and will not be, who they are. Depending on the extent of their illness, they may not fully understand the distinction between an intended and unintended action. Still, that a careprovider goes to lengths to convey the distinction may have a restorative effect.

Patients may experience shame with every loss they encounter from the beginning of their illness. They may feel shame, for example, when they first forget how to tie a necktie or a shoelace. Loved ones may, unfortunately, be critical—perhaps because their anger serves to protect them from their fear. Such criticism may shame patients. Thus, careproviders might take the initiative to alert loved ones about this risk before these first events occur.

Some new difficulties may require absolute limits. Patients may, for example, no longer be able to drive safely. It may be possible for loved ones to allow patients to continue to drive just down the block to a store in a quiet neighborhood, so that they give up driving gradually, in stages. Here, as in most instances, as Kitwood urged, it is optimal to negotiate with patients.²⁴ This approach seems to be optimal even in some cases that would allow slightly greater risk. A slightly greater risk may be outweighed by potential gains in the relationship between patients and loved ones, and/or in patients' quality of life. Another example is the relative gain versus the slightly increased risk involved in leaving patients with early dementia to live alone at home. I consider this shortly. Patients should have the greatest possible role in decision making about their care and treatment. The degree to which this is possible should be tested and re-assessed routinely, so that patients' roles can

be optimally tailored to their specific needs, wants, and capacities on an ongoing, timely basis. This should help them to maintain their self-esteem, because they can then continue to feel that they have some control.

One of the biggest risks that is worth taking is to allow patients who are early in their illness to be alone in their home for a limited span of time. This risk will only increase as their illness gets worse. A common danger is that they will forget to turn off the stove after they prepare food. When such dangers are only possibilities, this may make a difference in decisions about what should be done. Since removing patients from their home may quash the main source of quality in their life, moving them may be too high a price to pay at this time. Their home may be closely associated with their memories of who they have been and thus, even, who they are. Like having pictures of loved ones in their bedroom on their nursing room walls, the familiar setting of home may help to enhance their awareness of these personal factors, as well as their emotional stability.

Patients may become bedridden, and the loved ones who care for them—often adult children—may have to leave the house to go to work each day. I recall such an instance in which a son cared for his bedridden father at their home. The son had to work away from the house during the day. Some of the father's careproviders wanted to admit the father to a nursing home—with or without his consent. The available nursing home was far away, and the son would have only been able to see his father on the weekend. But his father lived to see his son every night. The careproviders finally gave the most weight to the father's quality of life and decided to allow the risk. The father was able to stay at home with an instant 911 call device.

Eventually it may be necessary for patients to move to an assisted living residence. As patients' illness worsens, loved ones may face what is the worst challenge yet for both: leaving patients at the residence. It may be harder still to figure out how to do this if the patients refuse to stay. One family member described the situation this way: "Her grip was like a vice. She was unexpectedly strong and quite unwilling to let go. I had to literally pry her fingers off."²⁵

Consequently, some families try to trick patients. They have a nursing home staff member distract them and family members quickly go away. Feil sees this as unequivocally a mistake. She asserts that families above all should retain

patients' trust.²⁶ She suggests instead that loved ones tell patients what they will do ahead of time, and seek to weather the trauma together.

Moderate Dementia

Case example: Mrs. Smith. A patient who was not faring well became highly irritable. She had not lost all control and had not physically acted out her anger. Her husband decided that he would take her by car on what he imagined would be their last trip together. They were staying in a motel for the night in another state when he called me at 2 a.m. (This was possible because all my patients have my home number.) He had locked himself in the motel bathroom to protect himself from his wife who was threatening to kill him. She couldn't find jewelry that she'd thought she had with her and believed that he had stolen from her, even though he had been consistently caring and had never done anything like this. When a patient forgets and can't find a possession, acting as this patient did and blaming others isn't uncommon, even when the others have been near saints throughout their life with the patient. After such an event, a patient may feel the kind of shame I discussed earlier.

I advised the patient's husband to call the police. He would not. I was able to help him calm down, and he was able to help his wife calm down. He was able to unlock the bathroom door, and they went to sleep.

Months later, due to the progression of her illness, she was bedridden at their home. She was not able to take down much food, and was hospitalized. The doctors there refused to insert a PEG tube. It may be that abdomen feeding will not help when patients have lost weight due to cachexia (a general wasting of the body due to severe chronic illness). This patient had not lost weight, although she was weak, also characteristic of this syndrome. The doctors advised the husband that the time had come to allow his wife to die. He would not. He signed his wife out of the hospital and fed her, spoonful by spoonful, a way that these patients may be able to take and keep food down. They could still talk and even laugh together, exemplifying the kind of case in which a PEG tube placement might be indicated, to provide patients and their loved ones additional months or even years of quality in their life together. Later, the wife needed to be hospitalized, and she died there.

Guidelines for mild dementia. As noted above, some patients begin to have paranoid reactions. When this gets worse, they may for-

get and blame others, even loved ones. Therefore, careproviders may benefit loved ones by telling them about this in advance, and telling them what they should *not* do when this occurs: namely, they should not confront patients. Even gently, since it may only increase patients' anger. Rather, loved ones might, perhaps counter intuitively, express their empathy and help patients look for what they think has been stolen. Loved ones could even say that they would feel the same way if there was a piece of jewelry (or whatever it is) that they couldn't find, and even conclude that someone must have stolen it! Both of these empathic, validating responses are true. Who among us has not suspected another when something we knew was there is missing?

Feil takes this same approach when patients forget that a loved one, such as a spouse, has died, and asks where they are. Feil expresses empathy and distracts patients, and remarkably does this in the present tense, as I describe shortly. But when paranoid responses persist, patients may need antipsychotic medication to have relief, and even, in some cases, to enable them to continue living with caregivers in their own home. These drugs have "black box warnings," which means that when these medications are prescribed, patients are at a higher risk of experiencing serious side-effects, including death. As this is the case, careproviders may understandably hesitate before prescribing the medications. Yet since these medications alone may preserve patients' quality of life, taking the risk may be necessary.²⁷

As patients continue to get worse, they may respond less to the content of what others say and increasingly to how the words are said. Thus careproviders who have patients in this moderate stage should particularly pay attention to their own body language and the meanings they convey nonverbally. Words and sentences may add to what careproviders say, rather than being the means by which they convey what is most significant.

A new ethical question may arise for loved ones: whether they should engage in deceit. For example, patients who live at home may wander off. This may occur for the majority of patients. It's easy to obtain a door alarm, an alarm that goes off when a patient gets out of bed, a weighted blanket, or 911 alerts, but some loved ones may prefer to cover exterior doorways with a large curtain so patients will not recognize them as a way to get out. But even this use of deceit may cause family members angst. The

strongest case for deceit—one that may cause the greatest anguish—is the instance noted before: when patients forget that a loved one has died, and continually ask where she or he is.

For example, a woman with advanced dementia has forgotten that her husband died 10 years ago. She asks family members where he is. If they say that he died, she may experience the news as though hearing it for the first time. This would be devastating, yet she may not remember that she has asked, and so ask again. And again and again. If her family responds truthfully each time, she may experience the devastating pain over and over. Alternatively, her family may lie. They may say, for example, “Dad went to the store. He’ll be right back,” she may say “Fine!” But this may be agonizing for her family, as they will be lying to someone they love, and perhaps for the first time.

If we wish to not harm patients, it may be best to lie. Many caregivers do this, and some even see it as almost a “no brainer.” They may call it “emotional truth-telling” or a “therapeutic fib.” Feil disagrees. She says, first, that at a deeper level, patients always know. They know when a loved one has died. As an example she cites a conversation that she had with a man when he asked where his mother was, years after she had died. “Do you miss your mother and want to see her?” Feil asked. “Yes,” he said. “Where is she?” “Tell me about your mother,” Feil said, and “What does she look like?”²⁸

Note that Feil used the word “does,” which is in the present tense. She advises that we should ask factual questions—who, what, when, and how—in the present tense to validate the patient’s question. “What kinds of things does she do for you?” Feil asked. Asking in the present tense enables the careprovider or loved one to be with patients where they are, in the moment. We might ask, as a further example, “What is the color of your mother’s eyes?” as opposed to “What color were they?”

The patient told Feil, “You must think I’m crazy, an 86-year-old man looking for his mother. I know she’s gone.” Although only one example, it verifies Feil’s contention that patients know.

A second contention is more important. Feil says that patients are able to discern when others are lying to them, from their behavior. This may particularly be true if patients have become sensitive to others’ nonverbal behavior. Lying may only increase patients’ isolation and emotional pain. Feil states, “We do not believe . . . that any kind of lying can be therapeutic.”

However, Norman Quist suggests that there may be “a middle way that honors the patient’s self, which is essential, while not pushing back too much.” This is to respond to the patient’s concern by supporting the gist of it in a way that is clearly connected, but which also deflects it. He offers an example. “I remember touring a flea market with my father-in-law who had early-onset Alzheimer’s. As we walked about—this while my wife and her mother had time to be together at our home—he commented on the attractiveness and desirability of women he saw, asking my opinion, and expressing his preferences. In response, I acknowledged his observations and supported the general flow of the conversation, but deflected when I could: I chuckled and said, ‘but that might not go so well with your wife?’ ‘Oh, I’m married?’ he said. ‘Yes,’ I replied, ‘But otherwise. . . .’ I presume he felt supported and authenticated—or I hope so.”²⁹

Severe Dementia

Case example: Mrs. Gray. My patient, Mrs. Gray, gave no indication that she recognized her husband of several decades when he visited her in a home that provided care for her. Prior to receiving antipsychotic medication, Mrs. Gray been chronically agitated, but, with medication, she was able to accompany her caregivers to the supermarket, sit through church on Sunday morning, and allow her husband to kiss her without flinching. This is a real life instance in which an antipsychotic medication renewed the quality of a patient’s life.

Her husband couldn’t drive, so I would drive him to visit her. I did this in part because Mrs. Gray’s dementia was worse than it was for the two patients I described above. I mention this to indicate that, as patients’ conditions worsen, we may want to do more for them because they are worse-off, or we may want to distance ourselves to protect ourselves from feeling sadness and emotional pain. This distancing is what Kitwood most feared, and avoiding it is perhaps more important than anything else.

Guidance for severe dementia. The epitome of nonverbal messages may be the sense of touch. Touch greatly affects all of us, as William Ventres and Marc Tunzi say in their article in this issue of *JCE*, “Ways of Being in Generalist Practice: Using Five ‘T’ Habits of Mind to Guide Ethical Behavior.”³⁰ They assert, for example, that a caring touch demonstrates to patients that generalist physicians should be open to exploring whatever concerns might emerge in office visits. They

suggest insightfully and compassionately that careproviders who see children might try to offer them a gentle fist bump before taking their vital signs. An anecdote they share captures their insight regarding the relational magic of touching: “As I introduced myself, I shook her hand with both of mine—an act of compassion, spontaneously emergent, that I believe encouraged her to look up at me before we sat down and started talking.”

If patients show untoward behaviors, the challenge for loved ones is likely to become greater. Experts advise loved ones to regard all of these behaviors as having either triggers, on the one hand, or purposes, on the other.³¹ If loved ones can discern the trigger or purpose, they may hope that instances of these behaviors will be reduced. Alzheimer’s organizations and support groups may greatly help.

This is how we all work. We may be “triggered” when we see a picture of a deceased loved one, and our grief is rekindled. Like patients with dementia, we may become more irritable, without being aware of it, and displace our anger to those we most love. Patients’ triggers may be unknown, and even unknowable. An example of an unknown trigger is a urinary tract infection that has no symptoms. Only testing can confirm an infection, and, consequently, some caregivers test patients’ urine for an infection every month.³²

Pain may be a trigger. Patients may know that they have pain, but may not be able to express it. Thus, careproviders may choose in some cases to give patients analgesics, even though they don’t know whether patients actually have pain. They may even provide opiates, such as morphine.³³ Here, addiction and even respiratory depression are not likely to be chief concerns, but, rather, constipation and falling. Metabolites of codeine and morphine also may have a neurotoxic effect.

DECISIONS AT THE END OF LIFE

The most difficult question may occur in the last stage of illness: when to stop treatments.³⁴ Dementia is a terminal condition. Some patients have had difficulty acquiring hospice care.³⁵ This has occurred mostly because the length of time they will live is so uncertain.³⁶ This is another reason some patients seek the sweet spot—the period when they are not so demented that they can’t choose to end treatment and so end their life.

When to Insert a PEG Tube

A paradigmatic example of deciding when to stop treatment is one alluded to earlier: when, if ever, patients should have a PEG tube.³⁷ Many careproviders strongly oppose placing a PEG tube, for a sound medical reason. When patients who have dementia have cachexia, a PEG tube will not help them gain weight. Careproviders may see it as futile and as prolonging patients’ death, as opposed to prolonging life.³⁸

Still, there may be some cases in which this means of feeding will prolong patients’ lives and allow them and their loved ones to continue having precious moments together. For patients and family members, life may be very much still worth living. Fortunately, some now advocate that these decisions be made on a case-by-case basis.³⁹ There are many other decisions like this. For example, when should patients with severe dementia be rehydrated? Patients may not drink enough, and giving them fluids may prolong their life. On the other hand, too many fluids may cause them to have pulmonary edema, which may contribute to their death.

Who Should Decide?

How should these end-of-life decisions be made? Loved ones’ views may often differ from the views of careproviders. Taking these differences into account to the greatest extent possible, we might wish to consider what we do now in regard to parents and their children. When a child is suffering and dying, and there are no sound moral bases to keep the child alive or to let the child die, parents are permitted to make decisions for the child. This is perhaps because, for the most part, parents are closest to their child and whatever they decide, they will take the memory of their child with them.

When patients have severe dementia, their loved ones are in many ways like parents. Loved ones may be those closest to patients. They may be closer to patients than a child’s parents, in that loved ones often have known and lived with patients longer and perhaps have cared for them longer. We might ask whether loved ones might, for these reasons, be accorded greater decision-making authority than they may have now.

It may be, too, that most patients with severe dementia who have not expressed a preference regarding a surrogate decision maker would say, if they could, that they want a loved one, as opposed to their careprovider, to make decisions for them. They may want their careprovider to play no role. If so, this preference should be re-

spected, mirroring to a greater extent the “total role” that parents can play, in appropriate contexts, in making decisions regarding their child. Since the possible outcomes for patients are often severely limited, they might even want a loved one to make decisions based on what the loved one would want, regardless of what the law allows. Ideally, we can ask patients in advance whether they want a loved one to make decisions for them, making sure they understand that loved ones can only do the best they can, as there may be no clear way forward. Saying this may enable patients to reduce loved ones’ possible, subsequent guilt from second guessing themselves. This may give patients an additional opportunity to give back to loved ones for all their loved ones have given them.

This would be a profound change, and, rightly, a controversial change. Some loved ones find meaning in being able to be with patients as long as they can. In some cases loved ones’ decisions may go greatly against the advance directives for patients described by Bunnell and colleagues in this issue of the journal.

A final consideration may be one raised by Giuliano Testa, Liza Johannesson, and Anji E. Wall in their article in this issue of *JCE*, “Considering Uterus Transplantation for a Same-Sex Couple: A Case Study.”⁴⁰ The authors ask, in regard to what concerns should be allowed in analysis of couples who seek a uterus transplant: “Is the value of gestational parenthood defined at the level of a couple or the level of the individual?” Following their lead, we might ask whether, in considering inserting a PEG tube for a severely demented patient, whether patients’ loved ones should have some say in situations where they presently don’t.

CONCLUSION

We have examined how Kitwood, Feil, and Post, three experts, view patients with dementia and have considered some guidelines regarding what careproviders may do at different stages of patients’ illness. Careproviders should give patients as much control as they can, help caregivers, and consider not deceiving patients.

The point I wish to stress is that patients with dementia may find meaning themselves and give meaning to others, even up until the end of their life.⁴¹ I end this article, therefore, repeating the daughter’s report of what she experienced during her last times with her mother: “It seems incredible that caregiving can be so

satisfying. I look into her bedroom now and I can feel her presence . . . and I am thankful for the final gift she gave me. . . . I remember when she was in control, and when I needed her — and she was always there for me. As her memory worsened, I began to appreciate my mother in a way I never knew possible.”⁴²

EXPRESSION OF APPRECIATION

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CONFIDENTIALITY

The names and details of cases have been altered to protect the identity and privacy of patients and family members.

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