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Shame, Slap Jack, and Families That Should Lie

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In this issue of *The Journal of Clinical Ethics*, Hilde Lindemann tells about a visit with her mother, who has Alzheimer’s disease. Lindemann recalls, “I went into her bedroom and opened the drawer. As I slid my hand inside, I felt a hot rake of pain. I could smell the blood before I could see it. Blood was everywhere, flowing freely falling in great drops. I could see the razor blades that had been stuck to the top of the frame.” Her mother says, “That’s what happens to thieves. Get out of my house before I call the cops on you.” This passage is from “On the Mend: Alzheimer’s and Family Caregiving,” that is as viscerally gripping as any piece *JCE* has published. It conveys accurately the horror patients with Alzheimer’s and their loved ones may undergo.

This horror may involve violence. Much more often, it is silent: patients who have known and have been close to loved ones for decades no longer recognize them. Lindemann suggests that her initial response to this incident might have been “more kindly” if Lindemann had been able to see her as she had been at her best times, in the past. This would have been more beneficial for her mother. Quoting Wittgenstein, Lindemann states that persons are the “product of socialization and training,” and so, she declares, are “essentially social.”

The insight that loved ones might try to treat patients with Alzheimer’s as kindly as possible can be highly beneficial to patients — improving their quality of life, if not its duration — and it is an insight that has been increasingly recognized and emphasized clinically in recent years.¹ Some of the new approaches that are advocated seem to be wholly counterintuitive, however, as they challenge what appears to be right, and raise ethical concerns that have hardly been addressed. In this essay I will discuss the three most important of these ethical questions.

The first is the extent to which loved ones should discuss with patients the difficult decisions that will arise for both of them in the future. Discussions could involve, for instance, what patients would want should the time come that they can no longer recognize those they love.²

The second question is the extent to which loved ones should try to “manipulate” patients; for example, asking patients about their preferences in ways that might tend to “predetermine” how they will respond. This approach may maximize patients’ positive feelings and enable loved ones to proceed efficiently with the tasks they must carry out that involve patients, but, at the same time, it is implicitly deceitful.

The third question is whether loved ones, especially, should directly lie to patients in the third and final stage of their illness. This possibility is exemplified in Joanne Koenig Coste’s recommendation on how

loved ones should respond when patients accuse them of "crimes," as the mother in Lindemann's article did: "To the accusation 'You stole my special coat,' the best answer may be 'I forgot to tell you that I put it in storage for the summer,' even if the coat was sold twenty years ago."³ Extrapolating from this, the daughter in Lindemann's article might have said, "Yes, you're right. I have taken some of your things. I'm sorry. I must have forgotten to tell you!" Both examples are outright lies, but they may leave patients more comfortable. As I shall discuss, this goal — to leave patients feeling comfortable — may be one of the most important for loved ones when they make choices involving patients with Alzheimer's. It is critically important for patients to know that loved ones won't abandon them. Coste states, "Paranoid behavior is usually directed at the closest family member, and that person should remain in the patient's world . . . no matter how bizarre the accusation."⁴

I will also present some general considerations that may help loved ones respond "better," and, finally, will discuss what patients and loved ones may be able to experience together, in spite of the patients' deficits.

Loved ones do not care for patients alone. Ethics consultants and other careproviders often work with loved ones and advise them how to best care for patients. It is thus essential that careproviders know both what loved ones can do to help patients and the ethical problems that may be involved. Thus, while this discussion focuses on what loved ones ideally should do, the issues raised are as critical for careproviders. As Lindemann contends, and as is true in most cases, careproviders may help patients most by helping their caregivers.

CORE PRELIMINARY CONSIDERATIONS

THE LIMITS TO WHICH LOVED ONES CAN BENEFIT PATIENTS

Even if loved ones respond to patients with Alzheimer's disease in ways that are optimal, it may not affect their course of illness. It is very important to wholly acknowledge this uncertainty; otherwise, loved ones may fear that they haven't done all they could. Such emotional adversity, in most contexts, has physical effects.⁵ It is noteworthy that studies have reported that family conflict can take a short-term and a long-term toll.⁶ By helping patients to feel more comfortable and thus provide them an "emotional safety net," loved ones may benefit the disease process indirectly.⁷ All of the approaches I will recommend may enhance how patients feel, and, as a result, patients may feel more motivated to seek out treatments that will benefit the course of their illnesses. For instance, the medications currently available may slow down the progression of Alzheimer's disease; this, in turn, has been found to benefit patients' loved ones.⁸

LOVED ONES' WILLINGNESS TO "CHANGE COURSE"

Patients with Alzheimer's go through profound changes as their illness worsens. Thus, what may be best for them at the beginning of their illness may be bad for them later on. For instance, they may benefit most, early on, from being fully involved in planning the course of their futures, to the degree that they can. Later they may find this degree of involvement upsetting, and, more problematically, they may deny that it is. They may, for example, become extremely frustrated when they lose the capacity to sufficiently understand what their loved ones are saying.⁹

Thus, loved ones must be aware at the outset that what patients most need at any one time may change. In all stages of illness, however, some responses to patients will remain consistently important. It is critical, for example, that loved ones always affirm what patients feel. In this issue of *JCE*, Tia Powell, in "Voice: Cognitive Impairment and Medical Decision Making," gives an example that suggests how this can be done:

The daughter tucks an afghan blanket around her mother's legs. . . . the daughter says, "There, Mother. How is that?" The mother looks her daughter straight in the eye. . . . She says, "Lousy."

The daughter doesn't refute her mother, and, by not doing so, may imply that she understands. A loved one can go further and implicitly agree. Rather than remind her mother what about her life is still good — a reflex

to which many of us might be prone — the daughter could say, "Yes. Surely it is lousy." Claudia J. Strauss, an authority on those with this illness and its treatment, says, "You can agree that life sometimes stinks."¹⁰

In many other responses, however, loved ones must be alert to changes they should make. Early on in patients' illness, for example, patients may find it essential for loved ones to tell the truth and the whole truth, because, otherwise, patients may feel distanced and infantilized. In time, though, patients may no longer understand as much. An example of this kind of change is when loved ones use pictures to communicate; a patient who has just begun to lose the capacity to understand verbal communication may find an offer to communicate in this way demeaning. In a more advanced stage of illness, however, the same patients may appreciate this strategy. Looking at pictures may even "elicit delight."¹¹ Loved ones must accept that, regardless of how much they try, there will be no "safe haven." To communicate most effectively with patients, for example, loved ones must increasingly, over time, slow down the pace of what they say. If they don't slow down enough, it may be frustrating to patients, but, if they talk too slowly, patients may find it condescending.

The obvious question this raises is how loved ones should know when to change what they are doing. The first answer is simply *to_ask*. Loved ones can always ask, even when patients are no longer able to communicate verbally, it is still best to ask them what they prefer. For example, loved ones still can ask, "Is it okay with you if I touch you?"¹² Regardless of the answer, merely to ask such questions continues to give the patient a genuine choice, which remains extremely important. It also conveys that loved ones continue to love the patient because they continue to attempt to be caring. This may be more important than anything else to patients, as it implies that the connection they so much fear to lose, and, thus, crave, will continue. A particularly instructive (and sad) example is offered by Diane McGowin, when she was a patient still in the early stage of this illness. She tells of the recurring fear she felt that her husband might abandon her: "I repeatedly sought his vow to take care of me for the rest of my life. Upon receiving his assurance once again, I would inquire if he knew just how difficult keeping it may become in the future."¹³ In other cases, loved ones can only try to infer what they might best do based on patients' behavior or responses. Here, the ground rule may well be: when in doubt, loved ones should try to leave patients feeling as comfortable as possible.

THE COURSE OF ILLNESS IS UNIQUE FOR EACH PATIENT

Daniel Kuhn states that the "experience of the disease is as unique as the individuals that have it."¹⁴ This assertion may seem self-evident, but, with Alzheimer's patients, this is particularly, and counter-intuitively, the case. The most important example of how patients may differ is that some may show new, advanced capacities, early on, before their illness progresses. The quality of art they create and their artistic productivity, may, for example, increase, although this may depend on the subtype of Alzheimer's. As Kuhn says, "The emergence of visual creativity in dementia [hints at] the extraordinary cognitive flexibility of individuals experiencing progressive loss of cortical neurons. . . . the art of individuals with AD [Alzheimer's disease] can show appealing use of color and form."¹⁵

The artist Willem de Kooning may be the best-known example. His art changed, and, for some, it got better. James C. Harris states that de Kooning's "final work was allusive rather than expository. Yet to many, [it] seemed beautifully simplified."¹⁶ Such positive changes may occur, much more importantly, in patients' capacity for emotional richness. This change may be of greatest significance to loved ones, since it may change entirely what they may experience together — if loved ones are open to the possibility.

An example of a program in which patients have reportedly shown growth in both capacities (in art and in emotional richness) is a program called *Memories in the Making*. In this program, patients with Alzheimer's in the early and middle stages create paintings. Patients in this program often show more sustained attention, and some also express exceptional pleasure. One said, for instance, "In here I feel like a person again."¹⁷ This may reflect that, in this setting, the patient didn't experience shame. (In the next section there will be more about the significance of this, and how loved ones can try to help patients not feel shame.) Another patient began the program "withdrawn," but, in time, "began to smile." After this change, the same patient observed that another participant was "having a difficult day." She said to the patient, "'everyone in here has it rough, some days. . . . I understand.'"¹⁸

ETHICAL DILEMMAS AT EACH STAGE OF DISEASE

STAGE 1: SHOULD LOVED ONES INVOLVE PATIENTS MORE?

When patients first become ill, they still can understand and converse in regard to their needs, wants, and future preferences. Yet, more often than not, at even this earliest time, loved ones will leave patients out of discussions on these topics. Careproviders do this as well, sometimes, even talking to loved ones as if patients weren't there. Patients, fully aware of this, may feel enraged. As Strauss states, being talked about "makes them invisible — as if they are being erased."¹⁹ Why does this happen? Are the reasons for this sound? These questions are considered below.

Insight Does Not Lead to Depression

There are many reasons that loved ones leave patients out of such discussions. They may do this, in large part, because they want to try to protect patients from knowing the worst that could befall them later. They are likely to believe, for example, that if patients know what most likely will occur, they will become severely depressed. It has recently been found, however, that when most patients acquire insight about their illness and their probable futures, they do not become depressed.²⁰ This finding has profound clinical implications for loved ones (and careproviders) who want to help these patients. They can feel more free, for example, to bring up with patients even very painful topics, such as what patients would want if they later lose awareness of who they themselves are, or who their loved ones are. The optimal approach may be to give patients a choice of being included in discussions and decisions as long as possible.

One reason to do this is that it respects patients' autonomy. A benefit for loved ones, obviously, is that they will know to a greater degree what patients think they will want, and then may feel less guilty if and when they carry out patients' stated desires. When loved ones feel less guilty, it may leave them more capable of loving patients fully, later. Patients may benefit markedly as a result. Kuhn says, accordingly, "First of all, you should include the person with AD in decisions regarding his or her welfare whenever possible."²¹ The strongest argument against this is that patients who indicate they want to remain fully part of discussions and who continue to make choices for themselves, as long as they can, may find the experience devastating. It may be that it is ethical to shield patients from what will eventually happen to them, as there is little that can be done for them, to spare them unnecessary worry. This is similar to the argument posed by those who adamantly oppose offering genetic test results to patients; even if the predictive value of genetic testing becomes much improved, patients should not have access to test results to spare them unnecessary worry.²²

The finding that, in general, persons in the earliest stages of Alzheimer's don't become depressed when they acquire insight about their disease suggests that we should at least offer them the opportunity to discuss all present and future issues of possible concern for as long as they can do this. Patients can indicate when they would prefer not to. Alternatively, if patients want to be involved but become visibly distressed, loved ones can interrupt the discussion and ask patients what they are thinking and feeling, and whether they wish to continue. This may benefit patients as it shows a continuing commitment to them and to how they feel.

If, on the other hand, patients become very upset but deny it, this may be when loved ones begin to consider not offering them an opportunity to be involved to the same degree.

Loved Ones Can Help Patients Overcome Feelings of Shame

The earliest stage of Alzheimer's offers patients a unique opportunity to accomplish what they can't later, as their capacity to understand is still essentially intact. Since patients with early Alzheimer's generally don't become depressed when they discuss their probable futures, the question is: What else can loved ones do at this time to benefit patients?

One answer is that loved ones can try to help patients reduce their vulnerability to experiencing shame. The feelings of shame to which these patients are vulnerable are profound; the extent to which shame can

strip patients of their capacity to spontaneously enjoy themselves is illustrated by a patient who was in a group of persons who were, as he said, "like him." Only in this group, he said, was he again able to "feel like a person." He added, " 'I am at peace when I'm with my group. I can be myself without pretending that I am a hundred percent.' ”²³

This loss of the capacity to feel wholly "okay" about themselves and to relate openly and spontaneously with their loved ones occurs, all too commonly, even in families and between couples who love each other dearly, and have for years or decades. An example is what the author Iris Murdoch apparently experienced with her husband, John Bayley. After Iris acquired Alzheimer's, John described their life together in a book, *Iris*.²⁴ The subtlety with which shame can manifest itself, even in patients who have known and loved each other as much as Iris and John did, is illustrated in the following passage John wrote: Iris, he says, "she used to weep quite openly, as if it were a form of demonstrable and demonstrated warmth and kindness. Now I find her doing it as if ashamedly, stopping as soon as she sees I have noticed."²⁵ He comments, "It makes me feel she wants to conceal it from me. Can she want to protect me from it?"²⁶ A goal that loved ones might pursue in the early stages of Alzheimer's is to help patients "get to the point" that they never feel shame at any time, for example, even when they can no longer identify loved ones, and can acknowledge this openly, without emotional pain. Feeling shame may cause patients to feel increasingly separated from loved ones, and such a loss of connection may be patients' greatest fear.

How can loved ones try to help them? They can repeatedly "rehearse" interactions in which both the patient and loved ones pretend to forget things. When patients' loved ones also pretend, it may give them a greater sense of "being equal." In any case, it might also provide an opportunity to laugh together.²⁷ After enough "dry runs," patients may be able to laugh about forgetting, or at least feel accepted, if and when such forgetting occurs later.

Mary S. Mittleman, Cynthia Epstein, and Alicia Pierzchala recommend both rehearsal and role reversal for patients' caregivers as a way to help them better cope.²⁸ I suggest extending this to include patients. These "rehearsals" can continue until patients reach a point that they can simulate forgetting and experience no shame. A test case might be when a patient's loved ones can say, "Hello, dear," and the patient can say, without feeling shame, "I'm sorry, but I don't know who you are."

Loved Ones Can Help Patients Reduce Anticipatory Grief

A still more difficult goal during this same period is for patients and loved ones to go through "anticipatory grief" together — to the degree possible. Anticipatory grief occurs before a loss and involves "the constant recognition" of the future loss and the process of gradual, continual, incremental detachment.²⁹ Unlike typical grief, which occurs after a loss and primarily involves acceptance, anticipatory grief is "a constant living with the uncompleted loss," and moving forward is more "complicated" when this is the case.³⁰ By confronting anticipatory grief together, purposefully, rather than just waiting, patients and loved ones can become "emotionally freer," and so be able to relate more meaningfully to each other later. This work is commonly done in hospices, for the same reason. As Beatrice Turkoski and Brenda R. Lance note, for patients and loved ones, "done constructively . . . anticipatory grieving can facilitate a healthier resolution of the entire grieving process."³¹

Patients and loved ones each grieve for something different: Patients grieve the eventual loss of even knowing who they are, in addition to dying; loved ones grieve the loss of the patients, first, as the persons they were, and, second, the loss once they die. Anticipatory grief, to the extent that it involves "letting go," occurs automatically, to some degree, if patients and loved ones discuss together patients' future options, as discussed above. Discussing the future in this way allows patients and loved ones to anticipate the grim realities that they may expect.

If they do this, they may also share painful feelings, and merely sharing this way may help patients and loved ones feel less alone. Careproviders can facilitate this process by adding guided imagery:³² careproviders can encourage patients and loved ones to allow spontaneous visual images related to their discussions to

emerge, to describe the images, and then discuss the feelings that they associate with them. Patients and loved ones can try to imagine the outcomes they would like to experience together in the future; they can also recall times they have enjoyed together.³³ The use of guided imagery with hospice patients and their families has often allowed both to "achieve a greater degree of intimacy."³⁴ This may be because it reduces "feelings of helplessness, hopelessness, depression, and apathy that often discolor the time a patient has left to share with family and friends."³⁵

Visualization, like rehearsal and role reversal, is an approach that is already used to help caregivers of patients with Alzheimer's disease. It is particularly helpful in helping loved ones find new approaches to helping patients when they feel they are "stuck."³⁶ The approach suggested here involves not only loved ones, but also patients.

It might be asked whether patients with Alzheimer's are sufficiently capable of visualization, even at the earliest stage of their illness, for it to be successful. It might be assumed that this approach would be precluded because they can't sufficiently imagine themselves in past or future states. It may take these patients more time; still, with extra time, patients may be able to visualize effectively. This was demonstrated by a patient who had dementia and needed a spinal tap, but was "phobic" about having the procedure done.³⁷ Hypnosis can enable some patients to overcome a "needle phobia" such as this. Patients must be able to become relaxed enough to achieve a hypnotic state and, in this state, they must be able to visualize enough to actually change their "instinctive responses" of experiencing fear and pain so that a spinal tap or other desired intervention becomes a procedure they can "endure." Slowly closing one's eyes is one method by which hypnosis can be initially induced. As patients slowly close their eyes, they are instructed to let themselves become exceptionally relaxed and go into a trance. This typically takes approximately five minutes. With this patient who had dementia, it took nearly 15 minutes to achieve.³⁸ The therapist also had to change how he gave the patient instructions; usually, these are only verbal, but, in this instance, the therapist found it effective to give the instructions non-verbally. He motioned with his head to show how the patient likewise should respond. It worked. He numbed the spot on this patient's back where he needed the spinal tap with lidocaine, and then told him that the injections he was giving were like "three mosquito bites." He also told a story about how the sweetest children are the ones that mosquitoes bite.³⁹ The patient was then able to tolerate the procedure.

STAGE 2: SHOULD LOVED ONES MANIPULATE PATIENTS?

As patients lose their capacity to understand and remember, they find making decisions more difficult. Consequently, loved ones may want to respond in ways that avoid forcing patients to make decisions — because this may evoke patients' frustration — but, at the same time, allow patients to feel fully involved. One approach is to use a so-called last-word connection. Here's how the technique works: "The care partner asks, 'Would you like to wear this green shirt today or the one that's blue?'" Nine times out of ten, the patient says, 'Blue' — simply because it was the last word he remembered hearing."⁴⁰ Patients may respond to the use of this technique by feeling better, even though the involvement it invites is, to some degree, an illusion, as it allows them to maintain the sense that they have some control. Feeling they have some control and involvement may be exceptionally important to patients at later stages of their illness. Coste advises, "Guide the patient or take over as inconspicuously as possible to allow him to maintain a sense of control for as long as possible."⁴¹

This approach is manipulative, and, ethically, it is paternalistic; it is also deceptive. But it may have merit. Key questions in considering whether this deceit is justifiable (or at some point even morally obligatory) are: What are the alternatives? Is it possible, at this stage, that patients echo their loved ones' last words "nine out of ten times" because they believe, rightly or wrongly, that this response is what their loved ones most want to hear?

Patients may want to hold onto their connection with loved ones more than anything else, and so may do whatever they can to enhance this relationship. This could include agreeing with loved ones' "last words"

even when they would prefer something else. Patients may respond to loved ones' last words in a way that actually is an attempt to manipulate their loved ones — they may do this to maximally maintain loved ones' positive feelings toward them. If this is the case, loved ones could ask "last-word connection" questions in a way that is not manipulative, but wholly genuine; they could also take special care to reassure patients that, regardless of which choice they make, it is "fine" with them.

The possibility that patients assign their relationships with loved ones top priority supports Lindemann's view that social factors are exceptionally important to patients with Alzheimer's.

STAGE 3: SHOULD LOVED ONES LIE?

During the middle and last stages of Alzheimer's, patients have greater loss of memory. Further, if confronted with this loss, patients, like Lindemann's mother, may deny it and instead feel enraged. It may be less emotionally painful to distort this particular reality than to accept it as it is, especially since this loss will probably continue. Lindemann's mother may have found it less painful to believe that her daughter stole from her, rather than accept that she was having trouble with her mind.

The question loved ones may face at these later stages is whether they should be honest and risk evoking patients' rage. Here, the overriding principle that authorities suggest is to avoid provoking distress. Strauss offers this guideline: "If you can't give a truthful answer that is believable or acceptable or not hurtful at the cognitive level, then tell an emotional truth."⁴²

An example illustrating how loved ones can apply this concept is when patients repeat themselves because they forget what they have just said. It is important in this instance to keep in mind that patients truly believe that what they are saying, they are saying for the first time. Strauss suggests, "Every time they ask the question, it is a new question to them. You must act as if it is a new question to you."⁴³ Accordingly, loved ones should not say, "You just told me that." They should say, "That's interesting; I didn't know that," even though it is untrue.⁴⁴ Loved ones should respond to patients in as emotionally supportive a way as possible, regardless of the truth of the content, as this reduces patients' stress and leaves the relationship intact, or even enhances it.

An extreme example of memory loss occurs when patients can't recognize their loved ones. Then, as I have suggested above, it may be best for patients to be able to say openly, "I don't know you," without feeling shame.

This may not be possible. In such cases, Strauss recommends that loved ones should respond with "emotional rather than cognitive truths," that is, they might say something like, "No, we haven't met before, but it's really nice to meet you."⁴⁵

CORE EMOTIONAL REALITIES

Authorities on Alzheimer's have recommended that loved ones try to meet patients' emotional as well as cognitive needs, but what are these emotional needs? I have suggested that loved ones can affect patients profoundly, as Lindemann contends, but what are *their* needs? Later stages of Alzheimer's may include hidden, significant potential for increased emotional richness for patients and loved ones. What, more precisely, could this potential be? The answers may help loved ones and the careproviders who advise them to better implement the specific approaches described above.

WHAT ARE PATIENTS' PRIMARY EMOTIONAL NEEDS?

All of these ethical questions involve the degree to which loved ones should abandon truth-telling to better meet patients' emotional needs. Strauss offers this general guideline: "Everything comes down to a simple question you can ask yourself: Will this make my loved one more comfortable or less comfortable?"⁴⁶

It may be helpful to know more about what patients' most important needs are. It is difficult to know this with certainty, especially since, in the later stages of illness, patients may be unable to describe them ver-

bally. Still, these needs, even then, may be reasonably imagined, if not inferred, from three sources: what patients say when they can still describe their feelings; what loved ones and others, such as careproviders, report; and what patients may reveal through other means, such as their art.

As a starting point, it must be recognized that patients with Alzheimer's can't seek the same goals as most other patients. They cannot, for example, seek to communicate intimately with loved ones during the final days of their lives. Likewise, careproviders can't respond as Cicely Saunders, who has done so much for hospice, advised; she suggests that careproviders say, "We will do all we can to help you live until you die."⁴⁷

These patients may lose the capacity to communicate, as well as the knowledge of who they and others are. At best, careproviders may be able to help them find meaning in other ways. They may explore with them, for example, whether they want to find ways to bear their losses gracefully, either for their own sake or for loved ones, such as the suggestions above regarding shame and anticipatory grief. As the disease progresses, patients' needs may change and be much like those experienced through childhood, but in reverse. Strauss adds that they also "need to make sense of why they are there."⁴⁸

It is much harder to be a patient with Alzheimer's than to be a child. Unlike children, patients were formerly independent, and they may find it humiliating that others do not let them do what they were once able to do.⁴⁹ This suggests what has implicitly been stressed already: loved ones should give great priority to enhancing patients' comfort, and, in doing so, to maintain patients' self-esteem. This guideline can be useful to loved ones who are trying to decide what to do in other contexts. Patients may, for example, despite their impairments, give parental advice to adult children who care for them, or even reprimand them. Strauss says, when patients are "parental," "Don't say, 'I'm an adult, not a child.' Do say, 'You always look out for me. I love you for it.'"⁵⁰

As patients get worse, their needs may then become more like those of younger and ever more younger children. What they may need most, for example, is frequent touching. What one can do to comfort these patients as this "regression" occurs is, however, limited only by loved ones' imaginations. Coste notes that "many good Alzheimer's programs now use aromatic therapy to help evoke pleasant memories."⁵¹ Beyond this, and more specifically, Kuhn states that "people with AD require three things [other than physical needs] to be relatively happy: intimacy, community, and meaningful activity."⁵²

The first, intimacy, particularly needs elaboration. Kuhn continues, "Without intimacy, fear and loneliness prevail. Just being in the physical presence of a trusted person at all times may offer reassurance to someone with AD who otherwise feels fearful while alone or with strangers."⁵³ It may be difficult for those of us who have not experienced intense fear, or who have not been exposed to someone who has, to imagine how important it is to be with someone who loves us when bad things happen. Patients who have panic attacks will know what a relief this can be. During these attacks, patients may fear they will die. They may develop an additional illness, such as agoraphobia, a fear of going outside in open spaces. Some patients can still function normally, but only in the company of those whom they trust. An example is a policeman I met who was decorated for bravery many times throughout a career of more than 20 years. He and his partner hadn't missed a day "riding" together during all that time. When his partner suddenly became ill, the policeman was unable to function; he could not go out in his squad car, even with another partner.

WHAT ARE LOVED ONES' PRIMARY EMOTIONAL NEEDS?

Any number of factors can cause a patients' loved ones to become "unglued." Among the most difficult emotions that they are likely to feel are helplessness and uncertainty, which often stem from, in large part, not knowing or being able to know what patients experience. As John Bayley, worried, "Does Iris speak, inside herself, of what is happening? How can I know? What is left is the terrible expectancy."⁵⁴ Helplessness and uncertainty are, some assert, among the most painful emotions we can experience.

Emotions such as these can affect loved ones profoundly and cause them to become different persons; it can also cause them to respond in ways they never had before. Iris's husband gives an example, of when he

became angry: "I find myself looking in the mirror at the man who has been speaking. A horrid face, plum colour."⁵⁵ He asks, "What can loved ones do about this?" and "I wonder briefly, if we'd had a child, would I have learnt not to be angry with it? In which case would I not be angry with Iris now?"⁵⁶ The answer for most loved ones is, probably that it is possible to learn not to respond to an infant with anger, and so it may be possible to learn to not become angry with patients, no matter how "regressed" they are due to Alzheimer's.

Kuhn suggests two approaches. First, loved ones can try to remember, at all times, that fear is often behind the anger that patients express. "If you can remember that," Kuhn says, "you'll be able to handle the anger washing over you with relative tranquility, and you'll be able to react with compassion."⁵⁷ Loved ones can repeat this to themselves, silently, like a mantra. If they do, each time they repeat it, it may reduce their anger. A second approach is to recall as vividly as possible a time that they, too, felt as the patient does. As Kuhn says, "much of it isn't foreign to you . . . the emotions people feel are familiar [within] your own experience."⁵⁸

One example is the feeling of shame. The feeling of embarrassment, a less severe version of shame, is very common. When someone says or implies that we have just done something wrong, we may feel an impulse to come up with an elasticized or at least mildly stretched excuse. If our doctor says to us, for example, "Hmm. I see here that you were going to call for a follow-up appointment," if we didn't make that appointment, we might feel some shame.

A well-known writer who felt shame was August Strindberg. He wrote to his third wife, Harriet Bosse, "I feel shame without reason, remorse without having sinned, disgust with myself without knowing why."⁵⁹ He depicts shame in the words of Miss Julie, in the play by the same name. After Miss Julie "gave in" to the seductive efforts of a man who was "lower in station than she," she says, "I'm incapable of feeling, not able to be sorry, not able to go, not able to stay, not able to live — not able to die." Then she takes her life.⁶⁰ This description may come close to capturing what patients may feel when they can't remember. As a patient told me, when he is with his friends he is careful to not speak very often.

Loved ones who seek to remain close to patients with Alzheimer's shouldn't give up too easily on patients, but should proceed in the most emotionally soothing ways possible. As Kuhn notes, "It may take months, even years, before you become comfortable with using a new set of communication skills in your relationship."⁶¹

Yet there is another realm of possibilities to consider: some loved ones may find it nearly impossible to continue to feel strongly for patients; they may feel they need to distance themselves emotionally. They may be more acutely affected than others when patients' diseases worsen, and patients become more and more mere shells of the persons they once were. Loving patients may become too painful to bear. John S. Rolland says, "Clinicians should be sensitive to nodal points that may require discontinuous change for the family. For instance, one family tried at all costs to preserve the deteriorating father's role functions. . . . As disability increased, successful adaptation required acceptance of that which could not be changed."⁶²

Accepting this need to "distance" may be also be difficult because of guilt, which may be compounded when loved ones can't keep the patient at home. As one person said, "It was a question of both obligation and gratitude, a way of paying back."⁶³ I experienced a need to distance myself after my father first had a persistent vegetative state. His heart stopped for several minutes before a rescue squad could get to him at his home. Before this, my father had been a person you would not want to play Scrabble with. He loved to make puns: in one rhyme he wrote, he described a tribesman looking for his wife at night in a tent in a desert in the Mid-East, who lifted up a tent flap and called, "Which Bed-u-in?" In a pre-persistent vegetative state, he would sit in his hospital bed, staring blankly.

I didn't want to visit my father daily. Or weekly. I wanted to be with him as little as I could. Patients' loved ones may feel this way, too, and experience the patients' bodies, as I did my father's — as a cruel mockery of the person he had been. The tasks for loved ones, for their own emotional survival, may be to accept that the person they loved is no longer there, and to accept the change in their feelings that may go with it.

WHAT IS POSSIBLE IN PATIENTS' AND LOVED ONES' RELATIONSHIPS?

There is a third possibility that, for many loved ones, is quite far from gloomy. As Stephen G. Post says, "Because our culture so values rationality and productivity, observers easily characterize the life of persons with dementia in the bleakest terms. . . . The experience of the person with irreversible and progressive dementia is clearly tragic, but it need not be interpreted as half empty rather than half full."⁶⁴

Patients may retain a considerable capacity of their ability to relate to others non-verbally. Thus, they and their loved ones may be able to continue an emotional relationship, even though it may be far different from what they experienced. Since patients may have lost all of their cognitive capacity, they may make no judgments about others based on "superficial" factors, such as what they *do*. Rather, patients may respond only to how their loved ones *are*, when they are with them. In earlier stages of illness, for example, patients may respond bluntly, like children. As Strauss says, "if you *really* want to know how your hairdo looks — just ask him!"⁶⁵ Later in their illness, patients may respond only to the moment at hand. As Coste says, "People with Alzheimer's live in the moment; to convey positive emotions, you need to live in the moment, too."⁶⁶

Loved ones can learn to cherish the unique and unprecedented emotional richness of emotionally intimate experiences such as holding and comforting the patient, which may be very much like discovering (and later missing) similar opportunities with an infant or a very young child. For instance, I can recall the joy I felt as a young child playing Slap Jack for hours with my mother. In this game, one player flips over cards, and the first person to slap a hand down on a Jack "wins" that hand. The game is absolutely mindless, but the sense of peace and wholly un-selfconscious bonding I had with my mother is the closest I have come to feeling bliss. I can't actually recall a greater joy. I suspect that patients can feel this kind of pleasure in intimacy at the end of their illness with their loved ones.

Loved ones may experience a new sense of meaning they wouldn't in any other way. As Strauss says, "they will only see *you*. They may be the only people who can do that. . . . When you are with them, you are stripped to your essence. . . . This is a great gift they can give *you*."⁶⁷ I think in this regard of the singular, immense joy some parents experience, even with most severely impaired children, in response just to a smile. One parent and his wife provided continuous care, 24 hours a day, to their child. He said to me, "But it's all worth it every time I see him smile!"

Iris Murdoch's husband provides another example: "Tone is what matters," he says. "I stroke her back or pull her backwards. . . . I imitate the fond way her father used to say (she told me this long ago) 'Have you no sense at *all*?' . . . Iris's face always softens if I mention her father in this way. Instead of crying she starts to smile."⁶⁸

CONCLUSION

Having Alzheimer's disease is, without question, among the greatest misfortunes any person can undergo. In the discussion above, I have explored three possible ways that loved ones can try to lessen patients' emotional pain. Patients' and loved ones' relationships, in sum, may become richer. Are there, however, real life examples of this? I refer once again to Iris and John.

John says, "Every day we are physically closer; and Iris's little 'mouse cry', as I think of it, signifying loneliness in the next room, the wish to be back beside me, seems less and less forlorn. . . . She is not sailing into the dark: the voyage is over, and under the dark escort of Alzheimer's she has arrived somewhere. So have I."⁶⁹ Why would John say this? Because, in large part, of the incredible, rare love such patients sometimes can bestow. John reports, for example, "I make a savage comment today about the grimness of our outlook. Iris looks relieved and intelligent. She says: 'But I love you.'"⁷⁰

NOTES

1. J.K. Coste, *Learning to Speak Alzheimer's* (New York: Houghton Mifflin, 2003); D. Kuhn, *Alzheimer's Early Stages* (Alameda, Calif.: Hunter House, 1998); and C.J. Strauss, *Talking to Alzheimer's* (Oakland, Calif.: New Harbinger, 2001). For a discussion of the original "case," see M. Strassnig and M. Ganguli, "About a Peculiar Disease of the Cerebral Cortex: Alzheimer's Original Case Revisited," *Psychiatry* 2005 2, no. 9 (September 2005): 30-3.

2. Some have said that, if they would experience this state, they would rather be dead, but since, at the time this occurs, they may not remember saying this, they should have assistance while they still can in dying.

3. Coste, see note 1 above, p. 112.

4. Ibid.

5. See, e.g., I. Hickie et al., "Reduced Hippocampal Volumes and Memory Loss in Patients with Early- and Late-Onset Depression," *British Journal of Psychiatry* 186 (2005): 197-202.

6. G.P. Sholvevar and P. Perkel, "Family Systems Intervention and Physical Illness," *General Hospital Psychiatry* 12 (1990): 363-72.

7. A. J. Cunningham, et al., "A Randomized Controlled Trial of the Effects of Group Psychological Therapy on Survival in Women with Metastatic Breast Cancer," *Psychooncology* 7, no. 6 (November-December 1998): 508-17; D.W. Kissane et al., "Cognitive Existential Group Psychotherapy for Women with Primary Breast Cancer: A Randomized Controlled Trial," *Psychooncology* 12, no. 4 (September 2003): 532-46.

8. See, e.g., P.N. Tariot et al., "Memantine Treatment in Patients with Moderate to Severe Alzheimer Disease Already Receiving Donepezil," *Journal of the American Medical Association* 291, no. 3 (21 January 2004): 317-24; and C. Holmes, "The Efficacy of Donepezil in the Treatment of Neuropsychiatric Symptoms in Alzheimer Disease," *Neurology* 63 (2004): 214-9 for benefits of medications to patients and their loved ones, respectively.

9. Likewise, "open-ended questions may work in the early stages, [but] eventually questions will be a source of confusion." Strauss, see note 1 above, p 39.

10. Ibid., 63.

11. Coste, see note 1 above, p. 45.

12. "When to touch? When not to touch? It's simple. Ask." Strauss, see note 1 above, p. 56.

13. D.F. McGowin, *Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's* (New York: Delacorte Press, 1993), 103, cited in Kuhn, see note 1 above, p. 83.

14. Kuhn, see note 1 above, p. 85.

15. B.L. Miller and C.E. Hou, "Portrait of Artists," *Archives of Neurology* 61 (June 2004): 842-44, 842-3.

16. J.C. Harris, "Excavation," *Archives of General Psychiatry* 62, no. 4 (April 2005): 359-60, <http://archpsyc.ama-assn.org.lrc1.usuhs.edu/cgi/content/full/62/4/359>, 4.

17. C.A. Rentz, "Memories in the Making: Outcome-Based Evaluation of an Art Program for Individuals with Dementing Illnesses," *American Journal of Alzheimer's Disease and Other Dementias* 17, no. 3 (May/June 2002): 175-81, p. 178.

18. Ibid., 180.

19. Strauss, see note 1 above, p. 54.

20. C.G. Lyketsos et al., "Major and Minor Depression in Alzheimer's Disease: Prevalence and Impact," *Journal of Neuropsychiatry and Clinical Neurosciences* 9 (1997): 556-61, 557.

21. Kuhn, see note 1 above, p. 125.

22. See, i.e., M.A. Drickamer and M.S. Lachs, "Should Patients with Alzheimer's Disease Be Told Their Diagnosis?" *New England Journal of Medicine* 326, no. 14 (April 1992): 947-51.

23. Kuhn, see note 1 above, p. 95.
24. J. Bayley, *Iris* (London: Abacus, 1998).
25. *Ibid.*, 275.
26. *Ibid.*
27. For comments on the potential importance of the use of humor with these patients, see M.S. Mittleman, C. Epstein, and A. Pierzchala, *Counseling the Alzheimer's Caregiver* (Atlanta, Ga.: AMA Press, 2003), 18-9.
28. *Ibid.*, 66.
29. B. Turkoski and B. Lance, "The Use of Guided Imagery with Anticipatory Grief," *Home Healthcare Nurse* 14, no. 11 (1996): 878-88, p. 880.
30. *Ibid.*
31. *Ibid.*, 878.
32. Turkoski and Lance, see note 29 above. Visualization is presented as a technique for caregivers in Mittleman, Epstein, and Pierzchala, see note 27 above, p. 67.
33. *Ibid.*
34. Turkoski and Lance, see note 29 above, p. 884.
35. *Ibid.*
36. Mittleman, Epstein, Pierzchala, see note 27 above, p. 67.
37. E.P. Simon and M.M. Canonico, "Use of Hypnosis in Controlling Lumbar Puncture Distress in An Adult Needle-Phobic Dementia Patient," *International Journal of Clinical and Experimental Hypnosis* 49, no. 1 (January 2001): 56-67.
38. *Ibid.*, 60.
39. *Ibid.*, 62.
40. Coste, see note 1 above, p. 81.
41. *Ibid.*, 114.
42. Strauss, see note 1 above, p. 14.
43. *Ibid.*, 27.
44. *Ibid.*, 101.
45. Coste, see note 1 above, p. 81.
46. Strauss, see note 1 above, p. 94.
47. I. Byock, "Patient Refusal of Nutrition and Hydration: Walking the Ever-Fine Line," *American Journal of Hospital Palliative Care* 12, no. 2 (March-April 1995) 9-13, p. 13.
48. Strauss, see note 1 above, p. 94.
49. *Ibid.*
50. *Ibid.*, 101.
51. Coste, see note 1 above, p. 46.
52. Kuhn, see note 1 above, p. 93.
53. *Ibid.*
54. Bayley, see note 24 above, p. 266.
55. *Ibid.*, 270.
56. *Ibid.*, 271.
57. Kuhn, see note 1 above, p. 63.
58. *Ibid.*, 14.
59. A. Strindberg, *Letters of Strindberg to Harriet Bosse*, ed. and trans. A. Paulson (New York: Thomas Nelson and Sons, 1959); 129, from a letter dated 4 October 1905.
60. A. Strindberg, *The Plays: Volume One*, trans. G. Motton (London: Oberon, 2000), 139.
61. Kuhn, see note 1 above, p. 150.
62. J.S. Rolland, "Anticipatory Loss: A Family Systems Developmental Framework," *Family Process* 29, no. 3 (September 1990): 229-44, p. 232.

63. L. Albinsson and P. Strang, "Existential Concerns of Families of Late-Stage Dementia Patients: Questions of Freedom, Choices, Isolation, Death, and Meaning," *Journal of Palliative Medicine* 6, no. 2 (2002): 225-35, p. 232.

64. S.G. Post, *The Moral Challenge of Alzheimer's Disease* (Baltimore, Md.: Johns Hopkins Press, 1995), 15, cited in Kuhn, see note 1 above, p. 85.

65. Strauss, see note 1 above, p. 115.

66. Coste, see note 1 above, p. 17.

67. *Ibid.*, 16.

68. Bayley, see note 24 above, p. 287.

69. *Ibid.*, 284

70. *Ibid.*, 249.