Multiple Transitions, Because No Advance Directive

“T he life of the party” described Jim. He was funny, gregarious, and the man everyone loved to be around. Even while his insidious dementia progressed, his wit maintained the veneer of normalcy that we often see in cognitively impaired people.

Jim’s ability to laugh off the misplaced items and forgotten names, even of close friends, hid what was painfully obvious, in retrospect: At 89, Jim was entering the dark territory of dementia. His wife of more than 60 years played her loving role by assisting in the coverup. She even provided him directions as he continued to drive well beyond a safe capability. Living independently in their condominium, they formed the symbiotic relationship often seen in such couples. Jim provided the brawn, while Helen provided the brains to enable them to stay in their home.

Helen’s abrupt death unmasked Jim’s dementia. In fact, at the funeral and then back at the condo, the couple’s two daughters were astounded at how far Jim had descended into memory loss. That most painful of questions now faced the children: What to do with Dad?

Since both daughters lived out of state, the next few weeks were filled with multiple returns to town. There were trips to the doctor, who confirmed that Jim had moderate-to-severe Alzheimer’s disease and lacked the capacity to make his own health care decisions. Next, father and daughters found an assisted living facility that the family’s minimal financial assets could bear, and Dad was admitted. The daughters painfully emptied the condo, encountering and dispatching a thousand details. The sisters finally congratulated themselves on having done everything—almost.

Within days of Jim’s admission, he began nocturnal wandering. Within a week, he had fallen and sustained a left femoral neck fracture. Hospitalization and an accompanying surgical repair brought Jim to a skilled nursing facility for rehabilitation. The SNFologist who admitted Jim found out several disturbing things: Jim had no advance directive, no power of attorney, no Physician Orders for Life-Sustaining Treatment (POLST) form, and no capacity to speak for himself on end-of-life matters.

The ensuing call to the daughters revealed that they had never asked Jim his wishes. One daughter felt that Jim was so engaged in life that he would never want to leave it and that every intervention should be used to keep him alive. The other was so passionate about the good things in life that he would never want to be alive in a state where he could not enjoy all the things he loved, so he should not be resuscitated, receive artificial feedings, or be sent to the hospital again. Decision paralysis began, never to be resolved. Jim remained full code.

Jim became febrile. He was sent to the emergency department, where pneumonia was diagnosed, and was admitted to the hospital. After returning to the SNF, Jim’s oral intake was poor. Staff noted further deterioration of his mental status, which soon prompted dehydration and a urinary tract infection, with a return to the hospital.

Back at the SNF again, Jim was losing weight. A dietician noted his poor eating at mealtimes and recommended snacks and supplements. A speech therapist noted no specific swallowing issues but indicated that Jim would not be able to consume adequate calories, so a feeding tube was recommended. Frenzied phone calls flew among the daughters, social services, and Jim’s attending physician. The sisters, once close and loving, had developed a contentious relationship by then, as their polar differences on end-of-life interventions escalated.

By default, a feeding tube was placed. Feedings began and were continued, despite Jim developing diarrhea. Over the next 6 months, he was readmitted to the hospital five times. A distraught nurse at the SNF appealed to the medical director to try to bring some sanity to the situation. Reluctantly, the warring sisters agreed to a conference call with the medical director as the facilitator.

The call confirmed several facts. Neither sister had ever discussed end-of-life issues with her father. Decisions were being made on the basis of the daughters’ perspectives rather than that of their father. The standoff between the sisters was never going to be resolved.

A stage III pressure wound and two rehospitalizations later, Jim died. The life of the party, the man in love with life never participated in the most important decisions of his life. No one knew whether Jim would have chosen to refuse a feeding tube and decline rehospitalizations once it was determined that such interventions were futile. His daughters, the loves of his life along with his wife, never spoke to each other again.

Good, respectful medical care follows the ethical wishes of the resident involved. This course also eliminates unwanted, potentially dangerous interventions and unwarranted care transitions. SNFs and primary care physicians have the opportunity to save many residents like Jim from the technological vale of pain that he entered, or we can at least ensure that doing so was his wish.

Our obligations:
▶ Seek the wishes of a resident early after arrival at a facility: Once our ability to determine these wishes is lost, the resident loses the ability to control his or her destiny. External decision makers, some with their own agendas, then drive the care.
▶ Guide families into the decisions that reflect what the resident wants, not the feelings of the family members. Even the most caring of families may abandon the resident’s choices for what the family members feel should be done.
▶ Determine health care decision-making capacity as soon as possible after admission: Doing so enables the physician to determine the true advance directives of the resident. It then becomes simple to support the desires of the resident, even after decision-making capacity is lost.
▶ Determine a power of attorney: Doing this while the resident is able to share his or her own health care wishes with a trusted person ensures that the resident is heard and those wishes are respected.
▶ Execute a POLST or another physician-orders form (such as Medical Orders for Life-Sustaining Treatment) if your state recognizes one: This transforms an advance directive from a preference to a medical order that must be respected by law. If a POLST-like law has not been passed in your state, at least make sure each resident has an advance directive.

Dr. Lett is the medical director at the Charles E. Smith Life Communities in Rockville, Md. A past AMDA president, he chaired the AMDA workgroup that created the clinical practice guideline “Care Transitions in the Long-Term Care Continuum” and currently is chairman of the AMDA Transitions of Care Committee.

By James Lett II, MD, CMD