Dear Dr. Jeff:

A 74-year-old childless widow in our facility had a mammogram that revealed probable breast cancer. She is refusing all further diagnostic tests and treatments, including needle biopsy, lumpectomy, and primary radiation therapy.

A consulting psychiatrist was called and diagnosed probable Alzheimer’s disease, based on a Mini-Mental State Examination score of 19 with disorientation to time and marked short-term memory deficits. He determined that the patient lacked decision-making capacity.

She is otherwise fairly healthy with a life expectancy of more than 5 years. Her designated representative with power of attorney, the lawyer who supervises her husband’s estate, refuses to make any medical decision. The surgeon is asking either the nursing facility’s administrator or medical director to sign a consent form so that he can proceed with an excisonal biopsy and possible lymph node dissection. What do you suggest?

Dr. Jeff responds: This letter raises the obvious point that no practitioner should order a test if he or she is not prepared to deal with the results. Most nursing home residents do not have a life expectancy that would justify a mammogram.

Nevertheless, if this lady, despite her disorientation to time and her short-term memory deficit, had agreed to the treatment and signed her own consent form, would you or anyone else have questioned it, much less obtained a psychiatric evaluation? Consenting to what well-meaning professionals recommend is usually seen as evidence of sound judgment. Yet the capacity to say “no” should be measured on the same scale.

The determination of decision-making capacity seems to represent a source of controversy for many institutions. Because so much confusion exists in this area, it is wise for nursing facilities to have written policies regarding the determination of capacity: how it is done, by whom, and what documentation is required to support a decision. Capacity is a clinical and ethical concept, a determination as to whether a specific decision at a specific time reflects the autonomous will of the decision maker.

This area has been further confused by the notion of competency, which is a legal concept. Ultimately, judges and courts determine competency, at times with the assistance or advice of medical and or mental health professionals.

Capacity (or, more formally, decisional capacity) is the ability to make a valid choice among specific alternatives. We recognize this capacity in a resident, who may be severely demented, when she is offered a choice between her red dress and her blue dress in the morning. To make a valid choice, she doesn’t need to know what all the dresses in the closet are, by whom they were made, or from whom they might have been gifted, much less have the ability to put the dress on herself.

So long as the resident understands that she is being offered a choice and that she will wind up wearing the chosen dress, she has dress-choosing capacity. Similar decisions are offered to severely impaired residents throughout the day, such as coffee or tea, cottage cheese and fruit or a tuna sandwich, and bingo or a religious service or Judge Judy. Recognizing and honoring these choices is a demonstration of respect for the autonomy of the individual, for her personhood.

We may think that the blue dress picks up the color of her eyes while the red dress makes her look pale, that the tuna fish has too much mayonnaise, or even that she would benefit more from a group activity than from time spent watching mindless television. But these are “mistakes” that it is her right to make, not ours. Medical decisions are a category among the many decisions residents make every day.

Decisions, Decisions

Some have argued that medical decisions, because they may have more serious consequences, require a higher level of capacity. Although the potential outcomes may be more difficult to understand, and thus the cognitive abilities required to evaluate them may be somewhat higher, the process is essentially the same.

The components of medical decision-making capacity are threefold. First, the resident must be able to make and express a choice. While an aphasic patient could certainly point to a preferred option, a comatose or unresponsive patient obviously lacks the capacity to make medical decisions. Second, the resident must be able to understand the essential nature of the choices being offered. In this case, the resident would need to understand that the choices might include an operation and/or a series of radiation treatments away from the facility or leaving things exactly as they are. Finally, the resident would need to understand the likely risks and benefits of those choices.

In this case, the benefits of surgery or radiation therapy or the two combined is a likely cure of her cancer while the benefit of doing nothing is avoiding the treatment. The risk of surgery is the risk of bleeding or infection plus the likely postoperative pain. For radiation, it is fatigue and anemia lasting several weeks and radiation burns. For doing nothing, it is invasive or metastatic cancer, breast ulceration, bone pain, fatigue with malaise, and ultimately death.

Her understanding of this discussion would imply being able to explain these risks and benefits back to you in lay language, not necessarily being able to retain every detail and percentage, much less remembering them the next day. These are cognitive abilities that many Alzheimer’s patients still possess.

Furthermore, residents who lack the capacity to perform this feat may still have the capacity to identify a friend or relative whom they trust to make these decisions for them. In a study that I coauthored many years ago, we found that most nursing home residents with a Mini-Mental State Examination score above 10 still possessed the capacity to reliably and consistently identify a health care proxy (durable power of attorney for health care) and that they chose these proxies among the same category of relatives and close friends as did cognitively intact residents.

Consent is not a form. It is a process. When proxies sign consent for a medical procedure, or decide to forgo an intervention, they are supposed to be taking part in a conversation as the voice of the resident and carrying out the resident’s will as they understand it. Simply getting someone to sign a form has no moral validity, and having an unauthorized individual sign a document won’t even give the resident the desired legal cover.

Your Obligation

Ultimately, the evaluation of decision-making capacity should fall to the attorney for the health care proxy (durable power of attorney for health care). This resident should have been told her physician believes is in over-all good health and is likely to live for many years. True consent comes when we talk to our residents, know their values and preferences, and routinely explain their medical situation to them.

These discussions, with frequent repetitions, may be even more important for those with impaired memories, limited education, or low levels of health literacy. And they must be in the resident’s preferred language. This resident can’t simply surf the web for discussion of her treatment options. She needs the help of her health team to make a truly informed choice.

Dr. Nichols is the medical director of Our Lady of Consolation and Good Samaritan Nursing Homes in Suffolk County, N.Y., and senior vice president for clinical effectiveness of the Catholic Health Care System of Long Island. He invites your questions for possible discussion in this column, to caring@longiservice.com. You can also comment on this and other columns at www.caringfortheages.com, under “Views.”

Helping Residents Make ‘Good’ or ‘Bad’ Decisions

By Jeffrey Nichols, MD

We recognize this capacity in a resident, who may be severely demented, when she is offered a choice between her red dress and her blue dress in the morning. To make a valid choice, she doesn’t need to know what all the dresses in the closet are, by whom they were made, or from whom they might have been gifted, much less have the ability to put the dress on herself.

So long as the resident understands that she is being offered a choice and that she will wind up wearing the chosen dress, she has dress-choosing capacity. Similar decisions are offered to severely impaired residents throughout the day, such as coffee or tea, cottage cheese and fruit or a tuna sandwich, and bingo or a religious service or Judge Judy. Recognizing and honoring these choices is a demonstration of respect for the autonomy of the individual, for her personhood.

We may think that the blue dress picks up the color of her eyes while the red dress makes her look pale, that the tuna fish has too much mayonnaise, or even that she would benefit more from a group activity than from time spent watching mindless television. But these are “mistakes” that it is her right to make, not ours. Medical decisions are a category among the many decisions residents make every day.

Decisions, Decisions

Some have argued that medical decisions, because they may have more serious consequences, require a higher level of capacity. Although the potential outcomes may be more difficult to understand, and thus the cognitive abilities required to evaluate them may be somewhat higher, the process is essentially the same.

The components of medical decision-making capacity are threefold. First, the resident must be able to make and express a choice. While an aphasic patient could certainly point to a preferred option, a comatose or unresponsive patient obviously lacks the capacity to make medical decisions. Second, the resident must be able to understand the essential nature of the choices being offered. In this case, the resident would need to understand that the choices might include an operation and/or a series of radiation treatments away from the facility or leaving things exactly as they are. Finally, the resident would need to understand the likely risks and benefits of those choices.

In this case, the benefits of surgery or radiation therapy or the two combined is a likely cure of her cancer while the benefit of doing nothing is avoiding the treatment. The risk of surgery is the risk of bleeding or infection plus the likely postoperative pain. For radiation, it is fatigue and anemia lasting several weeks and radiation burns. For doing nothing, it is invasive or metastatic cancer, breast ulceration, bone pain, fatigue with malaise, and ultimately death.

Her understanding of this discussion would imply being able to explain these risks and benefits back to you in lay language, not necessarily being able to retain every detail and percentage, much less remembering them the next day. These are cognitive abilities that many Alzheimer’s patients still possess.

Furthermore, residents who lack the capacity to perform this feat may still have the capacity to identify a friend or relative whom they trust to make these decisions for them. In a study that I coauthored many years ago, we found that most nursing home residents with a Mini-Mental State Examination score above 10 still possessed the capacity to reliably and consistently identify a health care proxy (durable power of attorney for health care) and that they chose these proxies among the same category of relatives and close friends as did cognitively intact residents.

Consent is not a form. It is a process. When proxies sign consent for a medical procedure, or decide to forgo an intervention, they are supposed to be taking part in a conversation as the voice of the resident and carrying out the resident’s will as they understand it. Simply getting someone to sign a form has no moral validity, and having an unauthorized individual sign a document won’t even give the resident the desired legal cover.

Your Obligation

Ultimately, the evaluation of decision-making capacity should fall to the attending physician and the interdisciplinary team, not to any consultant. Only the primary care team can determine capacity, because they can evaluate whether the patient’s understanding of the potential risks and benefits accurately reflects the reality of the situation and whether the decision is being made during deliberation.

The participation of psychiatrists in the evaluation of capacity may be valuable to identify a major depression or psychosis that might be interfering with the patient’s decision. A patient experiencing profound depression might feel that his or her situation is hopeless and that all interventions are pointless. A psychotic resident might be convinced that the surgeon is an enemy trying to kill with a knife.

The truly interesting question here is why this particular resident is making this choice at this time. Some patients use magical thinking, believing that ignoring a problem will make it go away. Perhaps the very word cancer has produced a profound fear reaction. Perhaps she hasn’t had the situation adequately explained to her. The responses to “I want permission to do an excisional biopsy of your probable breast malignancy” and “I want to cut out a small cancer in your breast before it gets bigger and causes you trouble” might be quite different.

Just as many patients sign consent forms that they do not understand because they trust the care providers, others refuse interventions out of fear and mistrust without truly understanding what they are refusing. Some dementia residents are afraid that they will be taken to the hospital and left there. Knowing that they can’t find their way back home makes them reluctant to go anywhere.

Possibly, the resident is confusing the proposed procedures with the radical mastectomies that friends might have had in the past and is frightened of deformity. Perhaps she fears that her health insurance will refuse to pay for her treatment and thus she will lose her life savings. She may simply value her current comfort much more than fear suffering in the future. Potential risks and benefits can be valued very differently by different patients.

This resident should have been told that her physician believes is in over-all good health and is likely to live for many years. True consent comes when we talk to our residents, know their values and preferences, and routinely explain their medical situation to them.

These discussions, with frequent repetitions, may be even more important for those with impaired memories, limited education, or low levels of health literacy. And they must be in the resident’s preferred language. This resident can’t simply surf the web for discussion of her treatment options. She needs the help of her health team to make a truly informed choice.