In 2019, the Ethics Committee of AMDA – The Society for Post-Acute and Long-Term Care Medicine authored a white paper on “Stopping Eating and Drinking by Advance Directives in the ALF and PALTC Setting.” When the paper came before the House of Delegates, there was a long and animated discussion about the issue, with delegates debating the risks and benefits. Ultimately, it passed by a wide margin. At PALTC21, the Society’s Virtual Annual Conference, a program session dove into the issue in greater detail with “To Feed or Not to Feed: The Ethical Question.”

### Principles of Ethical Analysis

We have a structure for ethical analysis, said Robert A. Zorowitz, MD, MBA, CMD, because there is no clear delineation between what counts as our own beliefs and what counts as common sense. The most common ethical principles include autonomy, beneficence/non-maleficence, justice, community, truth, and utility.

“In most Western cultures, autonomy is considered to be a major ethical principle. Our free society values autonomy and personal choice,” he said. “It requires a developed concept of self, capable of formulating goals reflecting one’s values.” Autonomy is about rights. As Dr. Zorowitz said, “Our respect for autonomy means we accept the right of individuals to take risks.” Advance directives are a means for preserving autonomy when decisional capacity is lost.

### The White Paper Perspective

James Wright, MD, CMD, one of the authors of the Society’s white paper, noted, “We felt there were two main issues: autonomy and justice.” He added, “You have to set up a dichotomy for SED [stopping eating and drinking] to work. The ‘now-self’ has lost the ability to influence the decision, to make any decisions or choice in the matter of eating or drinking, so it is the ‘previous-self’ who gets to make those decisions. We have to set up a situation between the then-self and the now-self.”

Although autonomy is the “bedrock of modern medical ethics,” Dr. Wright said, “it can’t be used exclusively over all other ethical principles. We wanted to use the principle of justice in this discussion.” Justice, he said, is a basic principle of ethical discussions and decision-making. “We as providers are sworn to treat patients as free as possible from discrimination. It is our role to uphold justice,” he said. “If you refuse to honor someone’s advance directive, you are inflicting injustice on that person.”

However, Dr. Wright noted, “the advance directive is operative only when a person has lost capacity. When does a person lose capacity to determine when they want nourishment? We don’t advocate force feeding or offer of food until the now-self expresses that he or she wants to eat.” He further observed, “SED by advance directive relies on the false assumption that capacity is an all-or-nothing phenomenon. If the person hasn’t lost capacity, SED by advance directive is invalidated.” He stressed that people living with dementia still retain the capacity to make some decisions.

Dr. Wright also referred to the challenges presented by ageism: “We must, as advocates for an underserved, disenfranchised population, be very careful that our practice doesn’t validate society’s disregard for people living with dementia.”

The white paper concluded, “It is the position of the Society that the care of our patients should always be informed by their current experiential interests.” This involves “offering hand feeding as long as the resident is not showing signs of distress and stopping the practice if distress or refusal develops.”

### The Ecological Perspective

“There is another dimension we may want to consider, and that is the relational perspective. We need to consider the impact ethical decisions have on others,” said Elaine Healy, MD, FACP, CMD. This, she said, offers an essential corrective to our current ethical principles by taking seriously a fundamental element of our theology — and even of our basic humanity — that we exist in relation to others.

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Dr. Healy noted that up until the 1960s benevolent paternalism was dominant in medicine. Under this principle, she said, the physician was deemed to know best and was expected to operate in the best interest of the patient. She said, “Physicians could withhold information or present it in such a way as to direct the patient’s decision.”

As the baby boomers grew up, they emphasized control and choice, as well as the right to challenge authority. They, Dr. Healy said, “became champions of autonomy.” These individuals embraced the use of advance directives to guarantee that their wishes about end-of-life care would be carried out if they lost decisional capacity.

At the same time, the boomers were the first to experience “both the individual and cultural impacts of widespread dementia,” said Dr. Healy. She added, “Their use of advance directives has expanded from prohibiting the imposition of unwanted medical care at the end of life to directing basic aspects of caregiving in day-to-day life.” Clearly, she suggested, advanced directives have limitations. Not only do people have “poor affective forecasting,” but they also underestimate their ability to adapt to adversity, and they fail to foresee how their own coping skills will reduce unhappiness or how what they value will shift.

With the ecological approach in medical ethics, Dr. Healy said, “ethical decisions are undertaken in [the] context of the culture and community in which they occur, as well as in relation to others who are impacted.” In the nursing home, this means acknowledging the community of care, appreciating that ethical decisions have implications for others as well as the patient, and addressing concerns about the moral distress of caregivers.

A CNA’s Perspective

“I was raised by my grandmother. I watched this woman I loved so much suffer after she had a stroke,” said Marguerite Johnson, a nursing home certified nursing assistant (CNA). It inspired her career choice, and she said, “I will go to hell and back for my residents. We have a family relationship. When they are down, I make sure they get what they need to feel comfortable.”

She added, “I have several patients in my ‘family,’ and they are all individual people. They are each different, and I love them all differently.”

“Could I take food away from a resident? Absolutely not,” said Marguerite Johnson, a nursing home certified nursing assistant. With the ecological approach in medical ethics, Dr. Healy said, “ethical decisions are undertaken in [the] context of the culture and community in which they occur, as well as in relation to others who are impacted.” In the nursing home, this means acknowledging the community of care, appreciating that ethical decisions have implications for others as well as the patient, and addressing concerns about the moral distress of caregivers.

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Advance directive or not, Ms. Johnson said, “Could I take food away from a resident? Absolutely not. I have watched what not getting food does to people. It hurts me to the core.” She explained that she asked to be removed from caring for one patient whose family initiated a stop eating order because she couldn’t stand to watch the person be deprived of food. She concluded, “I know I would want to be treated with the love and tender care that I give to my residents.”

Dr. Healy said, “Wouldn’t we want someone like Marguerite to take care of us or our family? In our facility, we decided we wanted to address this issue proactively. We now have a policy that we will provide food and fluids by hand to all residents who are capable and have a desire to eat and drink. We explain that on admission.”

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