Dear Dr. Jeff: On the list of recommendations during the COVID-19 pandemic from every expert is the suggestion that residents and families be approached regarding advance directives such as Do Not Resuscitate and Do Not Intubate orders and Living Wills. weren’t facilities always required to do this both by federal law and the federal Requirements of Participation in Medicare and Medicaid? Did the coronavirus pandemic change these requirements?

Dr. Jeff responds:
You are absolutely correct that the 1990 Patient Self Determination Act requires all nursing homes to inform every patient admitted to the facility of their right to execute an advance directive and to ask at every admission if they have already completed such a directive as part of the admissions process, typically within 48 hours of entry into the building. Most facilities include this information, often with blank forms approved for their state, in their admission packet. The resident’s chart should document that information was provided and the response to questions regarding existing directives. Every resident’s right to create advance directives and the right to have those directives honored is enshrined in the Resident Rights section of the federal regulations. Facilities have received high-level deficiency citations for attempting resuscitation of residents who had valid Do Not Resuscitate (DNR) orders as well as failing to attempt resuscitation of residents who lacked such orders.

Most facilities have concentrated on resuscitation status and the designation of a substitute decision-maker for individuals lacking decisional capacity. (The technical name for such individuals varies from state to state but includes “health care proxy,” “health care agent,” or “guardian for health care decisions.”) Some post-acute and long-term care facilities also use Medical Orders for Life Sustaining Treatment forms (referred to as MOLST or POLST in most states) for some or all admissions, which document a wider set of possible preferences, including rejection or acceptance of intubation, dialysis, antibiotics, rehospitalization, and other potential interventions. PALT facilities collaborating effectively with referring hospitals typically receive information regarding any existing advance directives along with the application or transfer documents and, ideally, copies of any executed documents as well. These preferences as recorded are typically carried over in the new facility. Depending on the documents and state legislation, there can be additional paperwork requirements. Although valid orders such as DNR require assent by a practitioner with written or electronic documentation, the actual discussions are often held by other members of the care team including admission nurses, floor nurses, and social workers. These conversations are confirmed by the practitioner during the admission medical assessment.

Revisiting Advance Directives
The whole structure assumes that patient choices or the choices made by their proxies on the patient’s behalf remain fixed over time. In fact, although these various signed documents represent the best available understanding of a resident’s values when an emergency decision needs to be made, all of us know that human beings change their minds as circumstances change. The COVID-19 pandemic has highlighted for many practitioners and medical directors how existing systems have failed to create opportunities for meaningful and informed discussions regarding resident preferences and resident preferences, particularly as they evolve over time.

Moreover, the scenes of overwhelmed emergency departments and refrigerator trucks used as temporary morgues have stripped away some of the veil of medical omnipotence and the illusions of miracles cures, which have been staples of our death-averse culture. The looming risk of a loved one being “proned” in an intensive care unit on a ventilator has made discussions of hospital transfers and intubation finally seem pressing and important. These decisions are also more immediate for the facility’s staff; performing cardiopulmonary resuscitation or intubation by staff or emergency medical technicians (EMTs) on a COVID-19-positive resident before hospital transfer can aerosolize large quantities of viral particles, putting everyone nearby at risk.

The changed situation on the ground presents new opportunities to revisit resident preferences, and it offers an imperative to improve on practices that have been complacent with regulations but often have served residents poorly. The risks and benefits of a variety of interventions appear differently now. The need to prevent inappropriate hospital transfers is more critical when the changed situation on the ground appears. The need to prevent inappropriate hospital transfers is more critical when the changed situation on the ground appears. The need to prevent inappropriate hospital transfers is more critical when the changed situation on the ground appears. The need to prevent inappropriate hospital transfers is more critical when the changed situation on the ground appears. The need to prevent inappropriate hospital transfers is more critical when the changed situation on the ground appears. The need to prevent inappropriate hospital transfers is more critical when the changed situation on the ground appears. The need to prevent inappropriate hospital transfers is more critical when the changed situation on the ground appears. The need to prevent inappropriate hospital transfers is more critical when the changed situation on the ground appears. The need to prevent inappropriate hospital transfers is more critical when the changed situation on the ground appears. The need to prevent inappropriate hospital transfers is more critical when the changed situation on the ground appears.

Understanding the Patient’s Perspective
The timing of the mandatory process is obviously necessary as new residents are integrated into the long-term care environment. But a process that requires decisions at the time when the decision-makers are least aware of their medical conditions and prognosis, when they are panicked or confused by the new and frightening events in their life, is unlikely to produce thoughtful decisions. Many patients transferring to post-acute settings have been advised that this is simply a two- to three-week interlude on their road to full recovery, and the endless barrage of negative publicity about nursing homes has left them suspicious of any commitments to forgo care or transfer back to the hospital.

A substantial majority of patients discharged to PALTCC do ultimately return home, but frequently they are more functionally dependent than they had been before their acute hospital stay. Only a quarter of elderly patients who sustain a hip fracture will ultimately walk independently. An additional half will be at least partially ambulatory with an assistive device such as a walker. Fully one-quarter will not walk again. Patients admitted to the hospital after sustaining a stroke may return home with some functional deficits, but among those who required skilled nursing level rehabilitation, very few will return close to their prior functional level. A substantial number will make little to no progress despite best efforts at rehabilitation. Patients admitted with metastatic cancer with a plan to “get stronger” so they will be able to tolerate chemotherapy rarely recover the strength and appetite needed for their planned therapy.

Unfortunately, it is rarely possible at the time of admission to identify with certainty which patients will make significant functional improvements. Even when a poor prognosis is obvious — such as with the all-too-frequent transfer of cancer patients with extensive metastases and malnutrition for restorative rehabilitation — it is difficult for PALTCC professionals, even experienced geriatric nurse practitioners or trained geriatrics liaisons, to overcome the stigma associated with nursing home care or the rosy predictions of hospital specialists. What resident or family member would choose to predict a rosy outcome without the need to face the potential for a potentially contagious environment while still providing quality care.

AMDA — The Society for Post-Acute and Long-Term Care Medicine recently produced new guidelines for advance care planning during the COVID-19 epidemic, along with new recommendations on CPR performance and techniques. These are available on the
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facility. The fear of not knowing can be worse than knowing the truth. We tend to conjure up horrid stories in our minds that get repeated and augmented, exacerbating the fear. Share with the families, even those who do not demonstrate any interest, what the facility is doing in terms of screening, especially when residents leave and re-enter the PALTC facility. Let them know what precautions are in place for the residents who share rooms and what would happen if a roommate tested positive.

• Ensure that families know whom to call if they have questions, and that the phone will be answered or the call returned.

• Teach families about personal protective equipment (PPE), and let them know how those items are being used to keep residents and staff safe. Let families know about the training that staff has received to properly use the PPE. If PPE is not available, tell families what the facility is doing to obtain it. And tell them what processes are in place in the meantime to keep everyone as safe as possible.

• Be honest about how this is a fluid situation that requires daily — sometimes multiple times a day — updates and renegotiations. Let families know how the staff are communicating with each other and how the leadership is staying abreast of staff and resident needs.

• Establish a communication plan that includes regular updates. Don’t make families ask for information — offer it willingly. Be proactive. Be honest.

• Acknowledge that nursing home staffing can be a tricky subject. The reality is that your facility may experience staff shortages, whether due to illness or staff making the difficult choice to stay home. Let families know how the facility plans to handle these situations, including how the residents’ needs will be met for personal care, meals, medication administration, and social engagement.

• For family members who are a resident’s surrogate decision-maker or power of attorney, inform them that they will be asked to clarify their treatment wishes in the event that their loved one becomes ill, either with COVID-19 or another condition. Update advance directive documents, especially code status. Consider discussing temporary Do Not Resuscitate status. “Prioritizing Advance Care Planning in the Time of COVID-19” is a free webinar offered by Johns Hopkins Medicine that offers valuable considerations for those conversations (https://www.hopkinsmedicine.org/gec/index.html).

• Ask families for their input. When people are invited to collaborate, especially during times of crisis, they will be more invested in the outcome and success of combined efforts. Families can be a wonderful support, and they may even welcome the opportunity to do what they can to help the facility and staff.

AMDA – The Society for Post-Acute and Long-Term Care Medicine has a webpage dedicated to resources to help providers and facilities. Go to https://paltc.org/COVID-19 to obtain information on the Society’s guidance, resources, and tools; COVID-19 daily email updates; podcasts and webinars; press coverage; and updates from the Centers for Disease Control and Prevention and Centers for Medicare & Medicaid Services.

Be prepared to repeat information. When people are stressed, their ability to retain information and recall it accurately diminishes. Exude compassion, expertise, and confidence, but also humility as we all learn how to function in this extraordinary time.

Ms. Hector is a clinical educator and public speaker. She is passionate about nursing homes and supporting staff to care for the most vulnerable people in their communities. She is an associate editor of Caring for the Ages.

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Society’s website and are extremely useful (https://paltc.org/COVID-19).

In the pre-COVID-19 era, the necessary response to the problems inherent in clarifying goals of care and creating treatment plans based on those goals and values required a schedule of repeated discussions regarding choices as the course of the nursing home stay evolved. In 2020, COVID-19 has pushed this need to the forefront. A task that was always difficult has not become any easier, but the critical need that these issues be addressed is absolutely clear to all.

Dr. Nichols is past president of the New York Medical Directors Association.