

AMDA- THE SOCIETY FOR POST-ACUTE AND LONG-TERM CARE MEDICINE

WHITE PAPER A17

SUBJECT: A PRACTITIONER’S GUIDE TO ADVANCE CARE PLANNING DISCUSSIONS
IN THE POST-ACUTE AND LONG-TERM CARE SETTING

INTRODUCED BY: ETHICS SUBCOMMITTEE AND ADVANCE CARE PLANNING WORK
GROUP

INTRODUCED ON: MARCH 2017

PURPOSE

The purpose of this White Paper is to highlight the importance of Advance Care Planning conversations and informed medical decision-making in the PA/LTC setting. Additionally, the White Paper will serve to delineate the prerequisites and key elements necessary to the adequate performance of an Advance Care Planning visit under the CMS billing codes, 99497 and 99498, which were implemented beginning January 1, 2016.

BACKGROUND

More than 1.4 million Americans live in one of more than 15,000 nursing homes (NH). 85% are over 65, with an average age around 82 years. With the growth in short-stay, post-acute (post-hospital) admissions to skilled nursing homes, there are increasingly two populations within the NH. First there are those who are long-stay custodial residents for whom the facility is their “home”. They often have multiple chronic comorbidities but generally stable clinical status. Second, there are those who are at the SNF for a shorter stay, receiving skilled care for rehabilitation therapy and/or medical treatments (intravenous therapy, enteral feeding, wound care); they often have multiple acute as well as chronic comorbidities. The divergence of the clinical trajectory of these two subpopulations is reflected in the fact that while the mean length of stay (LOS) in a NH is 835 days, the median LOS is only 463 days. About 25% of all NH residents have a stay >3 years, while the remainder of long-stay residents may have varying trajectories of decline to death in less than three years.¹

Within the short-stay post-acute NH population, approximately 20% are readmitted to the hospital within 30 days of hospital discharge. Of these, 67% experience additional subsequent readmissions. This group of NH residents with multiple readmissions has twice the two-year mortality, increasing from 15 to 30%.² A recent analysis of >400,000 post-acute residents from

trauma, surgical, and stroke services found that while 60.5% were discharged home, there was a mortality rate of 3.8% in the initial SNF stay and a 26.1% mortality rate at 1 year.³ Another recent analysis of 3246 all-cause post-acute admissions with a 22.8% 30-day readmission rate found that mortality rates at 30 and 100 days respectively were 18.9 and 39.9% for those who experienced a hospital readmission. This contrasted with mortality rates of 8.6% and 14.5% for those who did not experience a readmission.⁴

Clearly the fact of being a resident in a NH, whether for a short-stay or for long-term care, carries with it a high likelihood of shortened life expectancy, from days to weeks for the sickest, to a few years for the more stable residents. At the same time, there is also a group of NH residents who may live for many years before they die. Thus, the modern NH serves a heterogeneous population with a variety of clinical and life trajectories during their stay.

In this population and care setting, it seems intuitive that there is wisdom in introducing the topic of planning for end-of-life care. Advance Care Planning (ACP) is the process of preparing for medical decision-making as the end of life approaches in the face of potentially declining decision-making capacity. ACP aims to articulate and document the preferences of the individual regarding the desired *goals* of care and the corresponding extent of medical treatment (*levels* of care) to be provided in future medical conditions. Furthermore, ACP aims to communicate these preferences with the intent that they be honored when the individual is no longer able to speak for themselves. ACP may include the completion of Advance Directive forms such as Living Wills, assignment of a Power of Attorney for Health Care (POAHC) or Health Care Proxy, other directives such as Five Wishes, or the more recent POLST (Provider Orders for Life-Sustaining Treatment) Paradigm forms and similar documents now utilized in many states. The latter focuses on choosing levels of medical care consistent with the goals of the patient. Decisions such as Do Not Resuscitate and Do Not Hospitalize may be part of an ACP process, as may be decisions to enroll the patient in hospice.

A review of ACP decision aids found a disconnect between the wide availability of ACP tools and the lack of evidence of effectiveness. The authors noted that all adults would benefit from naming a health care agent, and advance care decisions for specific care choices should be limited to those with advanced illness or high risk of catastrophic health events.⁵ A more recent systematic review of the effects of ACP found that while there is a dearth of randomized controlled trials of ACP, ACP decreased hospitalization rates by 9-26%. ACP was not associated with increased mortality in the two studies that measured it, and it increased the proportion of deaths occurring in the NH rather than the hospital by 29-40%.⁶

An even more recent randomized trial of 302 NH residents with advanced dementia and their family decision makers found that those who received a goals of care video decision aid plus a structured discussion reported better quality of communication, better communication, and greater concordance of goals with clinicians at 9 months. Furthermore, those in the intervention group had more palliative care content in their treatment plans, more MOST (Medical Orders for Scope of Treatment, a POLST Paradigm form) order sets, and half as many hospital transfers. There was no difference in survival at 9 months.¹⁷

One of the challenges for ACP is the initiation of the discussion with the resident (or family in the event of incapacity for decision-making by the resident). Federal law since 1991 has

mandated that health care facilities advise residents of their right to execute an advance directive on admission, but does not require that any specific education be given. Some practitioners may avoid the discussion altogether, feeling that it is the job of the facility, or that admission is not the ideal time to have such a discussion, or that Medicare does not reimburse for such discussions. As a result, such discussions tend to occur at times of critical and sudden decline, rather than when a more deliberative approach can be provided. Making decisions in a crisis situation is not optimal and may result in patients receiving treatment that in retrospect they probably would not have desired. In addition, providers must be sensitive to cultural issues, as ACP choices may vary across cultural groups, with some cultures generally preferring more aggressive care than others.⁷

Beginning January 1, 2016 CMS has offered a new billing code for primary care providers to have ACP discussions with residents. This includes discussions of advance directives and requires a minimum of 16 minutes to submit charges for the first billable unit of 30 minutes (99497), with additional 30-minute increments (99498). **The specific language used by CMS to define a 99497 visit is “Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate.”**

A 2016 CME Webinar on visits using the billing codes, presented by Drs. Robert Zorowitz, Karl Steinberg and Charles Creclius is available at <http://bit.ly/2cY7Q9r>. The authors present helpful administrative details on the codes as well as practical steps, strategies and guidelines for conducting an ACP visit.⁸ CMS requires a face-to-face encounter, whether with the patient or surrogate (if the patient is unable to participate; if so, this must be documented). CMS recommends that documentation include participation in the ACP visit was voluntary; who was present; the content of the discussion; any advance directives or other documents completed; and the time spent in the visit. Under Medicare Part B these codes reimburse the practitioner about \$80; the patient has a 20% copay unless the ACP visit is performed as part of an Annual Wellness Visit. The reader is encouraged to review this Webinar for familiarizing oneself with the Medicare requirements of using the ACP billing codes. If the requirements and parameters for these codes change in the future, the webinar will be updated.

ETHICS, PREREQUISITES AND ELEMENTS OF AN ADVANCE CARE PLANNING VISIT IN PA/LTC

Professional integrity, compassion, beneficence, and respect for the patient as well as for the autonomy of the patient, are core aspects of the ethical responsibility of the physician or other practitioner in ACP. Yet discussion of ACP is a two-way street. While the provider comes to the discussion with expert medical knowledge and a desire for non-maleficence, the patient is the one whose life is under discussion. ACP is an intensely personal, value-laden matter for the patient and/or their agent. The physician or practitioner must be ready to listen as well as to teach. The patient may not wish to participate in this type of conversation, and when that is the case, the practitioner must respect the patient’s wishes. As the professional perspective on the relevant clinical evidence interfaces with the autonomous preferences and values of the patient or

agent, a commitment to justice will provide a safeguard to show respect for all views and seek to mediate a consensus on appropriate goals of care.

ACP will differ somewhat with the setting. In LTC, it is likely the physician or other practitioner can develop a longer and more substantial relationship with the patient and family than in the post-acute population. Also in LTC there can be an opportunity to observe the clinical trajectory over greater time. Thus, LTC ACP decisions can be less pressurized and can take place over a longer time until a settled decision is reached. These factors may enhance the probability of agreement on the clinical trajectory and appropriate goals. When performing an ACP visit in the post-acute short-stay setting, there may be additional complexity and sensitivity in the discussion because the primary care practitioner or specialists may also be involved in the patient's care and medical decision-making process.

The following steps to an ACP conversation are a conceptual framework that seeks to be mindful of the ethical responsibilities of the physician or other practitioner in these diverse settings and the even greater diversity from patient to patient. The steps are presented in a logical rather than a necessarily sequential order. While there is not a rigid linearity implied or required in the order of steps, a practitioner who intends to perform ACP visits should be familiar with these concepts. Steps that should be completed before the ACP visit are referred to as prerequisites; steps that are recommended to be done during the ACP visit are referred to as elements.

PREREQUISITES: Steps to be done before an ACP Visit

Step 1 – Know the Medical Context.

The Physician/Practitioner should become familiar with the medical history. Ideally the physician or other practitioner should have completed a history and physical previously and have established a patient-practitioner relationship, including getting to know the health care proxy/agent if appropriate, before an ACP session is scheduled. However, some clinicians may prefer, and some clinical scenarios may dictate, at least some discussion of ACP on the very first visit. Considering the acuity and burden of illness for some post-acute (and long-term) NH residents, this discussion should not be put off if the situation warrants it. Some patients arrive to the NH with some ACP documentation already in place, and this situation can facilitate conversations to confirm what is already available in the chart.

While knowledge of comorbidities and specific medical diagnoses is important, particular emphasis should be placed on defining the following, while respecting patient autonomy.

- If the patient or proxy agrees to discuss these matters, what is their understanding of their medical condition(s) and prognosis? Is it accurate? Do they want to know more?

- What is the clinical trajectory of the patient in the short term and the longer term? How does the patient describe their trajectory? How does the family/agent describe the trajectory? Does the patient/family want to know more about the likely trajectory?
- Have there been multiple hospitalizations recently? As described in the Background section above, multiple rehospitalizations are associated with significantly increased mortality.
- For a resident in either the post-acute or LTC population, has there been significant unplanned weight loss over the past year?
- What is the functional status of the patient? In patients with advanced cancer, functional impairment correlates best with increased mortality.⁹ Functional measures such as the Palliative Performance Scale or the FAST scale in dementia may be helpful tools.
- What is the physician or other practitioner's best estimate of prognosis? While this is admittedly an inexact science at best, there are tools to aid in estimation of life expectancy. Zorowitz et al cite the Porock Index (<http://eprognosis.ucsf.edu/porock.php>) and the Flacker 1 year Long Stay revised index (<http://eprognosis.ucsf.edu/flackerlong.php>).⁸ Other objective markers of poorer prognosis include pressure ulcers, delirium, dysphagia and frailty; the FRAIL-NH scale has been proposed as a guide to indicate those for whom hospitalization will likely not be helpful.¹⁰

Step 2 – Assess the Medical Decision-Making Capacity of the patient.

ACP is a form of medical consent for future care. Capacity for medical consent is a key requirement for informed consent. Capacity of an impaired older adult for medical decision-making, like other forms of consent capacity, may be robust, or intermittent, or partial. It may be task-specific; a patient may have capacity to select a menu, or refuse a medication, but may lack sufficient capacity for more complex decisions such as whether to undergo a surgery, or to make a decision to enroll in hospice.

The physician or practitioner who has been caring for the patient will usually develop a clinical sense of the patient's capacity for higher complexity medical decision-making such as an ACP discussion. Most often it is the clinical judgment of the physician or other practitioner that determines the capacity for a PA/LTC resident to engage in an ACP discussion. There are some tools to aid the practitioner such as the Aid to Capacity Evaluation (<http://jcb.utoronto.ca/tools/documents/ace.pdf>). A comprehensive resource on capacity determination can be found at <http://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf>.

In cases where the clinician is uncertain whether the patient lacks capacity, the opinion of the family or agent may also be taken into account. When there is consistency between the patient's expressed choices and those of the family or agent, it is reasonable to accept those decisions. However, if there is persistent uncertainty, there should be a presumption of capacity unless it appears to be demonstrably lacking in the course of discussion. A mental health consultation can be considered where decision-making capacity is not completely clear, or where there is conflict between a patient with some level of cognitive impairment and family or other surrogates.

In general, if the patient can understand the choices, communicate their preferences, explain their reasoning, appreciate the benefits and burdens of the choices, and if they are consistent over time with their choices, they have capacity for these decisions. It is prudent to document in detail the conversation with a patient who has somewhat impaired cognition, such as those with early dementia.

Step 3 – Gather the advance directive documents of the patient, if any, and familiarize yourself with the choices, goals and values expressed in those documents.

Advance directives are the formal mechanism for an individual to attempt to express and ensure that future medical care in the event of their incapacity will be informed by their stated preferences. Such documents are ideal when there are specific wishes stated, because this helps the practitioner feel comfortable that decisions are being made in accordance with the patient's known wishes. When the documents are more general, as they often are, they create the need for a proxy health care decision-maker when the patient lacks decisional capacity.

Usually the advance directives will include the appointment of a proxy agent, identifying the one person to whom the physician or other practitioner should direct ACP discussions in the event the patient lacks decisional capacity for ACP discussions. If not, this should be a key point of discussion with the patient at an ACP visit.

A patient may lack the capacity to make informed decisions about specific medical treatment options, but they are often still capable of stating which family member or other they prefer to be their proxy decision-maker.

When a patient lacks capacity for medical decision-making, the primary standard for guiding decisions should be the previously expressed wishes of the patient, whether verbally or in writing (substituted judgment). If knowledge of the preference of the patient relevant to the particular decision is lacking, the proxy should base decisions on what would be in the best interest of the patient.

Step 4 – If decision-making is lacking, identify the appropriate decision-maker.

The POAHC or Health Care Proxy form (these forms have different names in various states) will identify the agent. If no agent has been appointed, some states have a hierarchy for identifying a health care surrogate (e.g., the New York Family Health Care Decisions Act, and the Illinois Health Care Surrogate Act). If there is no specified mechanism for identifying a surrogate decision-maker, there may need to be a process of consensus building with the family stakeholders. Guardianship may be necessary in cases in which there is no family. Different states have differing mechanisms (or sometimes no mechanism) for making decisions on behalf of an incapacitated, unrepresented (unbefriended) patient. Practitioners should familiarize themselves with the applicable statutes in their state.

Step 5 – Offer prepared resources ahead of an ACP visit if appropriate or desired.

If family wishes to discuss ACP issues with the patient ahead of time (without physician or other practitioner), consider referring them to The Conversation Project (www.theconversationproject.org). This resource offers a detailed questionnaire that guides patients to offer their perspective on their health care, their expectations for the rest of their life, and what they value about their relationships and their care process toward the end of life. Other resources for the public include www.fivewishes.org and www.prepareforyourcare.com, which is available in English and Spanish.

Another resource published by the American College of Physicians includes a form letter to Medicare patients explaining the process of ACP and the new Medicare code. This letter contains links to useful resources including Five Wishes, POLST Paradigm programs, and links to every state's advance directive forms through the National Hospice and Palliative Care Organization. For this resource, see www.acponline.org/system/files/documents/practice-resources/business-resources/payment/advance_care_planning_toolkit.pdf. (Accessed 10/12/16).

A proposed patient questionnaire that may be useful before an ACP visit offers the following questions:

- What questions do you have about your health problems and treatments?
- What bothers you most about your current health situation?
- If the doctors do everything they can to prolong your life, how long do you think you will likely live? Would your doctors agree with your thinking?
- What do you value most in life? Identify as many things as you think important (e.g., being with family and friends, being comfortable, enjoying life, reading, living as long as possible).
- What is more important to you now, living as long as possible or quality of life?¹¹

Sometimes it is useful to use more collaborative, less interrogative types of communication to avoid making patients or family members defensive or feeling “on the spot.” Phrasing requests for information with terms like “Help me understand what...” or “I’m curious about...” may be advisable.

In addition, the provider should be familiar with the specific advance directive and other forms utilized in their state legally approved for use and honored, and should facilitate access to these forms available for completion.

Step 6 – Seek consent to have an ACP discussion, from the patient and/or agent as appropriate.

This is key, since such discussions can be stressful for the patient or agent, and because there may be a financial impact for the patient (the copay for the ACP billing is waived only if the ACP visit occurs as part of an annual wellness visit). It can be helpful to let the patient and/or agent know that such discussions are routine in the PA/LTC setting, and that in fact it is required for practitioners and NHs to determine what level of treatment their patients desire. If patients do not wish to have this discussion, it must be made clear that the default plan will be for them to receive the most aggressive and invasive treatments available.

Because some patients may still not wish to have an ACP discussion, the request for and the granting of consent should be documented in the medical record in the note for the ACP visit. There is also a copay under Medicare Part B associated with billing the ACP codes, so informing patients/agents of that fact, and documenting it as part of the consent process, is advisable.

Step 7 – Determine who should be at the ACP visit.

If the patient has decisional capacity, the meeting may involve only the practitioner and patient. However, with the patient’s permission, inviting the agent (and/or other trusted family members, friends or clergy if the patient desires them to be present) can be helpful in giving them a firsthand opportunity to observe the patient’s responses and preferences. Conversely, some patients may prefer to not have the agent present. It may be helpful to have a nurse or social worker from the nursing facility to provide additional perspective and to witness the discussion.

In the case of marginal, uncertain, partial or intermittent capacity for medical decision-making, it would be better in most cases to have the agent present. In cases where capacity is clearly lacking, it may be most appropriate to have the ACP visit with just the agent.

Documentation of the visit should list all who were present and their relationship to the patient, as well as the permission of the patient for those who were present.

ELEMENTS OF AN ACP VISIT

The actual discussion with the patient may be organized under the mnemonic **C – A – R – E**: Clarify, Assess, Respond/Reflect, and Execute.

Step 8 – CLARIFY: Introduce the purpose of the meeting as seeking to clarify the preferences of the patient for the goals of their care and the levels of care that would best correspond with their goals.

Help make the meeting be as comfortable as possible for the patient. Arrange to meet in a comfortable, appropriate, and as private a setting as possible, given the constraints of space in most LTC facilities.

Always try to sit down for an ACP discussion. This may help the patient feel more comfortable in sharing their perspective. Let the patient know it is standard practice to elicit the preferences of the patient for their health care: “We talk about these issues with all our patients here.” Verbalize and show concern, convey empathy, and show support for honoring the patient’s preferences. One can acknowledge the reality of potential decline in the populations served in nursing homes, while still holding out hope by acknowledging the inherent uncertainty of medical prognostication.

Step 9 – ASSESS: Approach the ACP Visit as a Conversation to elicit the patient’s perspective, not merely dispensing information and acquiring a decision. First ask for, then listen to, the patient’s perception of their medical situation as well as their values and goals of care.

A group of researchers at Mayo Clinic has found that shared decision-making requires more than the provision of information and the choice of the preferred option. Rather, it is the process of a patient-clinician conversation that is essential to truly shared decision-making.

“We emphasize conversation in shared decision making not as a nice-to-have moment of interpersonal connection, but as an instrument of care appropriate to the uncertainties of illness and treatment. Shared decision making is called for in situations in which the best option is not clear. These situations threaten the health of the patient, the expertise of the clinician, and the management of response. They are emotional in nature.

“In situations such as these, providing information may be helpful, but it isn’t sufficient. Patients and their clinicians require an environment in which they can think, talk, and feel their way through which treatment option makes intellectual, practical, and emotional sense for each individual patient. Conversation is an important environment for drawing out and exploring the significance of evidence and preferences. In conversation, evidence and preferences serve to identify what might be done in the present situation and to test why the patient and clinician value one course of action over others.”¹²

The physician or practitioner engaging in an ACP discussion should start by asking questions to elicit the patient’s understanding of their illness, their prognosis, and what matters most to them in their life situation. Some of the questions in Step 5 above may be helpful. Questions about their spiritual values and perspective on the end of life may be appropriate. The physician or other practitioner should ask the patient their perspective on quality of life concerns. How do they define quality of life? How do they perceive their quality of life in their current situation? And how would they perceive it if their condition worsened?

Cultural differences in spiritual values, beliefs, and attitudes toward death, dying, and the medical profession may affect treatment preferences. For example, the impact of historical injustices such as the Tuskegee Study experience may result in a greater mistrust of the medical profession among those in the African-American community. Furthermore, some cultural groups may be more likely to favor communitarian rather than individualistic processes for making decisions, and the attitude toward aging and respect for elders may shape the preferences

for approaching the discussion of terminal illness. Such culturally relative factors will require a culturally sensitive approach to ACP. An excellent resource for this can be found at <http://www.managedhealthcareconnect.com/article/culturally-responsive-approach-advance-care-planning-reflection> (Annals of Long Term Care November 2016, 13-16).

Patient preferences may relate to deeper underlying values that they are not articulating. They need a chance to express their thoughts and feelings. This should move toward clarifying what the patient's goals of care are and why those are their goals. There may be subtle clues in the patient's responses that shed light on some of the ambiguities of a situation. Listen for a desire to reach "milestones" (e.g., a next birthday or anniversary, a family wedding or graduation). Listen for hidden agendas, perhaps the patient wanting to stay strong and keep fighting primarily for the sake of the expectations of a spouse or child, or perhaps a proxy agent considering a choice of treatment more to please a sibling or the other parent rather than making the choice they feel would best represent the preferences of the patient.

Step 10 – RESPOND: Provide education to the patient and/or agent.

The provision of information should be tailored to the needs and preferences of the individual patient and clinical situation. It may require more than one visit to explore all of the medical diagnoses, treatments, and potential complications in a complex post-acute patient's care.

A realistic and honest summary of the patient's medical condition and trajectory of illness should be given in simple terms that are clear to a lay person. Prognostic information can be shared but should be qualified with a modest acknowledgment of the inherent uncertainty of such assessments. In most cases it may be wise to keep the language used in making prognostic assessments broad, using the terms "days," "weeks," "months," or "years," rather than rendering a specific quantitative assessment of prognosis. It is also important to explain that while we can make predictions for large cohorts of patients with similar conditions, it is much more difficult to predict an individual patient's trajectory. For patients with significant functional decline or with multiple rehospitalizations, the prognostic significance of these factors can be shared, though again with acknowledgement of the inherent uncertainty of applying statistics from a large population to one individual patient.

The existing advance directives, if any, of the patient should be reviewed. The physician or other practitioner should ask the patient if the directives and any specific choices contained therein still represent her wishes, or would she prefer to complete a new directive.

Options for care strategies can be laid out clearly. The POLST Paradigm, a portable order set that is valid across care settings, is very useful because it is immediately actionable by first responders and other healthcare professionals. POLST is helpful particularly for those patients who have complex illness and are likely in the last year or two of life (the POLST Paradigm is specifically intended for patients in last year of life, but the choice between levels of care is often relevant to patients with a 1-2 year prognosis as well). The typical POLST Paradigm form, which varies somewhat state-to-state, usually contains a choice of Do Not Resuscitate (DNR) versus Full Code, as well as a choice for one of three levels of care: Full Treatment (including

ICU care), Limited (or Selective) Treatment (basic hospital care but usually not including ICU/ventilator care), and Comfort Care (generally Do Not Hospitalize unless needed for comfort). In addition, these forms often contain other specific order options concerning enteral feeding, hydration and antibiotics.

Society members should be familiar with specific interventions and the format for such physician orders, and should strive to educate others in the medical and lay communities on proper use of these order sets. For example, a common and unfortunate misconception is that a patient cannot choose both “DNR” and “Full Care” because they are inconsistent with each other. In fact, “DNR” on POLST Paradigm forms applies *only* when the patient is pulseless and/or apneic. There are many patients who do not want CPR if they suffer a full arrest, but who are not opposed to being placed on a ventilator, for example.

If the patient has no advance directives, available directives forms particular to that state should be provided for their consideration. At a minimum, each patient should be strongly encouraged to complete the relevant available form for designating a substitute decision-making agent in the event of the incapacity of the patient, and to discuss their goals of care with the decision-maker. The practitioner should explain other available advance directive forms to the patient as appropriate.

In the PA/LTC setting, the choice whether to have CPR in the event of cardiac arrest, or to forgo CPR and sign a DNR form, is an essential aspect of proper ACP. To be properly performed, the initiation of CPR cannot wait for discussion at the moment of crisis. This decision should be a specific part of the initial ACP discussion and, if appropriate, subsequent discussions also.

The very limited effectiveness of CPR in nursing homes residents, and the risks and burdens of CPR in the rare patients who survive it, should be part of the education and discussion offered by the practitioner to the patient and/or their decision-maker. If patients say they do not want to be on “tubes and machines,” it is probably worth mentioning that in the rare event that they survive CPR following a full arrest, it is highly probable that if they wake up, they will be in ICU on a ventilator and unable to communicate with family and friends. This may be inconsistent with the patient’s idea of an acceptable quality of life.

Even for in-hospital cardiac arrest, the reported rate of survival to discharge was only 22.3% in 2009, and 28.1% of survivors had clinically significant neurologic disability¹³. For out-of-hospital cardiac arrest in 2006-07, the rate of survival to discharge was reported as only 4.6% in a large multi-regional study¹⁴. Evidence of CPR effectiveness in the SNF/NF setting is more limited, but available data suggests low single digit percentage survival rates.¹⁵ CPR effectiveness varies by whether a cardiac arrest is witnessed, what the initial rhythm is (ventricular tachycardia or ventricular fibrillation carrying a somewhat better prognosis than asystole or pulseless electrical activity), and time to defibrillation. However, it is also likely that the greater frailty and comorbidity of the PA/LTC population in a SNF/NF contributes to lower likelihood of survival of a CPR attempt for cardiac arrest in that setting.

At the same time, the growth of the post-acute population in SNFs has brought a cohort of younger patients with more aggressive approaches and goals of care aiming to return to the

community at higher levels of function. This group of patients may be more likely to prefer “Full Code” status, and their wishes and goals of care should be respected. However, discussion of the overall medical situation and the prognosis of the patient should be part of the process of making a CPR/DNR decision. It may be helpful to read the list of active medical problems to the patient and/or agent in the course of discussion to provide perspective.¹⁶

It is important for patients and families to understand that by choosing a DNR order, they are not saying, “Just let me die,” which is a common misconception. Most POLST Paradigm forms qualify that DNR comes into play only when the patient is pulseless and apneic – with specific treatment directed in the subsequent section if the patient has unstable vital signs. Thus, patients may choose DNR but otherwise desire full treatment, so that in the event of acute respiratory failure they will be intubated and ventilated. Hence it may be useful to explain DNR as, “If I am dead, let me stay dead; do not try to bring me back to life.”

Beyond the CPR/DNR decision, there may be a series of levels of treatment options, from more aggressive to less aggressive, which are relevant to the individual patient. ACP is often a process over time that involves a series of decisions at various points along the clinical course to specify additional limitations on the levels of treatment. For example, a patient may on the first ACP discussion request DNR but otherwise full treatment. A few months later as their clinical status has worsened, they may specify no further surgical interventions, but to continue providing fully aggressive medical treatment short of CPR. Some months later with further progression of disease and debility, they may request only basic hospital treatment excluding ICU care. Further down their trajectory of illness they may request a Do Not Hospitalize order, requesting comfort-focused care, and eventually hospice. This pattern of serial adjustments to ACP is best facilitated by practitioners who take a proactive approach to initiating ACP discussions with their patients at appropriate and opportune waypoints along the clinical course. In fact, some state advance directives, such as the New York MOLST (a POLST Paradigm form) require periodic review.

This longitudinal perspective on ACP offers the potential for facilitating a gradual reduction of aggressiveness of treatment such that the transition to the least aggressive levels (Do Not Hospitalize and hospice) is smoother. The aeronautical analogy is helpful here. In order to facilitate a soft landing at the final destination, the skilled pilot begins planning for the landing many miles before arrival by a series of steps that involve safely reducing power, speed, and altitude (“throttling back,” decreasing aggressiveness of the aeronautical approach profile) to align properly with final approach to landing. In ACP, practitioner and patient share roles in determining the waypoints along the course where reduced aggressiveness is desired and appropriate for the goals of care and as soft a final landing as is possible.

As with all aspects of an ACP discussion, the physician or other practitioner may share their advice and personal perspective as appropriate. Patients may even ask the physician or other practitioner what they would decide. Some physicians or other practitioners in some situations may find it appropriate to provide a more personal perspective if the patient asks and the practitioner feels it is appropriate. However, the discussion should affirm that ultimately the choice depends on patient preference.

Step 11 – REFLECT by reassessing the patient perspective. Ask the patient or agent their response to the discussion. Do they have additional questions? Have their preferences been clarified or changed? Do they need more information, more time to think, or an opportunity to dialogue further with family members, physician or other practitioner, or others such as clergy or social worker?

At this point the physician or other practitioner should seek to ascertain whether the patient is prepared to sign an advance directive, POLST or DNR form, or is there a need for further conversation, perhaps at a later date. Sometimes a key clarifying question may be helpful. For example, in the case of an ACP visit with an agent wrestling with making a decision to limit treatment such as a DNR decision, it might be helpful to ask, “Would you be surprised if your loved one died in the next 12 months?” For a post-acute patient experiencing functional decline after recurrent rehospitalizations in a short time span, perhaps struggling with a hospice decision, it may be helpful to ask, “Did the last hospitalization help you, hurt you, or make no difference?” While such questions do not directly make decisions regarding goals of care, they may serve as prompts to look at the goals of care in a different light, ultimately facilitating a change in thinking and preferences for care. For some patients, the latter question may give them implicit permission to state their desire for Do Not Hospitalize status.

The attitude and demeanor of the physician or other practitioner should strive to be facilitative to the patient rather than directive. The goal is to assist the patient or proxy to articulate treatment preferences that are consistent with their goals of care, life values, perception of quality of life, and stated wishes. The physician or other practitioner must be aware of their personal biases and strive to avoid letting those influence the patient’s choice.

Regardless of whether any decision was reached at the meeting, the ACP visit should conclude with an assurance that the physician or other practitioner will honor the patient’s preferences and be available to continue the conversation in the future as needed. Patients should be reassured that they may change their mind at any time, and that as their physicians/practitioners, our only agenda is to help them make informed decisions and then receive medical treatment that is in line with those decisions, their goals, values, and medical condition.

However, it is important to remember that healthcare professionals are not ethically required to provide medically ineffective (also sometimes referred to as futile or non-beneficial) treatments to patients. If a practitioner feels that they are being asked to order such treatments, further discussion, including Bioethics Committee type consultations when available, should be considered.

Step 12 – EXECUTE: Document the visit and enact any advance care decisions in the medical record.

The physician or practitioner should document in the medical record the performance of an ACP visit, including that it was voluntary, who was present, the general content of the discussion, and any specific decisions that were made, including whether an advance directive was completed

and what that document stated in regard to goals of care and treatment preferences. Any plan for follow-up ACP discussions should be documented. The duration of the visit should also be documented, along with consent of the patient and/or surrogate.

If an advance directive or other document was completed at the ACP visit, it should be properly signed, dated, and witnessed according to the state law. Copies should be made and given to the patient and/or agent and also added to the medical record. If the patient is going to be discharged, copies should be sent or faxed to the community primary care physician and/or specialists.

If a change in code status or plan of care has occurred such as a DNR or DNH decision, the appropriate order should be immediately entered into the medical record as well.

If a patient has completed a DNR or POLST Paradigm form, these are valid orders and the form should be sent home with the patient and placed in a conspicuous place such as on the refrigerator or bedpost so that first responders will see it if they are called to the home.

Keep in mind that a visit does not have to be exclusively devoted to ACP. When an ACP discussion occurs as part of a comprehensive initial examination, routine regulatory visit, or medically necessary visit, the codes for ACP (99497/99498) may be billed *in addition to the regular visit codes* (99304-99318).

FUTURE NEEDS FOR ADVANCE CARE PLANNING SERVICES IN POST-ACUTE AND LONG TERM CARE

As stated above, the empiric evidence for the effectiveness of ACP is scant. More research on the effectiveness of various ACP forms and strategies needs to be done. However, it is more than a science, and it about more than medicine; it is about life and death, and it helps ensure that patients will receive the care they want to receive, while avoiding treatments that they prefer to avoid. This is an extremely important task and an admirable goal, something that we as PA/LTC practitioners get the privilege of sharing with the patients we serve.

Moreover, ACP is still underutilized despite a growing population of frail elders who might benefit from it. The incentivizing of busy physicians and other practitioners to do more ACP remains a priority. Much of ACP occurs in less formal, less structured ways than outlined in this paper. In addition, it may take many informal conversations before a decision point is reached for a DNR or DNH decision. Many of these ACP conversations occur on the telephone with agents who may be out of state. Such conversations can sometimes exceed 30 minutes, especially for complex post-acute patients, but cannot be billed if there is no face-to-face contact. On the other hand, sometimes face-to-face ACP conversations with patients or agents occur on a post-acute unit on an impromptu basis and may last less than the required 16 minutes to be a billable encounter. In addition, when conversing with a post-acute patient who has capacity but is physically weak, it is common to find that they can sustain a conversation for only 5-10 minutes at a time, not the minimum required 16 minutes. Nonetheless, it is vitally important that we include this topic as we provide our usual care.

None of the above encounters would meet the current CMS requirements for a billable visit, yet it is in these settings where much of the day-to-day ACP occurs on a busy post-acute unit. CMS should be lauded for providing coverage for ACP visits, and Society physicians and other practitioners should perform them. However, if few ACP visits are being billed and many more are needed, it would seem appropriate for CMS to expand the range of billable encounters to include what happens in the real world of PA/LTC. The Society has already requested that CMS expand the coverage to telephone calls and telemedicine. As of January 2017, telemedicine ACP visits are billable in NH patients when the other criteria are met.

POLICY IMPLICATIONS

This White Paper reflects the policy of AMDA—The Society of Post-Acute and Long-Term Care Medicine and includes these tenets:

1. Knowledge of Advance Care Planning, including the ability to carry on proficient ACP conversations with patients and their families, is part of the core skill set of the PA/LTC practitioner.
2. Education of Society members on Advance Care Planning should be promoted and encouraged, including online and in-person offerings.
3. Society members should share their knowledge of Advance Care Planning, including use of the ACP billing codes, with colleagues and other healthcare professionals.
4. The Society supports ongoing reimbursement of healthcare professionals for time spent engaging in ACP conversations with patients and their families, discussion of prognosis and medical interventions, completion of forms and orders, and similar tasks, whether the interactions are face-to-face or remote.
5. The Society encourages members and others to continue to develop robust research efforts into the effectiveness of ACP interventions in the PA/LTC setting (e.g., the Hanson study cited earlier in this paper¹⁷), focusing on outcomes such as utilization of palliative care interventions, concordance of goals of care between patients, families and clinicians, and hospital transfers from PA/LTC.

ENDNOTES

1. Geriatrics Review Syllabus, 9th edition, Book 1. 2016;196-197.
2. Oakes et al, *Clinics in Geriatric Medicine*. 2011;27(2):259-271.
3. Hakkarainen T et. al. *Annals of Surgery* 2016;263(2):280-285.
4. Burke et al. *JAMDA* 17 2016;249-255.
5. Butler et al. *Annals of Int Med* 2014;161:408-418.
6. Martin et al. *JAMDA* 17 2016;284-293.
7. Rahman et al. *Gerontologist* 2016;56:714-722.
8. Zorowitz R, Steinberg K, Crecelius C. Parameters for Discussing and Billing for the New Advance Care Plan Code. Available at <http://bit.ly/2cY7Q9r>. Accessed 10/16/16.
9. Geriatrics Review Syllabus, 9th edition, Book 3. 2016;163-164.
10. Morley J. *JAMDA* 17 2016;279-283.
11. Crosby J. *Annals of Long Term Care* September 2015;28-30.

12. Hargraves I et al. *Health Affairs* 2016;35:627-629.
13. Girotra S et al. *NEJM* 2012;367(20):1912-1920.
14. Nichol G. *JAMA* 2008;300(12):1423-1431.
15. Shah M. *JAMDA* 2007;8: E.27-E.31.
16. Nichols J. *Caring for the Ages* 17(2):3.
17. Hanson L et al. *JAMA Inter Med* 2017;177(1):24-31.