Chapter 11

Capacity, Advanced Planning, and Buying Time

Hashim Q. Zaidi

Case Introduction

Ellen Roosevelt is an 89-year-old female with a medical history of coronary artery disease, hypertension, hyperlipidemia, and Alzheimer's dementia who is brought in the emergency department (ED) by emergency medical services (EMS) from her nursing home for mental status changes. EMS reports they were called to the facility where she resides after her nursing aide reported she has not been eating or drinking well for the last few days. Today she was noted to be less responsive to questions from staff. She was found to have a fever of 102 °F and was tachypneic and hypoxic. When you, as the emergency department (ED) care team member, examine her, you see an ill-appearing, cachectic, elderly female who is tachypneic and intermittently moaning in

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response to your questions. She withdraws from painful stimuli. She has pooled secretions in the back of her oropharynx and does not appear to have a gag reflex. She is hypotensive with pressure of 80/50 mmHg and is requiring 10 l of oxygen via nonrebreather mask to keep her oxygen saturation above 90%.

Your electronic medical records note the patient has been admitted multiple times over the last year for pneumonia and urinary tract infections, all treated with antibiotics to resolution. She has never been intubated in your facility. In the most recent hospital discharge summary, it is noted that she was listed as "Do Not Resuscitate (DNR)/Do Not Intubate (DNI)," a change from previous admissions, but it does not elaborate much further. The records also list the patient's adult sister as her designated healthcare power of attorney (POA).

EMS brings paperwork from the nursing home which includes her facility-administered medication list. There is documentation from the facility that also supports she is listed as "DNR/DNI" under the facility's code status. She is accompanied by another resident from the facility who identifies herself as a long-time friend of Ellen Roosevelt. When you inquire about care preferences or advance directives, she believes there may be a written set of advance directives as well as specific wishes on what she wanted done if she was gravely ill. She believes they may reside with her adult living sister but does not know what they state. She urges you to do everything you can to help her friend get well again. She informs you the patient is a widow with no living children and one adult sibling who has been designated as her POA. They do not know of any Practitioner Orders for Life-Sustaining Therapy (POLST) forms applicable to the patient.

Ms. Roosevelt has intravenous (IV) fluids started with basic labs sent off. A high-flow nasal cannula is applied to help comfortably oxygenate her which she tolerates well and improved her oxygen saturations to 94%. She is sat up to 30°, so her secretions do not bother her or pool in the back of her throat, and pillows used provide lumbar and neck support. She is given rectal acetaminophen with improvement in her fever. A chest X-ray reveals a right lower lobe pneumonia. She is started on antibiotics for the pneumonia. Given her oxygen requirement, the charge nurse is concerned that the general medicine floor will not admit her. Given the reported DNR/DNI status, the emergency physician does not want to intubate her or admit her to the intensive care unit (ICU). How should the emergency department team proceed? What interventions should or should not be performed in the acute setting given her clinical status, recent medical history, and reported desires? What advance care directive considerations should be taken into account in the emergency department or if the patient goes to the intensive care unit?

Capacity and Competence

One of the challenges facing clinicians in situations similar to that presented in the case example is determining if the patient has decision-making capacity. In the example above where the patient's clinical status is such that she is unable to communicate, it becomes straightforward to conclude she does not have the capacity to make her own medical decisions. Consider, however, if the patient had been verbally responsive or perhaps even able to hold a dialogue; the physician is obligated legally and ethically to determine if the patient has decision-making capacity.

The definition of capacity is broad reaching, context dependent, and often elusive. Additionally, capacity is often interchanged with competence in medical and legal literature. To standardize the terminology in this text, we will define capacity as “a threshold requirement for persons to retain the power to make decisions for themselves” [1]. Capacity in this sense refers to the ability to understand relevant information, communicate a choice, appreciate a situation and its consequences, and reason about treatment choices [2].

Competence is a term that is often interchanged with capacity in the medical setting. It is vital to distinguish medical capacity from the judicial use of word competency. As a legal term, competency refers to an individual’s sufficient ability in a broad sense to make legally recognized rational acts such as enter legal pleas, vote, prepare a will, testify, and make their own medical decisions [3].

Medical decision-making capacity is often determined by a physician and includes elements of the relevant criteria as seen in Table 11.1 [2]. Medical decision-making capacity is a dynamic process that is determined by many factors. A patient may not have medical decision-making capacity at one point in time, but a change in clinical status at a later point may reverse that. In addition, a patient may have capacity in one decision but not in another depending on the nature and potential consequences of the decision in question [5]. For example, a patient may be deemed to have capacity for a decision such as choosing the route of antibiotics for a low-risk infection in the emergency department but may not have decision-making capacity to refuse antibiotics all together if they are lacking in appreciating the situation and its consequences. Physicians caring for a patient in the acute setting have the added difficulty of having to determine decision-making capacity for complex far-reaching decisions in a short span of time. Hasty decisions without careful considerations to the principles of beneficence, nonmaleficence, and justice within the limitations of that patient's decision-making capacity may lead to compromised patient safety or autonomy.

Table 11.1 Definitions of the four decision-making abilities and the clinical characteristics of these abilities in the setting of older patients with dementia

Ability	**Definition**	**Clinical Characteristics**
Understanding	The ability to comprehend basic information about a problem, its potential solutions, and the risks and benefits associated with those solutions	This ability is often highly impaired in the setting of mild- to moderate-stage dementia benefits associated with those solutions May be influenced by level of education and intelligence and how information is presented
Appreciation	The ability of a person to recognize how a problem or solution pertains to his or her specific situation	Impairments manifest as a loss of insight or behaviors of denial in the clinical setting Depending on the type and complexity of the decision, the range of impairment may vary considerably among patients with mild- to moderate-stage dementia

(continued)

Table 11.1 (continued)

Ability	Definition	Clinical Characteristics
Reasoning	The ability to consider potential solutions to problems by:	This ability is frequently impaired in mild and especially in moderate stages of dementia
	1. Demonstrating how one solution is better in comparison to another	Performance in this ability may decline rapidly along with the progression of cognitive decline
	2. Describing how a solution would affect his or her everyday life	
	3. Demonstrating a logical thought process in determining a choice	
Expressing a choice	The ability to render a clear choice for the decision under consideration	Impairment is often preserved despite the presence of impairments in other decisional abilities and, when present, is associated with more advanced stages of dementia

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Determining decision-making capacity is a challenge given the time constraints encountered in the emergency department. However, it remains a critical component of care provided and has far-reaching consequences. Often a determination of medical decision-making capacity in the ED will persist until a change in the patient's mental status or ability to communicate. Occasionally, a more formal evaluation by a psychiatrist or ethics board will alter capacity decisions. The process for determining medical decision-making capacity may be influenced by local laws; therefore, local definitions for medical decision-making capacity as well as the institutional process should be well understood or reviewed when deciding if a patient has medical decision-making capacity.

When determining capacity, it is important to identify the patient's ability to express a choice, understand, appreciate, and reason [2, 6]. For example, if Ms. Roosevelt was awake and was able to express she did not want an IV placed, she would be expressing a choice. Patients may be able to express a choice such as with as much as yes or no answers, a nod, or even a grunt. Stability of choice is also something to be noted by the clinical team; patients may change their mind about decision, but an individual changing their mind minute to minute may not be adequately showing evidence of expressing a clear decision. Patients with thought, memory, speech, auditory, or cognitive disorders may have a preference or choice but may have difficulty expressing that choice. Reasonable efforts should be made to involve these patients to probe for a communicable preference or decision, but this again may be hindered by time constraints in the emergency department. For many older adults, a choice may be present but not known to the care team until effective communication is established through hearing amplification or translation into the patient's native language.

Despite being able to express a choice, decisional capacity may not be present if patients cannot express understanding of their current situation, appreciate the risks and benefits of the proposed choices, or reason through options logically. If Ms. Roosevelt is able to express that IVs are painful and expresses her choice that she does not want one, the conversation should advance to inquire if she understands why the medical team recommends IV access, what is her current medical state, what the other options are, and the risks of refusing the said intervention. Given that the ED is often filled with uncertainty, it frequently falls to clinicians in the ED to explain what the medical evaluation reveals or what the team is concerned about. One method is to discuss the situation, the decision to be made, and its risks, benefits, and alternatives with the patient and see if the patient is conducting logical reasoning with gentle probing. Asking them once again what their preference is, what they understand of what they have been told, and how they came to their decision can help clarify some of the above components. This series of questions not only determines the patient's ability to understand relevant information but also if they can appreciate the situation as well as its consequences. In terms of their ability to reason, the clinician must analyze the process by which a patient reaches their concluding choice, not necessarily the choice itself. How did the patient come to their answer? Does their logic weigh why one option is better than another? What important pieces of information are they able to manipulate to come to a conclusion and do they align appropriately with the current situation?

A common fallacy in determining capacity is presuming underlying cognitive or psychiatric disorders preemptively exclude patients from decision-making capacity. Physicians have been shown to often believe patients with dementia, depression, or psychosis or under involuntary commitment lack decision-making capacity without evaluation or consideration of the decision in question [7]. These patients cannot be presumed to lack capacity until thought is given toward the components of capacity they preserve and those they lack. For example, a patient with a chronic stable underlying psychotic disorder may have decision-making capacity in regard to many healthcare decisions. Scrutiny is required, and a higher standard for capacity is needed in a high-risk situation with increased chances for an adverse outcome.

To provide a more structured assessment of capacity, several validated decision-making tools have been developed such as the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) [8]. The interview typically takes

15–20 min and involves the clinical course beginning with the nature of the medical condition, treatment recommendation, risks, benefits, and alternatives and is followed by asking probing questions that delve into the patient's ability to choose, understand, appreciate, and reason through a medical decision. However, standardized tools, such as the MacCAT-T, are not practical for use in the ED. Alternatively, the CURVES assessment tool provides an abbreviated screen more appropriate for the ED [9].

This mnemonic being developed helps to consolidate some of the integral aspects to answer for a capacity assessment (Fig. 11.1). The "Emergency" and "Surrogate" aspects help to frame the assessment for the acute setting to weigh imminent risk to the patient and if surrogate decision-making is available. It is important to recognize that in the acute setting being able to communicate with a surrogate decision-maker can help clarify goals of care and should be reasonably attempted by providers but also depends on the acuity of the situation and availability of the surrogate. It should be noted that surrogates include advance healthcare directives. When available these documents should be located and reviewed.

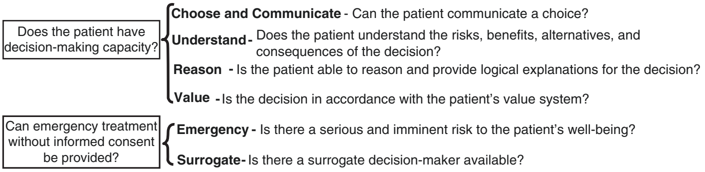


Figure 11.1 Mnemonic for the assessment of decision-making capacity and provision of emergency treatment. A patient lacks capacity if any of the prerequisite abilities (to choose and communicate, understand, reason, or value a decision) are absent. If a patient lacks capacity in an emergent situation and no surrogate decision-maker is available, then emergency treatment without informed consent may be provided for a medically warranted course of action. (Reprinted from Chow et al. [9], Page 423. Copyright 2010 with permission from Elsevier)

Advance Care Planning

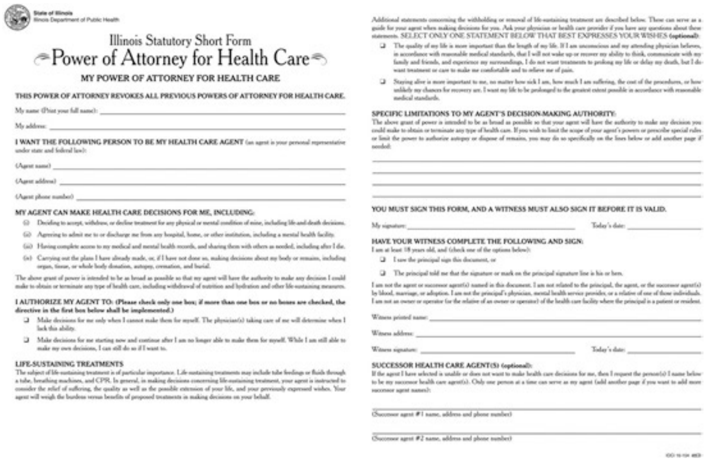
Advance care planning is a process that helps support adults of any age or health state understand and share their personal values, life goals, and preferences regarding future medical care [10]. This process helps to inform and empower patients about current and future medical care options. The goal of advance care planning (ACP) is to ensure that medical care is in line with the patient's values, goals, and preferences. ACP is particularly important near the end of life. This can help patients to receive quality end of life care which includes five valued components: adequate pain and symptom management, avoiding inappropriate prolonging of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones [11]. Advance care planning is a proactive, continuous process between a patient and their healthcare team. However, the term is often conflated with a set of documents known as advance directives. Advance directives, sometimes called as a living will, are documents to help outline care preferences and are completed while a patient has decisional capacity and is able to express those wishes. The contents of these documents are highly variable and may contain generalities about what a patient would or would not prefer up to highly specific contents on specific interventions. There are advantages and disadvantages for each of the advance directive formats available [12].

Advance directives are simply one set of tools to assist with advance care planning and help to document a patient's wishes. Since the passage of the Patient Self Determination Act of 1990, mandating that all Medicare-certified institutions provide information regarding patients' right to formulate advance directives, use of advance directives has been increasing [13]. Advance directives may be effective in reducing hospitalization and chances of dying in a hospital, decreasing the use of life-sustaining (or death-prolonging) treatment, and increasing the use of palliative and hospice care. However, simply having advance directives does not necessarily guarantee improved outcomes. The impact of advance directives depends on the type of advance directive a patient has completed and how ACP has been implemented overall [14].

Durable Power of Attorney for Healthcare and Living Wills

Several types of advance directives exist to help a patient clarify their wishes, and an emergency care provider may see one or more of these with a patient presenting to the ED in the United States. One of the most prevalent advance directive forms is the Durable Power of Attorney for Healthcare (DPAHC). This legal document may go by several different names depending on the state nomenclature including "Healthcare Proxy" or "Healthcare Power of Attorney" or "Medical Power of Attorney," but the contents are relatively similar. This type of form is a signed legal document authorizing another person to make medical decisions on a patient's behalf if they lack the ability or capacity to do so for themselves [15]. These forms can be state specific in the United States and may be combined with other components of advance directives. An example of a Power of Attorney for Healthcare for the State of Illinois can be seen in Fig. 11.2. One component often included in many DPAHC forms is a living will. The living will is a document that often helps outline a patient's wishes in specific medical circumstances. Commonly, it works to help clarify invasive resuscitation or prolonged life-support situations. This may be variable from state to state as well as patient to patient, and clinicians should be familiar with the state and local legal statutes surrounding validity and applicability of these documents.

Early studies of advance directives and the early formats of advance care planning failed to show meaningful improvement in important outcomes such as mechanical ventilation, days spent in the ICU, or reported pain [16]. Since then, however, an increased movement toward advance care planning



State of Illinois
Illinois Department of Public Health

Illinois Statutory Short Form
Power of Attorney for Health Care

MY POWER OF ATTORNEY FOR HEALTH CARE

THIS POWER OF ATTORNEY REVOKES ALL PREVIOUS POWERS OF ATTORNEY FOR HEALTH CARE.

My name (Print your full name): ______________________

My address: ______________________

I WANT THE FOLLOWING PERSON TO BE MY HEALTH CARE AGENT (an agent is your personal representative under state and federal law):

(Agent name) ______________________

(Agent address) ______________________

(Agent phone number) ______________________

MY AGENT CAN MAKE HEALTH CARE DECISIONS FOR ME, INCLUDING:

(i) Deciding to accept, withdraw, or decline treatment for any physical or mental condition of mine, including life-and-death decisions.
(ii) Agreeing to admit me to or discharge me from any hospital, home, or other institution, including a mental health facility.
(iii) Having complete access to my medical and mental health records, and sharing them with others as needed, including after I die.
(iv) Carrying out the plans I have already made, or, if I have not done so, making decisions about my body or remains, including organ, tissue, or whole body donation, autopsy, cremation, and burial.

The above grant of power is intended to be as broad as possible so that my agent will have the authority to make any decision I could make to obtain or terminate any type of health care, including withdrawal of nutrition and hydration and other life-sustaining measures.

I AUTHORIZE MY AGENT TO: (Please check only one box; if more than one box or no boxes are checked, the directive in the first box below shall be implemented.)

☐ Make decisions for me only when I cannot make them for myself. The physician(s) taking care of me will determine when I lack this ability.
☐ Make decisions for me starting now and continue after I am no longer able to make them for myself. While I am still able to make my own decisions, I can still do so if I want to.

LIFE-SUSTAINING TREATMENTS
The subject of life-sustaining treatment is of particular importance. Life-sustaining treatments may include tube feedings or fluids through a tube, breathing machines, and CPR. In general, in making decisions concerning life-sustaining treatment, your agent is instructed to consider the relief of suffering, the quality as well as the possible extension of your life, and your previously expressed wishes. Your agent will weigh the burdens versus benefits of proposed treatments in making decisions on your behalf.

Additional statements concerning the withholding or removal of life-sustaining treatment are described below. These can serve as a guide for your agent when making decisions for you. Ask your physician or health care provider if you have any questions about these statements. SELECT ONLY ONE STATEMENT BELOW THAT BEST EXPRESSES YOUR WISHES **(optional)**:

☐ The quality of my life is more important than the length of my life. If I am unconscious and my attending physician believes, in accordance with reasonable medical standards, that I will not wake up or recover my ability to think, communicate with my family and friends, and experience my surroundings, I do not want treatments to prolong my life or delay my death, but I do want treatment or care to make me comfortable and to relieve me of pain.
☐ Staying alive is more important to me, no matter how sick I am, how much I am suffering, the cost of the procedures, or how unlikely my chances for recovery are. I want my life to be prolonged to the greatest extent possible in accordance with reasonable medical standards.

SPECIFIC LIMITATIONS TO MY AGENT'S DECISION-MAKING AUTHORITY:
The above grant of power is intended to be as broad as possible so that your agent will have the authority to make any decision you could make to obtain or terminate any type of health care. If you wish to limit the scope of your agent's powers or prescribe special rules or limit the power to authorize autopsy or dispose of remains, you may do so specifically on the lines below or add another page if needed:

____
____
____
____

YOU MUST SIGN THIS FORM, AND A WITNESS MUST ALSO SIGN IT BEFORE IT IS VALID.

My signature: ______________________ Today's date: ____________

HAVE YOUR WITNESS COMPLETE THE FOLLOWING AND SIGN:
I am at least 18 years old, and (check one of the options below):

☐ I saw the principal sign this document, or
☐ The principal told me that the signature or mark on the principal signature line is his or hers.

I am not the agent or successor agent(s) named in this document. I am not related to the principal, the agent, or the successor agent(s) by blood, marriage, or adoption. I am not the principal's physician, mental health service provider, or a relative of one of those individuals. I am not an owner or operator (or the relative of an owner or operator) of the health care facility where the principal is a patient or resident.

Witness printed name: ______________________

Witness address: ______________________

Witness signature: ______________________ Today's date: ____________

SUCCESSOR HEALTH CARE AGENT(S) (optional):
If the agent I have selected is unable or does not want to make health care decisions for me, then I request the person(s) I name below to be my successor health care agent(s). Only one person at a time can serve as my agent (add another page if you want to add more successor agent names):

____
(Successor agent #1 name, address and phone number)

____
(Successor agent #2 name, address and phone number)

FIGURE 11.2 A sample of a healthcare power of attorney form from the State of Illinois

beyond a single document or discussion has been promoted to help a patient and family members understand what their own wishes are in a complex medical situation and how to express them to healthcare providers. More recent studies have shown that advance care planning, particularly in the form of meaningful discussions in conjunction with well-documented advance directives, helps patients receive care that is in line with their wishes and may help to reduce family stress, anxiety, and depression [13, 17]. Studies of bereaved family members also report greater hospice use and improved communication with healthcare providers when advance directives are involved [18].

The challenges with advance directives are multiple and also lie at the heart of the issue of attempting to plan end of life care, i.e., patient and their loved ones often don't know what they want for end of life care. Beyond the educational hurdles to be conquered before making informed planning decisions, even when that education is supplied, it may not stimulate informed advance care planning [19, 20]. If advance care planning does proceed, these preferences can be variable and may quickly change when hospitalization or illness occurs [21]. Additionally, physicians have difficulty extrapolating end of life preferences from advance directives; interestingly this was worse in primary physicians and more accurate in the emergency or critical care physicians that had never met the patient before [22]. This is also amplified in difficult clinical scenarios resulting in physicians frequently making treatment decisions not consistent with an explicit advance directive [23]. Though advance directives have not delivered the silver bullet for improving end of life care, they can be used as a foundation to help build advance care planning and lead to high-quality end of life care.

Surrogates

Surrogate decision-making or "alternate decision-maker" is anyone exercising decisional authority on behalf of an incapacitated patient. This may be an appointee by a court, by a patient's advance directive, or by DPAHC or a default surrogate depending on the situation. All US states honor the DPAHC or equivalent as well as court-appointed surrogate decision-maker. The DPAHC is described above in which a patient with decisional capacity identifies whom they would prefer to make decisions on their behalf should they lose capacity. Because advance directives are frequently not completed, surrogate decision-makers are often assigned via legal statute [24, 25]. Significant variability arises between state differences in the "surrogacy ladder" and with the terminology used between states and districts in the United States. Among the 50 US states and District of Columbia, 41 jurisdictions have a provision for appointment of a default surrogate for medical decision-making in the absence of an agent [25]. Of those, 35 establish a surrogate hierarchy with the highest priority given to spouse, children, or parents. Seven states provide for a domestic partner or common-law spouse to become surrogate decision-makers and allow for same-sex partners to occupy one of the top rungs. Physicians should carefully familiarize and stay up to date with their local practices for surrogate decision-makers. Six states require the surrogate decision-making hierarchy only be invoked in special circumstances, and four have no provisions on default surrogate decision-making. It is imperative the treating clinician be aware of local and state statutes regarding default surrogate decision-makers.

In the acute setting, it can be difficult to identify or contact the default surrogate decision-makers. In the clinical example above, most states, given no spouse or children, would default her sister as her decision-maker. This, however, could be overridden by specific, legally valid advance directives such as a DPAHC that employs a friend or significant other in the decision-making role instead of the default surrogate decision-maker. Of note, significant others not legally married or with a DPAHC may not be given the same rights of default surrogate depending on the state and local statutes. Not surprisingly, these situations can become complicated, and physicians should always avail themselves to the hospital ethics or risk management team in times of uncertainty. Figure 11.3 provides a general hier-

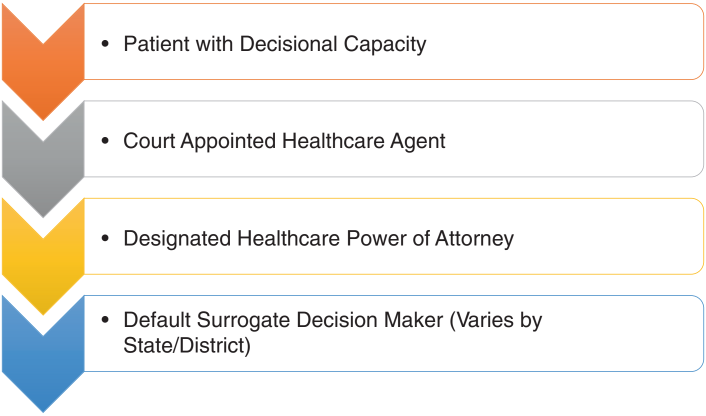


Figure 11.3 Hierarchy of decision-makers beginning from a patient with decisional capacity to the default surrogate decision-maker

archy of surrogate decision-makers following a patient with decisional capacity.

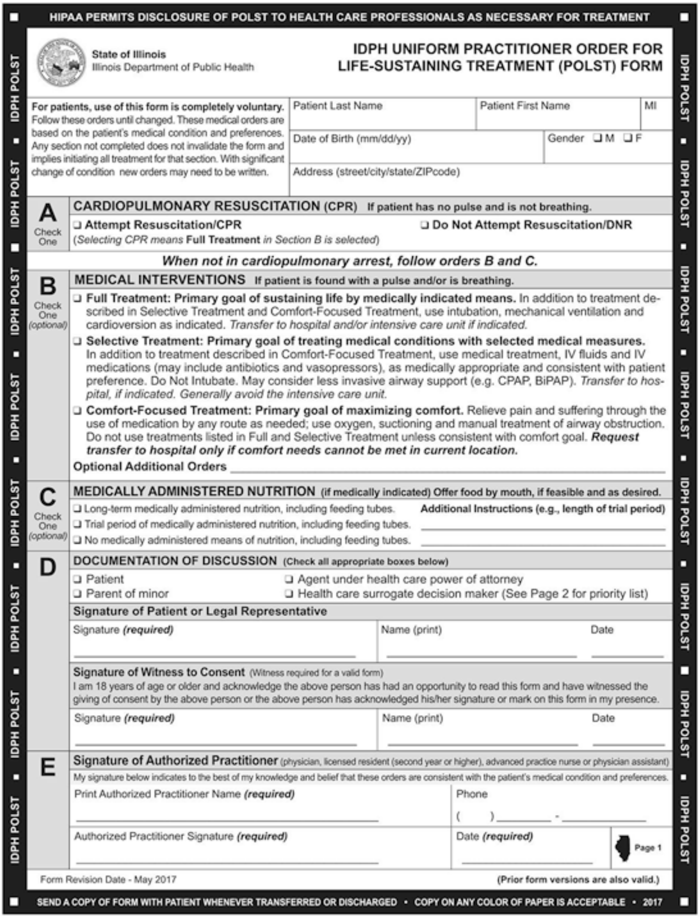
POLST

Advance directives have a wide range of forms as described above and can have limited use in the acute setting [26]. Patients and families often struggle with a multitude of choices even preceding end of life care, and the acute setting is often a suboptimal environment to establish meaningful discussions with patients or family members.

To standardize the instructions for healthcare professionals when death was imminent, the Physician Orders for Life-Sustaining Treatment (POLST) was developed [27]. The POLST form (Fig. 11.4) sought to standardized portable medical orders for patients with progressive, chronic illnesses regarding life-sustaining medical treatment, including resuscitation, intubation, antibiotics, artificial nutrition, and hydration. The format gained increased favor and popularity among healthcare providers as it was thought to address many of the shortcomings in typical advance directives at the time as well as its ability to span a variety of settings, e.g., prehospital, ED, inpatient, nursing home, hospice, etc. [28]. POLST forms support a degree of individualization that helps clarify patient preferences to actionable medical orders with ease [29]. Additionally, POLST forms can be used by nonphysician facilitators to guide patients through the process of identifying what, if any, life-sustaining treatments they would want near death.

End of Life Care Communication

Rather than simply filling out forms, advance care planning should bring together the person, individuals they trust in decision-making, and clinicians to support discussions about the patient’s preferences regarding medical care. These discussions should match the level of discussion the patient finds



HIPAA PERMITS DISCLOSURE OF POLST TO HEALTH CARE PROFESSIONALS AS NECESSARY FOR TREATMENT

State of Illinois
Illinois Department of Public Health

IDPH UNIFORM PRACTITIONER ORDER FOR LIFE-SUSTAINING TREATMENT (POLST) FORM

For patients, use of this form is completely voluntary. Follow these orders until changed. These medical orders are based on the patient's medical condition and preferences. Any section not completed does not invalidate the form and implies initiating all treatment for that section. With significant change of condition new orders may need to be written.

Patient Last Name	Patient First Name	MI
Date of Birth (mm/dd/yy)	Gender ☐ M ☐ F	
Address (street/city/state/ZIPcode)		

A Check One

CARDIOPULMONARY RESUSCITATION (CPR) **If patient has no pulse and is not breathing.**

☐ **Attempt Resuscitation/CPR** ☐ **Do Not Attempt Resuscitation/DNR**

(*Selecting CPR means* **Full Treatment** *in Section B is selected*)

When not in cardiopulmonary arrest, follow orders B and C.

B Check One *(optional)*

MEDICAL INTERVENTIONS **If patient is found with a pulse and/or is breathing.**

☐ **Full Treatment: Primary goal of sustaining life by medically indicated means.** In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, mechanical ventilation and cardioversion as indicated. *Transfer to hospital and/or intensive care unit if indicated.*

☐ **Selective Treatment: Primary goal of treating medical conditions with selected medical measures.** In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV fluids and IV medications (may include antibiotics and vasopressors), as medically appropriate and consistent with patient preference. Do Not Intubate. May consider less invasive airway support (e.g. CPAP, BiPAP). *Transfer to hospital, if indicated. Generally avoid the intensive care unit.*

☐ **Comfort-Focused Treatment: Primary goal of maximizing comfort.** Relieve pain and suffering through the use of medication by any route as needed; use oxygen, suctioning and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. ***Request transfer to hospital only if comfort needs cannot be met in current location.***

Optional Additional Orders ____________________

C Check One *(optional)*

MEDICALLY ADMINISTERED NUTRITION **(if medically indicated) Offer food by mouth, if feasible and as desired.**

☐ Long-term medically administered nutrition, including feeding tubes.
☐ Trial period of medically administered nutrition, including feeding tubes.
☐ No medically administered means of nutrition, including feeding tubes.

Additional Instructions (e.g., length of trial period) ____________________

D

DOCUMENTATION OF DISCUSSION **(Check all appropriate boxes below)**

☐ Patient
☐ Parent of minor
☐ Agent under health care power of attorney
☐ Health care surrogate decision maker (See Page 2 for priority list)

Signature of Patient or Legal Representative

Signature *(required)*	Name (print)	Date

Signature of Witness to Consent (Witness required for a valid form)
I am 18 years of age or older and acknowledge the above person has had an opportunity to read this form and have witnessed the giving of consent by the above person or the above person has acknowledged his/her signature or mark on this form in my presence.

Signature *(required)*	Name (print)	Date

E

Signature of Authorized Practitioner (physician, licensed resident (second year or higher), advanced practice nurse or physician assistant)

My signature below indicates to the best of my knowledge and belief that these orders are consistent with the patient's medical condition and preferences.

Print Authorized Practitioner Name *(required)*	Phone ( ) ________ - ________	
Authorized Practitioner Signature *(required)*	Date *(required)*	Page 1

Form Revision Date - May 2017 **(Prior form versions are also valid.)**

SEND A COPY OF FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED • COPY ON ANY COLOR OF PAPER IS ACCEPTABLE • 2017

Figure 11.4 An example of a Physician Orders for Life-Sustaining Treatment (POLST) form from the State of Illinois available at http://www.polstil.org/

comfortable and should be revisited when health or life circumstances change [10]. End of life care discussion has been shown to decrease costs and promote a higher quality of death [30].

ED Goals of Care

Advance care planning can help direct care in the ED if it is performed prior to an ED visit [14]. However, end of life care often brings patients to the emergency department. Up to 80% of cancer patients seek care in the ED in the last 6 months of life [31, 32]. The ED is often a difficult environment to begin a goal of care discussion much less an end of life one. Aside from prognostic uncertainty, logistical and time constraints, and lack of familiarity by the patient and family to the care team, many ED staff members are not trained in end of life care. Many providers report feeling underprepared and may feel the ED is an inappropriate place to conduct such care [33]. However, many critically ill patients in the ED have not had ACP discussions or do not have legal documentation. Though it is not the optimal site of ACP, discussions about advance care planning in the ED can go a long way to help identify and honor patients' wishes. The ED team should strive to provide care that is consistent with the patient's values and goals. The initial steps should be to identify or clarify any previous ACP and what the discussion has been to date with their primary physician or a specialist. The care team should inform the patient or surrogate decision-maker of their suspected diagnosis, prognosis, risks and benefits or treatment, and treatment alternatives. They should provide all options for care and treatment and attempt to connect the options back to any previously ACP and see if the current preferences align with previous preferences. Care values and goals can change dramatically moment to moment, and it should be noted not to assume they have remained unchanged in this particular acute setting.

One method to help clinicians walk through these steps is the "ABCD" method from the Education in Palliative and End-of-Life Care for Emergency Medicine (EPEC-EM) curriculum [34]. In this paradigm, A (advance care plan) refers to if there is an advance care plan available to review? B (better symptoms) asks if there can be better symptom control done to mitigate overwhelming symptoms such as dyspnea or pain? C (caregivers) requests caregivers for information on the patient's clinical context and recent functional changes? And finally, D (decision-making) asks if the patient has decision-making capacity to discuss goals or is the legal surrogate identified and accessible? This model helps ED clinicians frame many of the difficulty questions that immediately apply to the acutely ill patient where end of life care may be needed.

ED Interventions

Often the questions for the ED clinicians are related to choosing which interventions are appropriate for the patient? This is easy in the critically ill adult whose goals of care are to avail every medical therapy to prolong life or for the patient who has specified through clear advance directives that they should have comfort care only. The challenge lies in patients who may not have clear or any advance directives and are critically ill and there is uncertainty about what their goals are.

In our case example above, what should be done about Ms. Roosevelt's airway? What about fluids? Vasopressors? Antibiotics? One of the luxuries often not afforded in the ED is time to evaluate fully a patient's goals and care wishes and discuss with the family, friends, or long-term care providers to obtain that information. By identifying low-risk temporizing interventions, the ED team can help to facilitate appropriate care and be able to escalate or de-escalate care when and if the patient's goals of care are found to be clearer.

For Ms. Roosevelt, it would be appropriate to start an IV line, provide IV fluids, draw labs, and obtain basic data such as imaging and electrocardiogram. These are not only noninvasive for the large part but also help provide information on the diagnosis and prognosis of her condition. However, if she is tachypneic and hypoxic, has pooled secretions in the back of her oropharynx, and does not appear to have a gag reflex, it appears that she requires endotracheal intubation; however, because there is confusion about a previous DNR/DNI status, it is not clear if that would honor Ms. Roosevelt's wishes. In situations like this, one useful tool for buying time for the ED care team is to initiate noninvasive ventilation for a short term while more information is gathered. While this is often seen for certain patients with reversible etiologies of respiratory failure with an adequate mental status, it may be appropriate in certain clinical situations after careful discussion with relevant decision-makers present with explicit parameters for its intentions, uses, and success and failure parameters [35]. If aspiration is a significant concern, alternatives can include nasal bi-level positive airway pressure (BiPAP) and high-flow nasal cannula to help provide positive pressure and oxygenation short of endotracheal intubation.

Antibiotics are a controversial area in palliative care particularly in the emergency department. Many providers see little to no harm in treating empirically until definitive goals of care can be achieved. This may be appropriate in certain situations, but side effects, increased resistance patterns, and no data to show palliative effects of symptoms all weigh against its hasty use [36]. Nearly 90% of hospitalized patients with advanced cancer receive antimicrobials in the week prior to their death and similarly with nearly a quarter of hospice patients [37, 38]. The ED is likely a prime area to improve appropriate antimicrobial use, and it begins with identifying the patient's goals of care and advocating for them. Evidence-based and goal-directed counselling about infections at the end of life should be a component of advance care planning. If a patient's goal is to maximize comfort, then it is reasonable to recommend no infectious evaluation and antimicrobial intervention. Adequate antipyretics, pain control, and symptom management should be identified as the priority in this case.

Case Resolution

After initiating high-flow nasal cannula, the ED physician contacts Ms. Roosevelt's sister, her only known living relative. She states she is the DPAHC and that on her last admission *her sister had made it clear she did not want invasive therapies if she had another pneumonia. She states that Ms. Roosevelt had started a living will with her sister and her primary physician but did not yet complete it. She states her sister was looking for comfort rather than more time spent in a hospital. They had discussed if she were to ever become critically ill, they would arrange for home hospice. With this information, the ED team is able to transition her to home hospice directly from the ED to her sister's residence for comfort measures.*

Resources for Patients and Providers

American Association for the Advancement of Retired Persons Printable Advance Directive Forms: https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/

Aging with Dignity (5 Wishes) forms: https://www.agingwithdignity.org/

CaringInfo- National Hospice and Palliative Care Organization: www.caringinfo.org

POLST- National POLST paradigm: www.polst.org

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