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POLST®:
Co-Piloting, Not Hijacking, the Advance Directive
By Fay Blix, CELA, CAP, and Susan W. Tolle, MD

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POLST®: Co-Piloting, Not Hijacking, the Advance Directive

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I. Introduction

Nearly 30 years have passed since the portable orders for life-sustaining treatment (POLST®) initiative began.¹ Oregon was the first state to establish a POLST program, in 1991. POLST programs have now been initiated, with some variation, in almost every state.^{2 3} The growth in the use of POLST speaks to the overwhelming

yearning of individuals to have their preferences regarding end-of-life care known and respected. However, the phenomenal increase in those availing themselves of POLST also presents new challenges,^{4, 5} particularly in the present climate of managed care. Attorneys frequently express concern that POLST form orders have replaced the advance directive. Although an advance directive is often not sufficient, POLST form orders were always meant to

1 Oregon POLST, *POLST History Timeline*, <https://oregonpolst.org/history-timeline> (accessed May 7, 2019).

2 Natl. POLST Paradigm, *National POLST Paradigm [State] Program Designations*, <http://www.polst.org/programs-in-your-state> (accessed May 7, 2019).

3 U.S. Govt. Accountability Off., *Advance Care Planning: Selected States’ Efforts to Educate and Address Access Challenges* (Feb. 2019), <https://www.gao.gov/assets/700/696985.pdf> (accessed May 7, 2019).

4 Charlie Sabatino, *POLST: Avoid the Seven Deadly Sins*, 39(4) *Bifocal* 60 (2018), https://www.americanbar.org/content/dam/aba/administrative/law_aging/bifocal-39-4-final.pdf (accessed May 7, 2019).

5 Thaddeus Mason Pope & Melinda Hexum, *Legal Briefing: POLST: Physician Orders for Life-Sustaining Treatment*, 23(4) *J. Clinical Ethics* 353 (2012).

support, not supplant, the advance directive. Part of the reason for the misunderstanding concerning how POLST form orders complement the advance directive is that attorneys often lack familiarity with what actually happens in the clinical setting throughout the trajectory of a client's illness.

This article presents scenarios in which medical doctors work with patients and their families throughout the course of an illness to ensure quality care for patients and implementation of their end-of-life treatment preferences. The article also illustrates how both the medical and legal professions can ensure that patient's and client's wishes for care near the end of life are elicited sensitively, recorded accurately, and honored when needed. In addition, to highlight several important new developments in POLST programs, the article builds on the excellent in-depth POLST review by Wolf and colleagues in 2014.⁶ Elder law attorneys, in collaboration with health care professionals, can play a vital role in preserving the public trust by ensuring the integrity of advance directive and POLST discussion and implementation.

To illustrate the practical approach to the challenging medical and legal issues in health care decision-making, in Section II we trace the journey of an aging couple working with their children, their attorney, and the health care system as the couple's health declines. As we present the unfolding narrative in a series of scenarios, we discuss the key common legal issues confronting the attorney. In Section III, we provide a summary of lessons learned that

may serve as a helpful reference for legal professionals working with elderly clients.

II. Scenarios

A. Scenario 1: An Elderly Couple Faces Progressive Cognitive Impairment

1. Legal Issues Explored

This initial scenario presents a slow-moving tragic situation common among the elderly: progressive cognitive impairment. As a geriatric specialist begins to recognize her patient's symptoms, the patient's longstanding attorney is about to become engaged in the myriad legal challenges arising from his client's mental decline. This scenario focuses on (a) determination of the client's decision-making capacity, (b) identification of a surrogate to help the client make medical and legal decisions, and (c) the ethical and legal duties related to sharing the client's personal health information.

2. Scenario

Ralph O'Holleran is an extremely successful 82-year-old businessman. He and his wife, Judy, have been married for 60 years. They met in college and married the year they graduated. Judy is also 82 and mentally sharp. (She usually wins bridge games.) Judy raised the couple's three children and kept the household running while Ralph worked long hours building his business. Judy is involved in a range of volunteer activities and has always deferred all decision-making to Ralph. He manages all the finances and is the patriarch of the extended family. All three children live out of state. The oldest child, Jonathan, is a software engineer and tends to be somewhat overbearing with his siblings. His sister, Rachel, is a professor of English at a liberal arts college. She

⁶ Robert B. Wolf et al., *The Physician Orders for Life-Sustaining Treatment (POLST) Coming Soon to a Health Care Community Near You*, 49 Real Prop. Tr. & Est. L.J. 71 (2014).

returns home when emergencies arise but does not visit frequently. The youngest child, Larry, has struggled with substance use disorder and has been in and out of treatment for years.

During the past year, Ralph has experienced several memory lapses. Learning new tasks and remembering people's names have become more difficult; twice he forgot he paid a bill and paid it a second time. His geriatrician conducts formal cognitive testing and diagnoses mild cognitive impairment (MCI). She encourages Ralph to complete an advance directive and appoint a health care decision-maker.

3. The Geriatrician's Response

The geriatrician is acutely aware that receiving an MCI diagnosis is overwhelming and devastating for many patients. Although many patients are aware of forgetting things and may fear the onset of dementia, without a formal diagnosis, they commonly experience some degree of denial. The goal of Ralph's geriatrician at this visit needs to be modest; she must be supportive in sharing the diagnosis with Ralph and in providing him with the initial steps he needs to move forward on his new path.

After explaining the results of Ralph's formal cognitive testing and how the results were scored, the geriatrician pauses. Most patients are unable to process further information immediately after being given such bad news. By pausing, the geriatrician gives Ralph time to digest what he heard and to ask further questions when he is ready. It is important for the geriatrician not to give Ralph more medical information than he is ready to hear at this time. It is also entirely possible that Ralph is not yet ready to discuss the possibility of MCI progressing to dementia. The amount of information patients want

about a poor prognosis varies greatly.^{7, 8} As patients develop cognitive impairment, it becomes increasingly difficult for them to process information without a friend or family member present to help them remember what the doctor said and to follow through on next steps.

The geriatrician realizes that Ralph needs to begin planning while he is still able to participate and is capable of sharing his wishes and values. She knows that most people initially find it easier (less emotionally charged) to talk about who would serve as an appropriate surrogate than to talk about care preferences near the end of life. The geriatrician has cared for Ralph for a long time and realizes the heartache that Ralph and Judy have experienced because of their son Larry's problems with substance use disorder. The geriatrician is also aware that Judy is extremely passive and has always deferred to Ralph in decision-making and that none of the children live in the area.

Although Ralph may not yet be ready to engage in philosophical discussions about his goals of care, the geriatrician knows the importance of a cognitively impaired patient consulting an attorney. She feels strongly that Ralph should consult an attorney to appoint a surrogate decision-maker by completing an advance directive. She provides Ralph with the American Bar Association (ABA) list of resources on advance care planning,⁹

7 Kuldeep N. Yadav et al., *Approximately One in Three U.S. Adults Completes Any Type of Advance Directive for End-of-Life Care*, 36(7) Health Affairs 1244 (2017).

8 Nancy L. Schoenborn et al., *Older Adult Preferences for Discussing Long-Term Life Expectancy: Results From a National Survey*, 16(6) Annals Fam. Med. 530 (2018).

9 ABA, *Advance Care Planning Resource List*, <https://www.americanbar.org/content/dam/>

gives him a state-specific booklet¹⁰ about advance directives, and emphasizes that his first priority should be to formally appoint a surrogate. Although the geriatrician indicates that she can help with this, Ralph feels more comfortable doing this with his attorney.

In addition to the attorney referral, the geriatrician encourages Ralph to begin involving others in his health care. She senses that this will be extremely difficult for Ralph, who has always been the person in charge. She strongly urges Ralph to grant access to his medical portal to the person he will appoint as his surrogate and explains how the Health Insurance Portability and Accountability Act (HIPAA) authorization is done in her practice. She also indicates that over time he should begin bringing to his clinic visits those he trusts most. She suggests that he bring Judy at first and later bring one of his adult children.

The geriatrician strongly encourages Ralph to see his attorney and formally appoint a surrogate. This is an important first step in promoting attorney and health care professional collaboration.

As noted in number 10 in Section III, Lessons Learned, good advance care planning is the product of teamwork.

B. Scenario 2: The Attorney Introduces an Advance Directive

1. Legal Issues Explored

Following the suggestion of his geriatrician, Ralph consults with his attorney regarding an advance directive. This

scenario focuses on lost opportunities in such a legal consultation: (a) the attorney's cavalier attitude toward the client's advance directive, (b) the attorney's failure to explore the client's concerns about the diagnosis and end-of-life wishes, and (c) the attorney's failure to provide adequate instruction on what to do with the advance directive once it is signed.

2. Scenario

Ralph and Judy meet with their business attorney to update their estate plan. Ralph mentions his recent diagnosis in passing, and the attorney "throws in" advance directive forms as part of the couple's updated estate plan. No discussion occurs regarding Ralph's health care wishes other than Ralph indicating that because he does not want to burden Judy with difficult medical decisions, he wants to appoint his oldest son, Jonathan, as his surrogate and daughter Rachel as his alternate surrogate. He also mentions that he wants the "plug pulled" if he no longer recognizes his family members. Judy tells the attorney to name Ralph's surrogates to serve as her surrogates, and Ralph agrees.

Because Ralph is an especially private person and is ashamed of his diagnosis, he does not discuss his health care wishes with anyone other than making Judy promise that she will never put him in a nursing home. He does inform Jonathan and Rachel that he named them as his surrogates. Ralph mails copies of the estate planning documents for them to sign and return but does not provide them or his geriatrician with a copy of his signed advance directive.

3. The Attorney's Insufficient Response

It is perfectly natural for Ralph to meet with his business attorney to get his affairs in order. The business attorney knows

[aba/administrative/law_aging/acp-resource-list-final.pdf](#) (accessed May 7, 2019).

10 Natl. Hospice & Palliative Care Org., *Advance Care Planning*, <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3277> (accessed May 7, 2019).

Ralph well and is the attorney with whom Ralph feels most comfortable. However, if the attorney is not familiar with aging issues and advance directives, he could be doing Ralph a disservice by not referring him to an experienced elder law attorney.

Unfortunately, many attorneys make the same mistake that Ralph's attorney did in considering the advance directive a "throw-in" document. This practice not only devalues the document but also deprives Ralph of a discussion with another trusted professional about his choice of surrogate and his preferences regarding his future health care. In an elder law practice, the advance directive should be considered one of the most important documents the client will ever sign.

The fact that Ralph mentioned his MCI diagnosis should have triggered the attorney to be especially diligent about eliciting discussion on an appropriate surrogate. Ralph still may be too sensitive about his diagnosis to discuss his concerns about dementia and end-of-life decision-making; however, it is incumbent on the attorney to push Ralph a little by urging him to explore some of the resources suggested by his geriatrician. This may require several meetings, but it is well worth the effort.

The ABA Commission on Law and Aging recently published an excellent resource, *Advance Directives: Counseling Guide for Lawyers*, which details best practices for attorneys in drafting and disseminating advance directives.¹¹ It provides a checklist of issues for attorneys to discuss with clients. Because this guide was developed with input from both medical and

legal professionals, it effectively addresses the concerns of both professions in assisting patients and clients with advance care planning.

The guide suggests that the attorney send a copy of the advance directive to the client's primary health care professional along with a cover letter eliciting his or her input. It also suggests that the attorney provide copies of the advance directive to all surrogates named in the document and a list of resources to assist them in their future duties.^{12, 13}

It might also be useful for the attorney to seek the client's permission to send copies of the advance directive to all family members not appointed as surrogates to ensure that any concerns can be addressed while the client is still able to speak for himself or herself. This may minimize anger and surprise at a time of crisis, helping the family focus on the needs of the client, not on the ensuing battle concerning surrogacy. It may even be appropriate for the attorney to offer a family meeting if the client is worried about the consequences of sharing the advance directive.

In this scenario, Ralph's attorney makes the same mistake regarding Judy's advance directive. Little discussion takes place with Judy regarding her choice of surrogates or her health care preferences. Even though Ralph's need for an advance directive is

11 ABA Commn. on L. & Aging, *Advance Directives: Counseling Guide for Lawyers* (2018), http://www.americanbar.org/content/dam/aba/administrative/law_aging/lawyers-ad-counseling-guide.pdf (accessed May 7, 2019).

12 ABA Commn. on L. & Aging, *Making Medical Decisions for Someone Else: A How-To Guide* (2009), <https://www.americanbar.org/content/dam/aba/administrative/staff-diversity-council/making-hc-decisions-for-someone-else-final.pdf> (accessed May 7, 2019).

13 The Conversation Project & Inst. for Healthcare Improvement, *How to Choose a Health Care Proxy & How To Be a Health Care Proxy* (2017), <http://theconversationproject.org/wp-content/uploads/2017/03/ConversationProject-ProxyKit-English.pdf> (accessed May 7, 2019).

somewhat more urgent due to his diagnosis, the attorney should not have underestimated the importance of Judy's advance directive. When meeting with a couple, it is essential that both partners be given the opportunity to fully express their wishes and values and that "me too" utterances be explored for nuances and differences.

Above all, the attorney should emphasize that advance care planning is more than the preparation of a "one-and-done" document — it is a process over time.¹⁴ It is imperative to explore the client's willingness for the attorney to become involved with the client's health care professionals and surrogates and to have the client sign the appropriate waiver and consent forms if the client is willing.

The attorney should definitely suggest that Ralph discuss his new advance directive with his geriatrician and ensure that the physician places a copy of the document in Ralph's medical record.

For more suggestions, see numbers 1, 2, 3, and 4 in Section III, Lessons Learned.

C. Scenario 3: Ralph's Health Slowly Declines

1. Legal Issues Explored

Ralph's illness has progressed significantly in 2 years. This scenario focuses on (a) the issues involved when the client loses his or her driver's license and (b) the importance of revisiting the client's legal needs at various stages of progressive illness.

2. Scenario

Ralph's cognitive abilities are slowly declining. Although he and Judy never

speak of his memory lapses, she is increasingly covering for him, reminding him of peoples' names, all of his appointments, and when to take his medications and giving him driving directions on how to get home. About 2 years after his diagnosis, Ralph got lost while driving home, and Judy reported the incident discretely to the department of motor vehicles. Ralph failed the test the department subsequently gave him, and his driver's license was revoked. It is now slowly dawning on other family members and friends that Ralph is becoming increasingly cognitively impaired.

3. Loss of Ralph's Driver's License

The loss of Ralph's driver's license is a big wake-up call that Ralph needs assistance and must ensure that his affairs are in order while he is still able to express his wishes and values. He visits his geriatrician soon after losing his driver's license, reluctantly allowing Judy to attend the appointment. The geriatrician learns that Ralph has completed an advance directive and requests a copy. She makes a note in her medical record that Ralph has selected his oldest son, Jonathan, to serve as his surrogate, with his daughter, Rachel, as the alternate. She again encourages Ralph to give Jonathan access to the medical portal and consider giving access to Judy to enable her to help with appointments and follow-up. The geriatrician offers another visit with Jonathan to discuss supporting Judy in the home, maximizing Ralph's ability to stay engaged with friends now that he can no longer drive, and helping Ralph and his family have a conversation about what matters most to him.

Much of Ralph's geriatrician visit after losing his driver's license focuses on his anger and depression related to that loss, his despair about his worsening memory

14 Amber E. Barnato, *Challenges in Understanding and Respecting Patients' Preferences*, 36(7) *Health Affairs* 1252 (2017).

loss, and his frustration with his growing dependence. The geriatrician encourages Ralph to have a follow-up conversation with the attorney to ensure that his affairs, including his financial affairs, are in order and offers additional resources to support Ralph's advance care planning.^{15, 16, 17}

Had the attorney shared Ralph's advance directive with his geriatrician and surrogates shortly after Ralph signed it, the family may have been more prepared to support Ralph through the trauma of the loss of his driver's license.

See numbers 1, 2, 3, 4, and 10 in Section III, Lessons Learned.

D. Scenario 4: Four Years After Diagnosis, the Couple's Health Worsens

1. Legal Issues Explored

Judy's illness trajectory, which differs from Ralph's, presents its own inherent challenges. This scenario shows (a) the importance of listening to the client even if an advance directive exists, (b) how the advance directive could be a helpful springboard for discussion, (c) the value of supported decision-making for elderly clients, and (d) how the discussion about goals of care guides the POLST discussion.

2. Scenario

Ralph is beginning to wander; therefore, Judy no longer feels it is safe to leave him alone at home. When she attempts to arrange for additional help in the home to give herself some relief, Ralph fires everyone the home health care agency provides. Judy, at age 86, is becoming increasingly

stressed and exhausted and experiences more frequent chest pain. One day, while Jonathan is visiting, Judy has a severe episode of chest pain, and he drives her to the academic health center about 15 miles away. Judy is diagnosed with a severe myocardial infarction (heart attack), and Jonathan notifies Rachel, who arranges to fly in that afternoon. Fortunately, Judy remains cognitively intact, but she is now too frail to care for Ralph at home.

Judy's myocardial infarction was severe enough to reduce her heart's pumping ability, causing congestive heart failure. Judy's heart pumps out only 25 percent of the total amount of blood in its left ventricle with every beat compared with a normal heart that pumps out 55 percent. This loss of contraction ability causes Judy to become short of breath when walking. She tires easily and needs help with housework, grocery shopping, and other instrumental activities of daily living. She needs to limit the amount of salt in her diet and take medications for her heart failure. Judy's condition requires that she be closely followed by her medical team.

Judy is at increased risk of having a life-threatening abnormal heart rhythm at any time. As a result, she is offered an internal cardiac defibrillator (ICD), a surgically implanted device that will give her heart an electric shock if she experiences a severely abnormal heart rhythm, with the goal of preventing sudden cardiac death. Judy informs Jonathan and Rachel that she is unsure whether she wants an ICD and wants their help in making this decision.

Judy's reservations and the severity of her heart disease lead the medical team to begin asking questions about her goals of care. The team asks whether Judy has an advance directive. She tells the team she has one and has appointed Jonathan as

15 ABA Commn. on L. & Aging, *supra* n. 11.

16 The Conversation Project & Inst. for Healthcare Improvement, *supra* n. 13.

17 Prepare for Your Care website, <https://prepareforyourcare.org/welcome> (accessed May 7, 2019).

her surrogate and Rachel as the alternate. Judy tells Rachel where all of her legal paperwork is at home, and Rachel agrees to bring in a copy of Judy's advance directive for placement in her medical record.

Because Judy is a capable decision-maker, her medical team, without having a copy of her advance directive, begins discussing with Judy (and with her permission, Jonathan and Rachel) her goals of care. Judy, after talking with Jonathan and Rachel, indicates that she wants to return to the hospital if she has another cardiac event but does not want cardiopulmonary resuscitation (CPR) or to be placed on a breathing machine. Her medical team records these wishes as medical orders on a POLST form as "do not attempt resuscitation (DNR) and limited treatment." Both Judy and her doctor sign the form, a copy is placed in her medical record, and Judy is given a copy to take home. With Judy's permission, copies are provided to Jonathan and Rachel.

3. Judy's Declining Health

Judy's trajectory to death¹⁸ is profoundly different from Ralph's; therefore, her medical team approaches the discussion of her goals of care differently from the approach Ralph's geriatrician used to discuss his goals. Although frail, Judy is cognitively intact and capable of serving as her own decision-maker. Thus, her advance directive is not determinative because she is still capable of guiding her own care. Nonetheless, if Judy's advance directive had been available to her medical team, the team would have become aware of her ultimate intention to involve Jonathan and Rachel in her care. Discussing what

Judy wrote in her advance directive would have been an excellent starting point to facilitate deeper conversation with her medical team about her care goals¹⁹ in the context of her congestive heart failure.

Being able to refer to a patient's advance directive provides a helpful way for health care professionals to initiate a deeper conversation with families regarding a specific medical decision. For many patients, the advance directive makes it easier to express their goals beyond the four corners of the document and to speak more specifically about treatments related to their current state of health.

Judy's medical team should review the advance directive with her while she is still capable of doing so to confirm that the document still reflects her wishes and that the surrogates she listed are still the people she wants to speak on her behalf if she becomes unable to speak for herself.

Because Judy has capacity, an advance directive is not needed for making a decision about placement of an ICD. However, having an advance directive is important for Judy in the event she someday loses capacity. In most states, her default decision-maker is her spouse,²⁰ Ralph, who, unfortunately, is now incapable of making medical decisions on his own behalf, let alone hers. In addition, she definitely does not want Larry (her youngest son) making any medical decisions for her. Thus, in Judy's case, it is especially im-

18 Jennifer Moore Ballentine, *Supporting Patients During Serious Illness* (Cal. St. U. Inst. for Palliative Care 2018).

19 Rachele E. Bernacki & Susan D. Block, *Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices*, 174(12) *JAMA Internal Med.* 1994 (2014).

20 ABA Commn. on L. & Aging, *Default Surrogate Consent Statutes* (Jan. 1, 2018), https://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf (accessed May 7, 2019).

portant to ensure that a formal appointment of a surrogate is made in an advance directive and that a copy of the advance directive is placed in her medical record to ensure that she receives care according to her wishes.

It is common, however, for frail elders who are still capable of making their own health care decisions to seek support and consultation from their surrogates. The terms “assisted decision-making” and “supported decision-making” are often used to describe the process of frail but capable elders turning to trusted advocates for consultation and reinforcement.

Judy differs from Ralph in another important way. She not only has capacity to make her own medical decisions but also is more comfortable and willing to engage in a goals-of-care conversation. She is more interested in receiving information about her prognosis and treatment options than Ralph is in receiving information about his. Following a conversation about the risks and benefits of treatment with her medical team, Judy indicates her preference for “DNR and limited treatment” on her POLST form.

Judy’s medical team makes her aware that few people with similar advanced health problems survive an out-of-hospital cardiac arrest.²¹ The team informs her that television and movies misrepresent the truth by portraying survival rates for out-of-hospital cardiac arrest that are much higher than those in real life.²² Studies of out-of-hospital cardiac arrest for patients of all ages and health conditions have found an approximately 8 percent rate of

successful resuscitation. For patients with advanced illness and frailty, rates drop to 3 percent or less depending on the health condition.²³

As a result of this discussion and reflection on her wishes and values, Judy feels strongly about avoiding resuscitation, intensive care, and mechanical ventilator support. Because emergency medical personnel are obligated to provide all indicated life-sustaining treatments unless they have medical orders to the contrary, her medical team is aware that her advance directive alone will not be enough to ensure that her wishes are honored in a crisis. Emergency medical personnel are not allowed to act on an advance directive because it is not a medical order.

The short video “POLST: When Advance Directives Are Not Enough”²⁴ helps demonstrate the importance of POLST form orders. POLST form orders are necessary to turn wishes expressed in advance directives into action as medical orders when patients want their wishes to be implemented in their medical care.²⁵ Attorneys and health care professionals alike might suggest to clients and patients that they and their surrogates watch this video together to enhance their understanding of the advance care planning process.

In Judy’s current situation, Jonathan and Rachel benefit from being integrated

21 Robert M. Taylor et al., *Improving Do-Not-Resuscitate Discussions: A Framework for Physicians*, 8(1) *J. Supportive Oncology* 42 (2010).

22 Susan J. Diem et al., *Cardiopulmonary Resuscitation on Television: Miracles and Misinformation*, 334(24) *New Eng. J. Med.* 1578 (1996).

23 Patricia Jabre et al., *Family Presence During Cardiopulmonary Resuscitation*, 368(11) *New Eng. J. Med.* 1008 (2013).

24 Oregon POLST, YouTube, *POLST: When Advance Directives Are Not Enough* (Apr. 8, 2013), <https://www.youtube.com/watch?v=mdPtHu0-KPU> (accessed May 7, 2019).

25 Oregon POLST, *POLST Guidebook for Health Care Professionals*, click link to guidebook, which is titled *Guidance for Oregon’s Health Care Professionals* (rev. Feb. 14, 2019), <https://oregonpolst.org/polst-guidebook> (accessed May 7, 2019).

into the decision-making process early and serving as consultants in supporting their mother's decisions. By doing so, they are able to learn much more about her wishes and values.

Jonathan and Rachel could have obtained further guidance on their roles as surrogates by watching the video "POLST: When Is the Right Time?"²⁶ when they initially agreed to become surrogates for their parents. All too often, those who are appointed as surrogates receive little guidance on how to perform their responsibilities. Surrogates need guidance from the person they represent, along with an in-depth understanding of his or her wishes and values, as well as guidance from the medical team. Both medical and legal professionals can provide assistance on how to conduct conversations about end-of-life care and provide tools for facilitating them.^{27, 28}

To more fully understand their role, surrogates need guidance on how the wishes expressed in a patient's advance directive will ultimately need to be turned into medical orders with a POLST form. In this case, Judy remains a capable decision-maker and signs the POLST form with her doctor. She may indicate that it may be more appropriate for her care to focus on her comfort when she no longer has capacity to make her own medical decisions. In this context, Jonathan would work with her medical team to complete a new POLST form that reflects her wishes for comfort measures only when she is in a more compromised state of health. See

numbers 3, 5, 7, and 10 in Section III, Lessons Learned.

E. Scenario 5: Challenging Surrogate Decisions Arise During Ralph's Acute Illness

1. Legal Issues Explored

This scenario describes the consequences of inadequate end-of-life care discussions with clients and their families, vague advance directives, and the lack of early surrogate involvement. The scenario focuses on (a) the need for good communication between clients and their families regarding end-of-life wishes, (b) the need for the advance directive to be part of the client's medical record; and (c) the need for greater specificity about the client's values guiding end-of-life wishes in the advance directive.

2. Scenario

Larry (the youngest son) comes to town later the same day that Judy is admitted to the hospital. He goes to his parent's home and finds Ralph, now 87, with a fever and extreme breathlessness. He calls 911, and Ralph is admitted, with aspiration pneumonia, to the nearest hospital (which is not the academic health center where Judy has been admitted). Because communication is terrible between Larry and his siblings, Larry does not immediately notify Jonathan and Rachel that Ralph has been taken to the hospital. Thus, Larry is the only family member in the emergency department, and Ralph is not able to provide any information. The hospital does not have a copy of Ralph's advance directive in his medical record. Larry instructs the emergency physicians to "do everything" to save Ralph. Ralph is placed on a mechanical ventilator in the intensive care unit (ICU).

When Jonathan and Rachel return to

26 Oregon POLST, *POLST: When Is the Right Time?* (Apr. 30, 2018), <https://www.youtube.com/watch?v=LoGM-ayzKc0> (accessed May 7, 2019).

27 ABA Commn. on L. & Aging, *supra* n. 11.

28 The Conversation Project & Inst. for Healthcare Improvement, *supra* n. 13.

the family home that evening, they find Larry's belongings and no sign of their father or Larry. They call Larry and go to the local hospital to find their father in restraints, sedated, and on a ventilator in the ICU. They tell the medical team that their father did not want Larry to make medical decisions for him and that they, not Larry, were appointed as surrogates in their father's advance directive. The medical team instructs Jonathan and Rachel to bring in a copy of Ralph's advance directive and schedules a family meeting for the next day. Fortunately, Judy told Rachel where their important papers are located. Rachel was able to find both Ralph's and Judy's advance directives, which confirmed that Jonathan is Ralph's chosen surrogate and that Rachel is the alternate. However, the directive gives no guidance about Ralph's treatment wishes other than stating that he does not want life-sustaining treatment if he no longer recognizes his family.

When Jonathan and Rachel return to the hospital with their families, Ralph has awakened confused; he appears to recognize Jonathan and Rachel but not his grandchildren. Jonathan and Rachel do not know what to do and cannot agree on treatments their father would want. Meanwhile, Ralph remains in the ICU for 4 days until he is breathing again on his own and is discharged to another medical unit to regain strength while plans are made to discharge him to a skilled nursing facility.

3. Consequences of Ralph's Advance Directive Not Becoming Part of His Medical Record

Had the attorney provided a copy of the advance directive to the geriatrician for placement in Ralph's medical record, much of this confusion would have been avoided. In addition, had the attorney

encouraged Ralph to have early surrogate involvement and discussion with the children, Jonathan and Rachel would have been more cognizant of his wishes and Larry would have been made aware that he was not appointed as surrogate.

Hospital personnel followed Larry's instructions because there was no advance directive in Ralph's medical record. They had no other choice because they were unaware of Ralph's treatment wishes for this emergency and the only family member available was urging the medical team to "do everything." Thus, the very person Ralph did not want making medical decisions for him gave directions for his care.

Even if the advance directive had been in Ralph's medical record, Ralph's advance directive would have provided little guidance as to his wishes. Although the advance directive would have clarified who is the appropriate surrogate, the vague instructions would have been of limited help to Jonathan. A previous discussion about Ralph's wishes and values would have provided greater guidance. Vague statements such as "when I no longer recognize my family" are of limited assistance without further clarification about who Ralph means by "family" and what "no longer recognize" really means.²⁹

If Ralph had discussed his goals of care with his geriatrician while he was still able to, it is likely that he would have expressed the desire to avoid mechanical ventilation and ICU admission as his dementia advanced.³⁰ Had Ralph involved Jonathan

29 Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34(2) Hastings Ctr. Rpt. 336 (2004).

30 Bertrand Guidet et al., *Effect of Systematic Intensive Care Unit Triage on Long-Term Mortality Among Critically Ill Elderly Patients in France: A Randomized Clinical Trial*, 318(15)

and Rachel in his medical care earlier, as Judy did, the three could have had meaningful discussions with Ralph's medical team on how to deal with such medical scenarios should they arise.

See numbers 3, 4, and 10 in Section III, Lessons Learned.

F. Scenario 6: Ralph Is Admitted to a Skilled Nursing Facility

1. Legal Issues Explored

The family has now reached the point of having to make the painful decision of placing Ralph in a skilled nursing facility. This scenario focuses on (a) the appropriate signatories for the POLST form orders, (b) the surrogate's role in the POLST discussion, (c) the interplay between the advance directive and POLST form orders, and (d) the appropriateness of offering a feeding tube to a client with advanced dementia.

2. Scenario

Judy feels tremendously guilty about placing Ralph in a memory care unit of a skilled nursing facility, but Jonathan and Rachel realize that she can no longer care for him at home. During Ralph's admission, the social worker asked Jonathan and Rachel for a copy of Ralph's advance directive and discussed how much medical treatment they thought he would want. The social worker indicated that they would need to meet with the advanced practice nurse, who is part of the care team at Ralph's nursing facility.

When Jonathan and Rachel meet with the care team, they agree that Ralph would not want CPR but cannot agree on whether he would want to return to the hospital if he became ill or whether

he would want to have a feeding tube placed. Thus, orders for both these options were included on his POLST form, which the advanced practice nurse and Jonathan signed.

3. Changes to POLST Form Orders as Ralph's Health Status Changes

The medical landscape has changed significantly since the POLST program initiative began. As a result, several important changes have occurred in the POLST environment, particularly since the comprehensive POLST review by Wolf and colleagues in 2014.³¹ One of those changes is the growing number of states that permit advanced practice nurses to sign POLST form orders.

The scope of practice for advanced practice nurses has expanded substantially since the early 1990s, when the POLST initiative began, in Oregon.³² At that time, only physicians could write medical orders regarding life-sustaining treatment; thus, the term "physician" was incorporated into the original POLST name when Oregon developed its POLST program. In 2001, advanced practice nurses were authorized to sign POLST forms in Oregon. A growing number of states, including California, West Virginia, and New York, have more recently authorized advanced practice nurses to sign their state's specific version of POLST forms. A study examining more than 25,000 POLST forms completed by advanced practice nurses in Oregon found that by 2015, 11 percent of all POLST forms in the state were being completed by advanced practice nurses.³³

31 Wolf et al., *supra* n. 6, at 71.

32 Pope & Hexum, *supra* n. 5, at 353.

33 Sophia A. Hayes et al., *The Role of Advanced Practice Registered Nurses in the Completion of Physician Orders for Life-Sustaining Treatment*, 20(4) J. Palliative Med. 415 (2017).

A small West Virginia study compared the rate of errors (e.g., failure to date the document) between physicians and advanced practice nurses signing POLST forms. Forms completed by advanced practice nurses had fewer errors than those completed by their physician colleagues.³⁴ Thus, having an advanced practice nurse meet with the family to complete the patient's POLST form is common practice in an increasing number of states.³⁵ As a result, in 2019, Oregon changed the first term of the POLST abbreviation: Physician orders for life-sustaining treatment became *portable* orders for life-sustaining treatment to include advanced practice nurses and physician assistants.³⁶

A second substantive change since the 2014 Wolf and colleagues review is the growing awareness in the medical community that feeding tubes are not effective for patients with advanced dementia. When POLST forms were created in the 1990s, the initial form included four sections: (1) Resuscitation, (2) Scope of Treatment (patient wishes regarding hospitalization, ICU admission, and mechanical ventila-

tor support); (3) Antibiotics; and (4) Artificial Nutrition by Tube. In 2011, Oregon removed the section related to antibiotics, finding that the medications were offered about one-third of the time in the final 60 days of life regardless of the orders on the POLST form.³⁷ An increasing number of states have removed the antibiotic section or never put it on their forms in the first place. In addition, there is no agreement in the medical community on a definition of "antibiotics for comfort," one of the treatment options offered in the antibiotics section of the early versions of the POLST form. Thus, in keeping with the commitment to data-driven quality improvement, it made sense to remove the antibiotics section from the form.³⁸

The section of the POLST form orders about artificial nutrition by tube has come into question more recently. Recent data about the use of long-term artificial nutrition by tube have not shown to be beneficial for those with advanced dementia.^{39 40} Specifically, such treatment does not lengthen life for those with advanced dementia and increases suffering. The rate of pressure ulcers is twice as high (likely due to the use of restraints) in patients receiving artificial nutrition by tube.⁴¹ Increasingly, national medical organizations have recommended against the placement

34 Lori A. Constantine et al., *Nurse Practitioners' Completion of Physician Orders for Scope of Treatment (POST) Forms in West Virginia: A Secondary Analysis of 12 Months of Data From the State Registry*, 30(1) J. Am. Assn. Nurse Pract. 10 (2018).

35 Natl. POLST Paradigm, *New Resource With POLST Form Signature Requirements for Each State* (Mar. 6, 2018), <https://polst.org/2018/03/06/new-resource-with-polst-form-signature-requirements-for-each-state> (accessed May 7, 2019).

36 Oregon POLST, *2019 Oregon POLST Form Summary of Changes Made* (authorized Jan. 2, 2019), <https://static1.squarespace.com/static/52dc687be4b032209172e33e/t/5bbbc8678165f502248927e2/1539033193475/2018.1.0.08+2019+POLST+Form+Summary+of+Changes.pdf> (accessed May 7, 2019).

37 Susan E. Hickman et al., *The Consistency Between Treatments Provided to Nursing Facility Residents and Orders on the Physician Orders for Life-Sustaining Treatment (POLST) Form*, 59(11) J. Am. Geriatrics Socy. 2091 (2011).

38 Oregon POLST, *supra* n. 1.

39 Joan M. Teno et al., *Feeding Tubes and the Prevention or Healing of Pressure Ulcers*, 172(9) Archives Internal Med. 697 (2012).

40 Shao-Hwan Lan et al., *Tube Feeding Among Elders in Long-Term Care Facilities: A Systematic Review and Meta-Analysis*, 21(1) J. Nutrition Health Aging 31 (2017).

41 Teno et al., *supra* n. 39, at 697.

of feeding tubes in those with advanced dementia.^{42, 43}

Artificial nutrition by tube does lengthen life in other medical contexts such as amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease), permanent vegetative state, and stroke resulting in difficulty swallowing. In all these contexts, an informed consent process is completed (often with surrogates) prior to the surgical placement of a feeding tube. However, such placement is never a medical emergency, providing an opportunity to weigh the risks and benefits of the treatment. Medical science is becoming clearer about the lack of benefit of feeding tubes in patients with advanced dementia.^{44 45} As a result, Oregon removed feeding tube orders from the POLST form in January 2019. Other states are also considering removal of these orders from their states' version of the POLST form.

Thus, it was not appropriate for Ralph's medical team to offer Jonathan the option of artificial nutrition by tube for Ralph, considering Ralph's advanced dementia, because it is anticipated that the treatment would increase Ralph's suffering without providing any medical benefit. Because such treatment is used in other situations, the advanced practice nurse could have in-

dicated to Jonathan why feeding by tube for his father would not meet his father's goals of care. Jonathan then would not have to wonder later why tube feeding was never considered as a possible treatment. It was appropriate for Jonathan to choose no CPR, given Ralph's present state of health and the low likelihood of treatment success.

For more in-depth discussion, see numbers 5, 6, and 8 in Section III, Lessons Learned.

G. Scenario 7: Ralph's Life Comes to an End

1. Legal Issues Explored

Despite some unnecessary interventions and some communication glitches along the way, Ralph reaches the end of his life without a final trip to the hospital, at peace with his family. This scenario focuses on (a) the correlation between POLST form orders and place of death, (b) how POLST form orders complement the client's advance directive, and (c) how POLST form orders change to reflect the client's goals of care while still honoring his or her advance directive.

2. Scenario

During the next 6 months, Ralph's cognition declines further. He rarely speaks and no longer recognizes Judy or his children. He is admitted twice to the hospital with pneumonia. He becomes agitated during his second hospital stay, has to be restrained to prevent him pulling out his IV, and develops a pressure ulcer. He is having increasing difficulty swallowing and is losing weight despite careful hand-feeding and supplements.

When not in the hospital, Ralph sleeps most of the time, is passive, and appears to be relatively content. Troubled by his obvious decline, Jonathan and Rachel

42 Am. Geriatrics Socy. Ethics Comm. & Clinical Prac. & Models of Care Comm., *American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement*, 62(8) J. Am. Geriatrics Socy. 1590 (2014).

43 Alzheimer's Assn., *Feeding Issues in Advanced Dementia* (2015), <https://www.alz.org/media/Documents/feeding-issues-statement.pdf> (accessed May 7, 2019).

44 Susan W. Tolle et al., *It Is Time to Remove Feeding Tubes From POLST Forms*, 67(3) J. Am. Geriatrics Socy. 626 (2019).

45 Oregon POLST, *Professional Resource Library*, <https://oregonpolst.org/professional-resource-library> (accessed May 7, 2019).

have heated discussions about Ralph's goals of care. Rachel is concerned about how trips to the hospital have become distressing for her father and thinks he should not be admitted to the hospital if he gets pneumonia again. Jonathan doubts what to do and sincerely wishes he had done more than just sign the advance directive as surrogate. He and Rachel both wish they had talked with their father about his care goals when he was still capable.

Judy quietly shares with Jonathan and Rachel the conversation she had with Ralph about "pulling the plug" if he no longer recognizes his family. A care conference is held at the nursing home, and Jonathan and Rachel decide the focus of their father's care should be completely on his comfort. Jonathan and the advanced practice nurse complete and sign a new POLST form, with orders for "DNR and comfort measures only," and Ralph is enrolled in hospice. Three weeks later, he dies peacefully at the skilled nursing facility with Judy holding his hand.

3. Location of Death

A majority of Americans prefer not to die in the hospital.⁴⁶ States vary substantially in the likelihood of people dying in hospitals, in nursing homes, or in homelike settings and of people receiving intensive care in the final 30 days of life.⁴⁷ Many factors, in addition to advance care planning, are at work in these regional differences, but it appears that differences in patient preferences are not.

Although a randomized controlled trial of POLST use has not been conducted,⁴⁸ multiple studies have shown a strong association between location of death and specific orders on a POLST form — stronger than that seen with an advance directive.⁴⁹ The first study demonstrating a strong association between POLST form orders and reduced deaths in the hospital, conducted in 1995, showed that 5 percent of patients with orders stating "DNR and comfort measures only" died in the hospital.⁵⁰ Subsequent studies in Oregon and West Virginia showed that the rate of in-hospital death of patients with POLST form orders for comfort measures only was substantially lower, 6.8 percent in Oregon and 10.8 percent in West Virginia.^{51, 52, 53} These studies support the use of POLST to turn pa-

46 Amber E. Barnato et al., *Are Regional Variations in End-of-Life Care Intensity Explained by Patient Preferences? A Study of the U.S. Medicare Population*, 45(5) *Med. Care* 386 (2007).

47 Susan W. Tolle & Joan M. Teno, *Lessons From Oregon in Embracing Complexity in End-of-Life Care*, 376(11) *New Eng. J. Med.* 1078 (2017).

48 Kendra A. Moore et al., *The Problems With Physician Orders for Life-Sustaining Treatment*, 315(3) *JAMA* 259 (2016).

49 Sandra L. Pedraza et al., *POST Forms More Than Advance Directives Associated With Out-of-Hospital Death: Insights From a State Registry*, 51(2) *J. Pain Symptom Mgt.* 240 (2016).

50 Susan W. Tolle et al., *A Prospective Study of the Efficacy of the Physician Order Form for Life-Sustaining Treatment*, 46(9) *J. Am. Geriatrics Socy.* 1097 (1998).

51 Alvin H. Moss et al., Ltr. to the Ed., *Physician Orders for Life-Sustaining Treatment Medical Intervention Orders and In-Hospital Death Rates: Comparable Patterns in Two State Registries*, 64(8) *J. Am. Geriatrics Socy.* 1739 (2016).

52 Erik K. Fromme et al., *Association Between Physician Orders for Life-Sustaining Treatment for Scope of Treatment and In-Hospital Death in Oregon*, 62(7) *J. Am. Geriatrics Socy.* 1246 (2014).

53 Dana M. Zive et al., *Change Over Time in the Oregon Physician Orders for Life-Sustaining Treatment Registry: A Study of Two Decedent Cohorts*, *J. Palliative Med.* (2018), <https://doi.org/10.1089/jpm.2018.0446> (accessed May 7, 2019).

tient wishes in advance directives into action as medical orders when patients desire treatment limits.

Jonathan and Rachel did not hold a conversation with Ralph regarding his wishes related to life-sustaining treatment in the event he developed advanced dementia. His advance directive stated and his limited communication with Judy indicated that he did not want life-sustaining treatment if he no longer recognized his family. It is difficult to know exactly when that line was crossed because Ralph had difficulty recognizing family members for some time, yet Jonathan and Rachel continued to authorize hospitalizations, including intensive care. Hospitalizations in those with advanced dementia are often associated with increased agitation and the use of restraints. Such transitions between care settings near the end of life are common and are considered burdensome by family members.⁵⁴

Some attorneys have raised questions about POLST form orders supplanting advance directives.^{55, 56} The completion of POLST form orders does not mean that the orders supplant the patient's advance directive. POLST form order changes are

common near the end of life as a patient's health status changes.^{57, 58}

When the patient has an advance directive, changes to his or her POLST form orders are guided by the advance directive, thus ensuring that the patient's wishes are honored more effectively as his or her health declines. As was true in Ralph's case, a POLST form order is changed not because the patient's wishes as expressed in his or her advance directive changed, but because the patient's health status changed. Thus, the POLST form orders must change in order to apply the patient's wishes to his or her change in health status.

Many frail patients wish to be hospitalized to receive basic medical treatment, not intensive care. As they get sicker (as in Ralph's case, no longer recognizing family members), a change in POLST form orders may be needed to comply with the patient's original goals of care. Patients often desire to have comfort-focused care as they near the end of their lives.⁵⁹ Although it appears that Ralph may have wished to limit trips to the hospital much sooner than Jonathan and Rachel authorized, in the end, his dying peacefully with his wife holding his hand and without life-sustaining treatment appears to align with his original goals.

Some people mistakenly believe that setting limits on specific medical treatment is the same as withdrawing care.⁶⁰

54 Joan M. Teno et al., *Site of Death, Place of Care, and Health Care Transitions Among U.S. Medicare Beneficiaries, 2000–2015*, 320(3) JAMA 264 (2018).

55 Kerry R. Peck & Kyle T. Fahey, *POLST Updates: What Attorneys Need to Know* (Sept. 27, 2018), https://www.americanbar.org/groups/health_law/publications/aba_health_esource/2014-2015/october/polst (accessed May 7, 2019).

56 Cal. Advoc. for Nursing Home Reform, *CANHR Policy Brief: Physician Orders for Life-Sustaining Treatment ("POLST") Problems and Recommendations* (2010), http://canhr.org/reports/2010/POLST_WhitePaper.pdf (accessed May 7, 2019).

57 Dana M. Zive et al., *Timing of POLST Form Completion by Cause of Death*, 50(5) J. Pain Symptom Mgt. 650 (2015).

58 Jennifer Hopping-Winn et al., *The Progression of End-of-Life Wishes and Concordance With End-of-Life Care*, 21(4) J. Palliative Med. 541 (2018).

59 Fromme et al., *supra* n. 52, at 1246.

60 Anna DeForest, *Better Words for Better Deaths*, 380(3) New Eng. J. Med. 211 (2019).

However, one can withhold or withdraw medical treatment and have a complex and extensive plan of care for comfort. A comfort-focused care plan is much more than the absence of specific treatments. It is an extensive care plan that, with the combined efforts of loved ones and the medical team, maximizes the patient's comfort and minimizes his or her physical, emotional, and spiritual suffering. Even though it was not possible for Judy to take Ralph home as he was dying, it was possible for Judy to be present and be supported as she spent her final moments with her dying husband.

See numbers 5, 9, and 10 in Section III, Lessons Learned, which follows.

III. Lessons Learned

Although Ralph died peacefully with Judy by his side, there are lessons to be learned from Ralph and Judy's journey. Their journey could have gone much more smoothly with much less angst and suffering for both Ralph and his family if Ralph's attorney and geriatrician had partnered more effectively with each other and the entire family. Lessons learned from Ralph and Judy's journey follow.

A. Lesson 1

One of the most important actions an attorney can take is to send a copy of the advance directive to the client's health care professional to ensure that it becomes part of the client's medical record. To rely on the client to do this, particularly a client with MCI, is unwise. Had the advance directive been available to Ralph's geriatrician at her next consultation with Ralph, she would have had the opportunity to review the document with Ralph and been able to clarify his wishes and enter his choice of surrogates into his medical record. In addition, the act of the attorney reaching out

to Ralph's geriatrician could have served as an impetus for dialogue between these two professionals as well as for a more in-depth discussion with Ralph himself.

B. Lesson 2

The second most important action an attorney can take is to send a copy of the advance directive to all surrogates appointed in the document. Many states do not require surrogates to sign the advance directive.⁶¹ As a result, many surrogates are not aware that they have been named in the advance directive until it is too late for them to discuss the principal's wishes because he or she lost capacity to engage in such a discussion. Even though Ralph told Jonathan and Rachel that he chose them as his surrogates and they each signed the advance directive, they neither understood the full import of the document nor recognized the need for further discussion. Relying on the client, particularly a client with MCI, to share copies of the advance directive with appointed surrogates is ill-advised.

C. Lesson 3

Sending a copy of the advance directive to the named surrogates without a copy of suggested resources to help them understand their responsibilities is insufficient. Many excellent resources are available that adapt to individuals' different learning styles, health literacy levels, and language and cultural backgrounds.⁶²

Although it may not be cost-effective for all clients, some clients welcome the opportunity to have the attorney meet

61 Charles P. Sabatino, *Overcoming the Balkanization of State Advance Directives*, 46(4) J.L. Med. & Ethics 978 (2018).

62 Natl. POLST Paradigm, *Resource Library*, <https://polst.org/resources/resource-library> (accessed May 7, 2019).

with them and their surrogates to discuss the advance directive and explain what duties are expected of the surrogates. Some attorneys offer an annual “Surrogacy 101” class, inviting clients to bring their surrogates for a general education about the surrogate role. Occasionally, attorneys invite a health care professional to join the teaching team to provide a more directed discussion about medical issues and various health care system challenges.

Had Jonathan and Rachel had the benefit of educational resources that encouraged them to hold conversations with Ralph about his goals of care while he was still able to converse with them, much of the family anguish could have been avoided and Ralph may have been spared some unwanted and uncomfortable invasive interventions.

D. Lesson 4

The attorney should send a copy of the advance directive, with the client’s permission, to all immediate family members not named as surrogates in the advance directive. Had Larry been made aware that he was not named as Ralph’s surrogate after Ralph signed the advance directive, he may not have been happy about Ralph’s choices, but he would have had the opportunity to discuss the situation with Ralph while Ralph still had capacity. This would have enabled Larry to better understand Ralph’s rationale. Also, Larry would have been made aware of his father’s wishes and may have been able to relay this information to the emergency medical team.

The emergency room is not the ideal location for a child to learn that he or she was not chosen as surrogate. It is difficult enough for the chosen surrogate to make immediate serious medical decisions on a loved one’s behalf without having to deal with an upset and angry family member.

It is also not fair for health care professionals to be forced to mediate such conflict when their focus should be on the patient’s needs.

Had Ralph called a family meeting right after he signed the advance directive, Larry would have had an opportunity to ask questions and Ralph could have appealed to all his children to support Jonathan as his chosen surrogate should a crisis occur. Of course, Larry could still have gone rogue, but there would have been less opportunity for him to interfere with his father’s care if everyone involved had been made aware of Ralph’s wishes and his advance directive had been placed in his medical record. If Larry had gone rogue, Ralph’s care could have been referred to the hospital ethics committee for appropriate resolution.

E. Lesson 5

Even though an advance directive is not enough, a POLST form should not be viewed as a replacement for an advance directive. In Ralph’s case, the advance directive, once accessed, provided the valuable service of naming Ralph’s surrogates — the people Ralph chose to make his health care decisions for him in the event of his incapacity. However, his advance directive provided little guidance to the health care professionals and Jonathan and Rachel about his wishes because it was difficult to determine when to act on the vague wishes that he did express.

Ideally, an advance directive should share more detail about a client’s values, wishes, goals of care, and philosophy of life than about specific treatment preferences. It should also provide the surrogate with enough flexibility to nimbly respond to unexpected complexities and circumstances that might occur in the course of an illness. Such an advance directive pro-

vides an excellent springboard for goals-of-care discussions with surrogates and health care professionals and encourages dialogue between the medical and legal professionals. Nevertheless, an advance directive does not provide actionable medical orders. The POLST form is needed to turn the wishes expressed in an advance directive into medical orders. Thus, the advance directive and POLST form orders work together to ensure that the patient's wishes are honored.

If a patient has capacity to discuss goals of care during a health care crisis, as Judy did, it is possible for a POLST form orders to be completed without an advance directive. However, POLST form orders should not be generated in a vacuum without either the patient's input or advance directive. With an advance directive, the health care professional has the security of knowing that he or she is dealing with the surrogate chosen by the patient. In addition, the health care professional is able to guide the POLST discussion on how to apply the patient's wishes, values, goals of care, and philosophy of life when selecting the best treatment options given the patient's current health care status. Although not ideal, a POLST form may be completed for an incapacitated patient with no advance directive or named surrogate. In this case, the surrogate would be established by state laws and/or regulations.⁶³

F. Lesson 6

A patient should never feel pressured into completing a POLST form.⁶⁴ Ralph's geriatrician was correct in dealing gently

with Ralph concerning his MCI diagnosis. Rather than launching into a discussion about POLST, she urged him to get an advance directive. Forcing Ralph into a POLST discussion after he received his diagnosis would have been inappropriate. At the time, Ralph was probably too healthy to have a POLST form. A POLST form is designed for individuals with an advanced illness or frailty in which death is likely in the foreseeable future. Signing a POLST form too early may cause a patient harm even if he or she agrees to full treatment of his or her illness.⁶⁵

A POLST form with the orders "attempt CPR" and "full treatment" does not change the care the patient will receive. Emergency medical services automatically provide these treatments in a crisis to all patients, both those with and those without POLST form orders to the contrary. Unfortunately, a POLST form with these orders "attempt CPR" and "full treatment" may give the appearance that a thoughtful goals-of-care conversation took place with the patient. And a POLST form with out-of-date orders may increase the decision-making burden on the family.

POLST form completion should never be mandated or counted as a quality measure in a health care system. Regardless of any financial or other incentives offered, it is a mistake for health systems to use the number of POLST forms completed as a quality measure.⁶⁶ In addition, POLST form completion should not be an automatic part of the "Welcome to Medicare" preventive visit because this

63 Natl. POLST Paradigm, *POLST Legislative Guide* (Feb. 28, 2014), <http://polst.org/wp-content/uploads/2017/02/2014.02.20-PO-LST-Legislative-Guide-FINAL.pdf> (accessed May 7, 2019).

64 Sabatino, *supra* n. 4, at 60.

65 Susan W. Tolle & Joan M. Teno, *Counting POLST Form Completing Can Hinder Quality*, Health Affairs Blog, (July 19, 2018), <https://www.healthaffairs.org/doi/10.1377/hlblog20180709.244065/full> (accessed May 7, 2019).

66 *Id.*

encourages premature POLST form use in older adults who are “too healthy to have one,” and bases the POLST form orders on hypothetical circumstances in the future rather than on an individual’s current health status. The POLST form is most effective for making critical care decisions that are likely to be encountered in the here and now. In addition, premature use of the POLST form may affect the patient’s ability to obtain life insurance,⁶⁷ with underwriters falsely believing the patient has a limited life expectancy. For all these reasons, an advance directive is generally the more appropriate document for relatively healthy older adults.^{68 69}

G. Lesson 7

The choice of “DNR” and “limited treatment” orders on a POLST form is not necessarily contradictory.⁷⁰ After learning the dismal survival rates of out-of-hospital cardiac arrest, Judy prefers DNR if she is discovered not breathing and without a pulse. Even though she declines intensive care and mechanical ventilator support, considering these interventions as burdensome and potentially nonbeneficial, Judy still wishes to be hospitalized if she experiences another cardiac event. She is not yet ready to choose comfort measures only.

Such treatment limitations are especially important from a medical perspective because decisions often have to be made quickly. Data from the Oregon POLST Registry shows clearly that other treatment wishes cannot be predicted by merely knowing the patient’s desire to avoid

CPR.⁷¹ The data also show that POLST form orders are not only about a person’s desire to limit treatment, but they are also about honoring a person’s wishes to receive selected types of treatment. Many patients choose a middle ground,⁷² and it is important to realize that critical illness is not necessarily the equivalent of the end of life.

H. Lesson 8

Education is needed about the ineffectiveness of tube feeding for the 86 percent of patients with advanced dementia who develop eating problems.⁷³ Research shows that tube feeding is of little benefit to those in the advanced stages of dementia; in fact, research has even shown potential for harm, with an increased rate of agitation and pressure ulcers.⁷⁴ Nevertheless, the option is frequently offered to families whose loved ones have advanced dementia, just as it was offered to Jonathan on Ralph’s behalf.

Reasons for offering feeding tube treatment include false beliefs in its effectiveness to achieve a goal of care (e.g., prolonged life, wound healing, comfort) and the complicated underlying symbolic religious/cultural beliefs related to food. For example, in one study, 74.6 percent of physicians believed erroneously that a feeding tube would offer improved healing of a pressure ulcer, yet pressure ulcers occur twice as often in those with feeding tubes, likely due to the use of restraints.⁷⁵

Were families better informed about the natural progression of dementia as an illness, they would be able to understand

67 *Id.*

68 *Id.*

69 Sabatino, *supra* n. 4, at 60.

70 Terri A. Schmidt et al., *Physician Orders for Life-Sustaining Treatment (POLST): Lessons Learned From Analysis of the Oregon POLST Registry*, 85(4) Resuscitation 480 (2014).

71 Fromme et al., *supra* n. 52, at 1246.

72 Schmidt et al., *supra* n. 70, at 480.

73 Susan L. Mitchell et al., *The Clinical Course of Advanced Dementia*, 361(16) *New Eng. J. Med.* 1529 (2009).

74 Teno et al., *supra* n. 39, at 697.

75 *Id.*

and be prepared for the time when the patient experiences swallowing difficulties. It is not simply a decision to feed or not to feed. It is a realization that the disease has reached its terminal stage and that there are better ways to ensure the patient's comfort.

Elder law attorneys should understand the natural trajectory of dementia, partner with health care professionals, and encourage the use of decision aids in educating families about the course of the illness. Attorneys should also be aware of the research on the lack of feeding tube utility for those with advanced dementia in order to help surrogates understand why this intervention may not meet the patient's goals of care. They also should know that patients with advanced dementia live just as long with careful hand-feeding. Hand-feeding enables tender social interaction between caregiver and patient, provides person-centered care, respects food preferences, encourages family routine, and promotes a pleasant environment. The close contact inherent in hand-feeding has the potential to help people build relationships with patients with dementia near the end of life and increase the quality of their lives.^{76, 77}

H. Lesson 9

POLST form orders work. Despite Ralph's convoluted journey as his dementia increased, Ralph's advance directive was ultimately honored because he did not receive any unwanted interventions at

the end of his life when he no longer recognized his family. Ralph's POLST form translated his wishes into orders for DNR and comfort measures only, allowing him to die peacefully in his skilled nursing facility.

POLST form orders do guide care, as shown by Ralph's story and by clinical research.⁷⁸ For example, studies in Oregon and West Virginia showed that those who chose "DNR and comfort measures only" had significantly decreased odds of attempted resuscitation and increased odds of having an out-of-hospital death.^{79 80} Because of the strong association between POLST form orders and location of death, POLST form orders reduce unwanted transitions of patients (e.g., transfer from home to the hospital). Where a person dies strongly influences how he or she dies.⁸¹

I. Lesson 10

Good advance care planning is a process, a product of teamwork that takes place over a lifetime. Ralph and Judy's scenario reveals that documents alone are not enough. Honoring their wishes involved much more than pieces of paper. Ongoing discussions about a plan of care are vital.

Completing an advance directive should not be considered a one-step process. Also, POLST form orders are not static. Both documents require updates as a person's health status, values, or living situation change. Much depends on good

76 A.M. Wren & S.R. Bloom, *Gut Hormones and Appetite Control*, 132(6) *Gastroenterology* 2116 (2007).

77 Eric J. Palecek et al., *Comfort Feeding Only: A Proposal to Bring Clarity to Decision-Making Regarding Difficulty With Eating for Persons With Advanced Dementia*, 58(3) *J. Am. Geriatrics Socy.* 580 (2010).

78 Jean Abbott, *The POLST Paradox: Opportunities and Challenges in Honoring Patient End-of-Life Wishes in the Emergency Department*, 73(3) *Annals Emerg. Med.* 294 (2019), <https://doi.org/10.1016/j.annemergmed.2018.10.021>.

79 Moss et al., *supra* n. 51, at 1739.

80 Zive et al., *supra* n. 53.

81 Fromme et al., *supra* n. 52, at 1246.

communication and trust. Had Ralph's attorney elicited more discussion from him concerning his preferences for future care and performed the simple task of directly providing a copy of Ralph's advance directive to his geriatrician and surrogates, Ralph may have been spared unwanted transitions and suffering. At each stage in life and each change in health condition, a person's overall philosophy may remain the same, but his or her evolving medical condition may change what orders are needed to honor his or her goals of care.

As death approaches, changes in treatment preferences often occur. Updating the POLST form to reflect changing circumstances ensures that the patient's wishes embodied in his or her advance directive are honored. This is more likely if good communication and teamwork

occurs among the client, attorney, surrogates, and health care professionals.

IV. Conclusion

POLST form orders, when used appropriately, function much like a trust protector does for a trust. It ensures that the client's intent, the client's wishes as expressed in an advance directive, are consistently honored despite changing circumstances. Rather than usurping the advance directive, the POLST form order functions as the co-pilot, translating the patient's wishes into actionable medical orders near the end of life to preserve the patient's autonomy. Attorneys collaborating with health care professionals toward a common goal of honoring client's and patients' wishes is a worthy aspiration.

Coming together is a beginning, keeping together is progress, working together is success.

— Henry Ford