

Northwest Geriatrics Workforce Enhancement Center
2022 Spring ADRD Geri Series

Advance Care Planning (ACP)
From Intent to Actionable Orders
That align Treatment Desired with Treatment Delivered

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or just to get even

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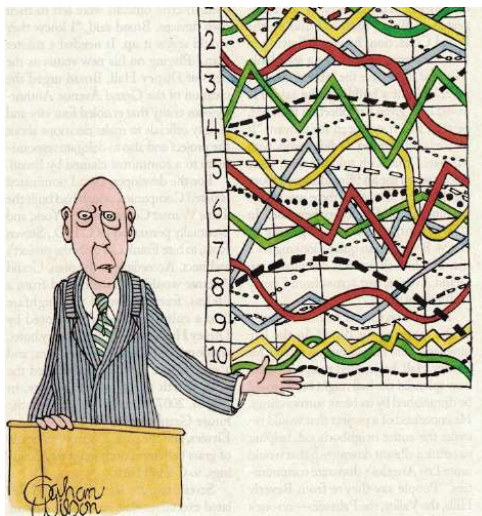
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My goals are to:

- 1) Remind you about the importance of ACP..
- 2) But devote the bulk of my presentation to the pragmatics of delivering this essential service. I will pay little attention to the research b/c IMHO studies in this area tend to be relatively weak and often inapplicable.

I hope you will create an ACP Toolkit by printing references 1, 2, and 3, and the slides with green writing.

Special thanks to the Swedish/Edmonds Ethics Committee and to Stephen Thielke with whom I did much of the work I will describe.



I will present the model of ACP that I have developed over the past 25 years. It is one of many options—but the one that I have found to be very effective.

The essence of my approach was described as follows by my friend Anatol Broyard, in his wonderful book: *Intoxicated By My Illness*.

I want my doctor to be “one who is a close reader of illness and a good critic of medicine...who is not only a talented physician, but a bit of a metaphysician, too,,, [one who is able to] go beyond the science into the person...imagine the loneliness of the critically ill...I want him to be my Virgil, leading me through my purgatory, or inferno, pointing out the sights as we go,” xv

ACP should be an intense, collaborative contact that benefits pt and HCP. I consider it a gift when pts allow me to share this critical moment in their lives.

US Evolution of Patient Autonomy

- US Constitution grants the right to privacy, that includes actions performed on one's body.
- The Fourteenth Amendment protects citizens against state interference.
- 42 U.S. Code § 1983 gives patients recourse if rights violated
- Congressman McDermott cosponsored the **PATIENT SELF DETERMINATION ACT**, enacted as part of the Omnibus Reconciliation Act of 1990 (P.L. 101-508).
 - This gave patients the right to stipulate the type of EOL treatment they want to undergo and required hospitals to record these requests
- **SEC. 4206. MEDICARE PROVIDER AGREEMENTS ASSURING THE IMPLEMENTATION OF A PATIENT'S RIGHT TO PARTICIPATE IN AND DIRECT HEALTH CARE DECISIONS AFFECTING THE PATIENT.**

Grants right to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives... and document in the individual's medical record
- **RCW 70.122.030 Directive to withhold or withdraw life-sustaining treatment**

Any adult person may execute a directive directing the withholding or withdrawal of life-sustaining treatment in a terminal condition or permanent unconscious condition

Since pts have the lawful right to create an AD and have it respected, with any failure to do so risking ethical, moral, legal and civil penalties.

Is ACP worth the effort? Well-done it helps pts:

1. Think about how they want to live until they die;
2. Accept the inevitable so they don't miss the chance to achieve a sense of completeness or coherence about their lives;
3. Understand options in EOL care while they can think clearly so they can choose treatments wisely;
4. Relieve their loved ones of the need to make decisions that can cause never-ending guilt; and
5. Avoid potentially family-destroying conflict about what could or should have been done

If you have delved at all in this area you know that

70% say they want to die at home—BUT

60% die in a hospital, nursing home, or long-term care facility

80% say that, if seriously ill, they would want to discuss EOL care—BUT

Only 7% said they fully discussed EOL care with their doctors

82% say it is important to put their wishes in writing BUT

Only 23% have done it (fewest in ethnic communities)

60% say it is important not to burden their families with tough decision

BUT very few ever do

Why doesn't every patient have an AD and why isn't every AD honored?

ACP has received some undeserved very bad press lately

Comparing patients who did and did not have ADs, there was no difference in the concordance of what they want and what their surrogates say they want.

There was also no discernible impact on real-time medical decision-making at the end of lif., ie, it does not reliably produce goal-concurrent care.

However, the authors acknowledge that this is partly due to deficiencies in the healthcare system, not ACP. (1) Patient care is often oriented around the system's culture and processes, rather than orienting the system around the patients' needs. (2) We don't as a society really have the capacity to support the needs and wishes of what people really want

Norrison RS, Meier DE, Arnold RM. What's Wrong With Advance Care Planning? JAMA. 2021;326(16):1575-1576. doi:10.1001/jama.2021.16430

Contributing to the problem, some HCWs say..

1. ADs are often vague, too long, or unavailable when needed. **True**, but correctable via the model offered today
2. Creating them is an undue burden on HCWs who are overworked. **True**, but it is a practical, moral, ethical, and legal necessity. It can be done efficiently, or if necessary, delegated to volunteer facilitators.
3. ACP is a "check box" exercise. **True** if done poorly: **False** if done properly. Creating ADs is very impactful inter-personal process that helps to humanize medical care for providers, pts, and significant others.



4. As Ulysses contracts, they are viewed as binding patients to choices made when they are healthy that may not be what they want when they are ill.

False. Decisions can be revised often as pts' conditions and preferences evolve

Do any of these self-justifications apply to you? I am..

1. Not trained, therefore uncomfortable doing it?
2. Not sure it is important to offer it?
3. Under too much time pressure to do it?
4. Prone to view pt death as failure or an option rather than a natural event—therefore avoid discussing it?
5. Uncomfortable with contemplating and planning for my own decline—how can I ask anyone else to do it?
6. Prone to believe pts don't want to discuss dying?
7. Committed to avoiding contentious discussions, eg. if pt wants what I regard as a futile intervention, if my plan differs from what my colleagues suggest, or if family members have strong differing perspectives

**WE WILL ADDRESS THESE ISSUES TO HELP YOU TAKE ACTION.
ACP IS FINE! IF DELIVERED SKILLFULLY.**

Framing the challenge

American healthcare does often sell pts short

Whether viewed as an end, transition, or even a beginning,

(Please don't blame me) but we will all die—
and the odds are that we will do it only once.

Since the way we die is in some way the ultimate summary of our lives and punctuates our legacy, it is important to do it right.

Unfortunately, many people die later than they want, others sooner.

Pursuit of a “Good Death” Drives ACP

In western cultures, a good death is defined as one that:

- Preserves personal dignity,
- Is free from excessive pain,
- Avoids or harmful treatments that delay death at high personal, social, and economic cost,
- Allows achievement of spiritual and emotional peace of mind, and
- Allows families to avoid unnecessary stress.

Steinhayuser KE et al. Ann Intern Med. 2000;13(2):825-832

But this is not universally accepted due to religious and cultural perspectives, eg, some welcome pain at the end. To each his own!
Since it is impossible to control every detail, It is probably best to seek “good enough” deaths.

Why are “good-enough” deaths elusive?

EVERYONE has an AD, often without knowing it.

This is due to an inherent, omnipresent, under-the-radar bias in healthcare that treats death as an enemy or even an option to be avoided rather than an inevitability that often can be managed to some extent

For example, among its many flaws, the bias is evident in the title of the widely-used POLST:

Portable Orders for Life-Sustaining Treatment

2021 Washington State Training Curriculum For EMS Providers

In fact, the majority of those asked want comfort vs. aggressive care when the quality of their life falls to a point at which living is viewed as more problematic than dying and want to use their AD to limit rather than expand their treatment.

Language often used is similarly biased!

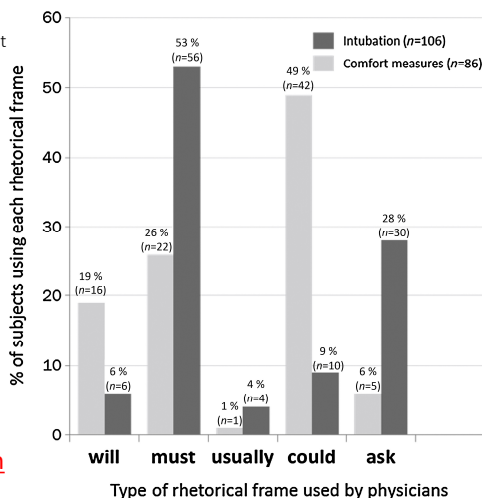
Well designed study of 106 emergency, hospitalist and intensivist MDs.
Mohan et al J Pal Med. 2015 18(9)
doi.org/10.1089,jpm.2015.0089

Life sustaining tx presented as required, paliative care as optional.

Prob with using research:

Can we generalize from small convenience sample in 3 midwestern hospitals to MDs in general?

Best to use literature as source of hypotheses to be tested in each situation



**The Operating Guideline for most:
hospital staff, 1st responders, and ethics
committees is:**

When in doubt....

Make the most reversible error:

Often by doing more, rarely less

**That's OK if you want more, but not if
your idea of a good enough death
involves less invasive treatment**



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 SWEDISH MEDICAL CENTER

ADVANCE DIRECTIVES AND CPR PREFERENCE

Clinical Policy and Procedure	
Approved: June 2013	Next Review: June 2016
Clinical Area: All clinical areas	
Population Covered: All patients	
Implementation Date: February 2002	

Related Policies/Procedures:

- Bloodless Program: Adult
- Code Blue: Cardiac/Respiratory Arrest in the Operating Room
- Conditions of Admission Form and Consent
- Management of Resuscitation Preferences
- Patient Rights

Purpose

To define the process for facilitating communication between patients and licensed independent practitioners (LIP) in order to obtain appropriate individualized care orders concerning Advance Directives and resuscitation.

Policy Statement

All patients who have a cardiac or respiratory arrest are resuscitated unless LIP orders to *not* resuscitate are obtained. If a patient is classified as "Do Not Resuscitate" (DNR), the attending LIP enters the resuscitation status order. Verbal resuscitation orders must be dated and signed or electronically authenticated by signature of the LIP within 24 hours. Until the resuscitation status order is obtained, all patients are considered full code. The Resuscitation Order Sheet is completed by the LIP, including identifying with whom (patient or legal next-of-kin) he/she discussed the orders. (See also Medical Rules and Regulations, Section 11.1 (Resuscitative Measures).)

If the patient arrives to a Swedish Medical Center (SMC) facility and provides a completed Physician Order for Life-Sustaining Treatment (POLST) form, these orders will be honored for up to 24 hours or until the content can be reviewed and converted into a resuscitation status order by the attending LIP or his/her designee.

Upon inpatient admission, all patients or their surrogates are also asked by nursing staff whether they have Advance Directives and/or have expressed wishes concerning cardiopulmonary resuscitation (CPR) or other care issues in order to develop an individualized plan of care that accurately reflects the patient's wishes. For patients who indicate they have an advance directive, but did not supply it, the patient is asked again within 36 hours for a copy.

No employee, hospital volunteer, attending physician, or physician's employee will act as a witness for any patient executing Advance Directives.

Clinical Policy/Procedure: ADVANCE DIRECTIVES AND CPR PREFERENCE
© 2014 Swedish Health Services Page 1 of 6

Unless pt is receiving palliative or hospice care,
organized medicine is often a juggernaut

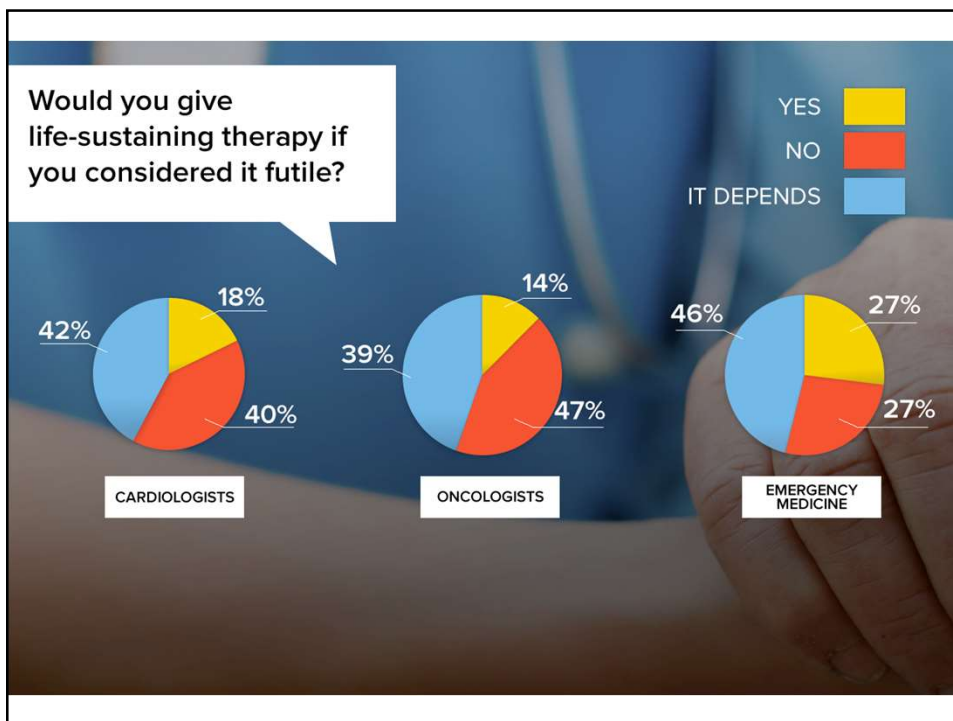
Each move deeper into the
healthcare delivery system-- brings
an escalation in the intensity of care

(Hart et al, 2015 JAMA Intern med. 175(6):1019-1026), at least
25% of which is of low value (Schwartz, 2014.

JAMA Intern Med. 174(7);1067-1076).

Excessive medical care includes:

1. Over-diagnosis and treatment of conditions that will never cause symptoms or death,
2. Over-use of treatment supported by limited evidence of benefit for specific conditions,
3. Use of treatment that is excessive in complexity, duration, impact, or cost relative to alternative accepted standards,
4. Use of treatments that are considered **futile**.



We pay dearly for what we don't want

More than 27% of Medicare budget is spent on fragmented and uncoordinated care for patients in their final year, 78% of this in the final month (Nakhoda, 2010). In the year before they died, 1.8 Medicare beneficiaries who died in 2008, 31.9% underwent major surgery, 18.3% had a major inpatient procedure in the last month of their lives (Kwok 2011)

US health care expenses exceed all 33 countries in the Organization for Economic Cooperation and Development—25% of GDP in 2015, and as the population ages and costs rise, 37% in 2045, 49% by 2082

Out-of-pocket costs >25% of baseline total house assets, 43% of non-housing assets, and are linked to 59% of personal bankruptcies

And that money and effort bought 30,000 iatrogenic deaths/year (Emanuel, 2002), **staff burnout** and moral and ethical distress as well as **low patient and survivor satisfaction**

Some causes of routine over-treatment

1. Fear of litigation
2. Rigid adherence to traditional practice protocols
3. Attention to narrow outcome vs. systemic effects
4. Failure to understand the power of palliative care
5. Economic incentives for institutions and providers
6. Inherent in the language used with patients

And the reasons we're here—

1. **patients' failure to exercise their right to choose, and**
2. **HCP's failure to motivate them to do so**

Pragmatics of ACP: Two templates needed

1. OPTIMAL-True ACP when relaxed thoughtful discussion is possible. Allow 45- to 90 minutes.
 - Help pt develop a perspective about coping with dying and death
 - Teach pt how to collect and evaluate the information they will need
 - Facilitate completion of a living will that includes a statement of pts' values and preferences,, eg. using 6-Steps, draft a CMO or MOELI that will be discussed and signed by person authorized to enter medial orders, and guide the appointment and preparation of a surrogate
 - This may involve follow-up contacts as pt's condition or preferences change or for yearly review.—a valuable opportunity for health promotion
2. CRISIS-when the pressure of a progressive life-threatening condition demands immediate action. Can normally be completed in 10-15 minutes with decision-capable patients.
 - Help pt stipulate values and goals
 - Draft a CMO or MOELI
 - Hopefully inform the surrogate about patient's wishes

All ACP discussions should be:

- **private**
- **free of distractions**
- **unrushed**
- **facilitative**
- **nonjudgmental, and**
- **should include major stakeholders if possible, (given that the power of an AD is greatly influenced by surrogate's skill in promoting it)**

Evaluate any barriers to pts' taking action

Physical health issues

Delirium

Inability to maintain orientation, eg. intractable pain

Mental health issues

Moderate to severe depression and/or anxiety

Poor executive ego functions (perception, judgment, reasoning)

Social pressures

Opposition to planning for death by family, significant others

Religious opposition to tampering with God's will

Any of these factors may require attention before attempting ACP

Preparation for these discussions is essential

1. PLEASE DO NOT OFFER ACP UNTIL YOU HAVE COMPLETED YOUR OWN LW, and CMO or MOELI. And, If possible, also help a relative or friend create one.
2. Understand the nuances of the physical, psychological, social, and spiritual trajectories toward death—i.e. rarely linear, usually gradual trending down with some s-t ups
3. Acquire the skills need to retain equanimity in challenging clinical environments. (If we're not calm, pts cannot be)
4. Learn the pros and cons of all likely measures including: (a) their treatment burden, (b) their short and long-term effects, and (c) their role in the sequence of probable ensuing procedures.

(See Appendix 2-prompt sheet for CMO)

APPENDIX 2
Prompts for Discussing Resuscitation, Oxygenation, ANH

Procedure/elements	Benefits	Harms
Resuscitation • 100-120 chest compressions/minute 2.0 to 2.5 inches deep As needed: • Electric shock to control fibrillation • Injection of epinephrine, • Oxygen via endotracheal tube or another device	• Can restore spontaneous circulation depending on co-morbidity ... • and prior condition • 15-30% chance of survival until hospital discharge	Possible treatment burden • Rib fractures • Lung contusions • Hematomas • Visceral and/or cardiac complications Possible long-term harms • Brain damage if not begun quickly or poorly delivered • Survival may require other invasive interventions
Oxygenation Routine options • Nasal cannula • Continuous airway pressure • CPAP • Bilevel positive airway Pressure (BiPAP) More invasive options • Extracorporeal membrane Oxygenation (ECMO) • Intra-aortic mechanical ventilation (ITV)	• Maintain oxygen access during and/or following surgery • Maintain blood/oxygen saturation during severe pulmonary illness	Possible treatment burden • Dry mouth/Inability to speak • Pain requiring sedation Possible long-term harms • Pressure ulcers • Musculoskeletal problems • Irreversible organ damage • Inability to be extubated
Artificial Nutrition and Hydration • Nasogastric tube • Catheter placed in central or peripheral vein • Tube inserted into stomach or small intestine surgically, endoscopically, or radiologically	Nutrients and fluids short- or long-term- • Following stroke or other head injury • Permanent vegetative state • Extreme short bowel syndrome • Amyotrophic lateral sclerosis	Possible treatment burden • Sepsis and ear infections • Dysphagia • Tube dislodgement and clogging • Insertion site infection • Aspiration • Agitation • Poor nutrition • Prolonged sedation to prevent tube removal due to discomfort
Voluntary cessation of eating and drinking • Termination of all forms of tube- and hand-delivered nourishment • Acceptance of only ice chips and lotions for comfort	• Depending upon organ condition, euphoria within 3 days, death normally within 3-10 days • Continued IV medication for pain control, comfort	• Possible discomfort prior to euphoria
Patient accurately describes resuscitation ___ Yes Understands its place in likely sequence of treatments ___ Yes Conditions for use:	Patient accurately describes ventilation ___ Yes Understands its place in likely sequence of treatments ___ Yes Conditions for use:	Patient accurately describes ANH ___ Yes Understands its place in likely sequence of treatments ___ Yes Conditions for use:

Discussions are more coherent if you are aware of your own belief about coping with serious illness. Here's mine:

Four requirements of successful coping with crises:

1. **Luck**—biological, situational, or socio-economic-cultural
2. **Radical acceptance**—without which risks are ignored and defensive options missed
3. **Social support**—to double-check perceptions and receive necessary assistance
4. **Solution-** vs. **emotion-focused coping**—attention paid to goal-oriented strategies without undue time spent on self-pity or self-reproach.

We can't offer luck (though we can teach risk-reduction), but we can teach and reinforce 2,3,4

As one way to access pts' cultural perspective, ask about their understanding of the role of hope

HOPE as **cognition** is expectation

HOPE as **emotion** is faith

Both are critical in radical acceptance

Cognition: critical in defining the challenge

Emotion: critical to accepting and acting on the definition incorporating the outcome

But as a drug **hope** should must be taken in moderation lest it become toxic

Hope can be **life-enhancing**—

Buddist proverb: The man who believes all roads lead to doom is surely doomed. We must have some optimism to try new things.

---**But it can also be life-ending**

Chinese proverb: The hungry man who stands with his mouth open hoping that a roast duck will fly into it will die a hungry man.

(Many therapy patients want to continue failing treatments, hoping for a better outcome)

Best to broaden hope beyond cure to include achieving meaning and closure as life draws closer to its inevitable end.

ACP is a goal-oriented, interpersonal process

1. Always show respect, concern, patience
 2. Do not preach or cajole! ADs are purely voluntary and pts have the right to decline. "If not now, perhaps we can discuss it at another time when we know more about your condition."
 2. Break the ice: Say a few words about yourself to humanize the process—but not about your EOL preferences., eg. "It was hard for me to do this alone: I hope to make it easier for you."
 3. GET TO KNOW YOUR PATIENT—NEVER PREJUDGE ON THE BASIS OF AGE WHICH OFTEN LEADS TO CONDESCENDING THAT WILL OFFEND PT. Ask the patient to say a few things about him/herself to become known as a person vs. "the patient in 8-E-103b" or "a dying cancer patient", eg. "my passion has been golf" (which allows you to use golf metaphors, eg. "we have to tee up your eol care".)
- See suggested protocol, Appendix 1, COM33. Step 3 in 6-Steps Living Will.
www.6stepslivingwill.org

Be prepared to address resistance before asking patients to make choices

1. Many patients are skeptical about providers motives when asked to complete ADs—eg. fear being manipulated
Explain that entering a hospital that is predisposed to "do everything" without an AD is equivalent to throwing the break pedal out the window when careening down a very steep winding mountain road. Your values and goals are the steering wheel: your AD the break.
2. Many patients believe that their doctors should make the decisions because they are not competent to do so.
Explain that while their doctors are experts on the facts, pts are the experts on their goals and values. As part of the process, you will help them learn enough facts to ask intelligent questions and make sound decisions consistent with their values and goals.
3. Many patients are apprehensive about committing in advance to mechanistic dichotomous decisions.
Explain that by using conditional orders, they retain the flexibility needed for sound decision making,

Other pt misgivings about ACP eg.,....

4. General phobia about dying and death, which, when addressed, is often couched in distracting euphemisms, eg. "passing" "Think of death as a stage in the cycle of life"
5. Sense of powerlessness due to not understanding the language, system, metrics (eg. "odds ratio" and polysyllabic drug names) "Your voice is your power, and ethics committee can amplify it if necessary"
6. Preference to rely on divine intervention: desire not to resist God's will "Hard to know whether prolonging life with artificial means accepts or rejects God's will"
7. Distrust of the medical system and providers, particularly those of different race or ethnicity. "Worst care likely if pts ignore or conflict with their providers."

Begin the process with reassurance:

Some people are confused: they think that the decisions they are about to make pertain to them as they are now.

1. Explain that these decisions will influence care **ONLY** if very ill with a terminal illness and unable to communicate...
2. And that the decisions can be changed at any time as long as the patient retains capacity.
3. Also—explain that the CMO/MOELI model creates flexibility so decisions are not mechanical

Depending on available time: **Sample questions for framing discussion of EOL intervention—choose a few**

- What do you think it is important for me to know about you as a person?
- What are your core values concerning a good life?
- What is left for you to achieve your life goals?
- How does your health status affect your ability to take these steps?
- What constitutes a good day for you?
- What is your understanding of your health now and in the future?
- What kind of care would you like if your health worsens?
- Do you think the available treatments will make a difference?
- Do the potential benefits of these treatments outweigh their costs?
- What tradeoffs are you willing to make in planning treatment?
- What do you think is the best way to die?
- How can we help you have a good enough death?

Patient name: _____	Age: _____	Gender: _____	Primary provider: _____	Date: _____
If possible, sit at eye level with the patient, introduce yourself, stating your role, and verify patient's name. Address patient formally, i.e., Mr, Ms, Dr, etc. and not by first name.				When possible, prepare by learning Primary illness:
Establish parameters for this discussion e.g. "We are here to discuss your preferences for critical care". If time constrained, "I wish we had more time, but I must meet my next patient in XX minutes and I do not like to keep my patients waiting".				Concerns/obstacles
Ask if patient is willing to allow surrogate to participate. If so, invite participation.				Name: _____ Contact info: _____
If this is a first contact, ask patient to tell you a few things that will help you understand him/her as a person. If second or later contact, ask if there are any changes patient thinks you should know about. Thank patient for being forthcoming.				Personal details
Ask if patient has an advance directive, POLST, MOBEI, or other form. If so, ask whether the form reflects their current preferences and whether it would be helpful to review preferences concerning resuscitation, ventilation, ANH.				___POLST ___Date ___MOBEI ___Date Full vs. Limited vs. ___Comfort ___
"Please tell me your major goal, e.g. longevity vs. quality of life, avoid pain or loss of independence, and other concerns, e.g. religion/spirituality etc."				___Longevity ___QoL ___Pain ___Religion/Spirituality ___Autonomy
"To be sure that I understand you, I would like to tell you what I heard. Is this accurate? Is there anything else you would like me to know?"				___Treatment Burden ___Other
"I would like to explain the meaning of some of the terms we will be using. Pitching the discussion to the patient's apparent level of health literacy. Define the terms "full treatment", "limited treatment" and "comfort care only" and explain their meaning. Then ask the patient to state how he/she defines the terms. Correct any misunderstanding. Then do the same for CPR, ventilation, and ANH.				Concerns? Inaccuracies? Full treatment Limited treatment Comfort care only
"Please look at this CMO which lays out the decisions we are about to make." Begin with general goals and state patient's choice. Then, using the Prompt List in Appendix 2 as a guide, describe CPR, ventilation, and ANH including potential benefits and harms again pitching the discussion to patient's apparent level of understanding. Add that "Medical language is hard for most people to understand so I understand so please tell me if any of the terms are unfamiliar to you".				CPR Ventilation ANH
Give this information, what actions are you considering. Discuss patient's reasoning and suggest possible mitigation of any negatives anticipated. Assess patient's capacity to understand this discussion.				Concerns
Now the hard part: Would you like to do this always? Sometimes—and if so under what conditions? or never? List contingencies if any.				1 ___ACPR ___DNAR X ___DNAR ___W ___V C ___DNH ___ANH ___ANH X ___DNANH ___VCED
Report the patient's preferences, then explain the likely outcome of each. If patient's preferences conflict with standard medical practice, discuss the implications. Once you are confident that the patient understands, complete the CMO, sign it, and ask patient and, if present, the surrogate to sign.				
Ask if the patient would like you to create and enter the orders, with the assurance that they can be changed as the patient wishes as long as she/he has the capacity to do so. If possible, offer to give the patient a copy of the signed CMO.				Where entered: EMR this institution Other: _____
If the surrogate is not present, ask the patient who might speak for him/her if he/she doesn't have the capacity to speak for him/herself and suggest that the patient describe their goals and preferences to verify that they are understood and will be respected. Encourage patient to share copies of these documents with surrogate and significant others.				

Our goal is to work within the spectrum of patients' beliefs as much as possible.

But if a core belief is premised on false information, we may have to respectfully provide facts that conflict with truths that pts hold dear, best done via questions eg. "did you know that"? Or "what's your response to someone who..?"

Very useful tool—(b/c it describes vs. categorizes)
Appendix C: A multicultural Tool for Getting to Know You and What Matters to You. pp, 347-9
Fulmer, T et al: Age-friendly Health Systems..

Research on religious, racial, ethnic resistance

Review of 33 (mostly weak) studies yet in my favorite resource—UpToDate

Non-White racial or ethnic groups generally lacked knowledge of ADs and were less likely than Whites to create advance directives.

African Americans were consistently found to prefer the use of life support distrusting "the system" that they fear will deny them adequate care--although this may be changing-

Von Scoy LJ, et al. Low skepticismJ Gen Intern Med. 2020 DOI: 10.1007/s1606-020-06224-z

Asians and Hispanics were more likely than other racial or ethnic groups to prefer family-centered decision-making.

***Variations within groups existed and were related to subcultural values and level of acculturation

<https://www.uptodate.com/contents/advance-care-planning-and-advance-directives/abstract/40>

Avoid stereotypes: treat pt as a unique person

Recalling what you learned in research 101—

Nomothetic data sets describe group tendencies.

Because members of groups differ in many ways, one cannot make **idiographic** predictions from group data.

Also, because much of this research is flawed—lacking theory, uses convenience samples, and non-standardized measures etc. its conclusions are at best hypotheses.

Use group data as guides to questions, the answers to which reveal important characteristics of individuals.

See: Stuart, R.B. (2004) Twelve practical suggestions for achieving multicultural competence. *Professional Psychology: Research and Practice*, 35, 3-9.

Stuart, R. B. (2005) Multiculturalism: Questions, not answers. *Professional Psychology: Research and Practice*. 36, 574-575.

**ADs are legal documents:
pts must have capacity to create them**

Capacity refers to an *ability, a clinical determination: it is issue- and time-specific*

Competence refers to a *property* or characteristic a person possesses and is a *judicial determination. It is a general, lasting inability.*

Default assumption is that patients and surrogates have the capacity to make informed judgements at key decision points in EOL planning.

Providers should facilitate capable decisions

- Before deciding patients lack capacity to make a particular decision, appropriate steps must be taken to enable them to make the decision themselves.
- For example:
 - Could information be explained or presented in a way that is easier to understand e.g. by using simpler words, a different language, or different visual or auditory format?
 - Could anyone else help with communication, such as a family member, chaplain, translator, etc.?
 - Are there particular times of day when the individual's understanding is better, eg. avoiding "sundowning" with the aged?
 - Are there particular locations where the individual may feel more at ease and be less distracted?
 - Does the patient have all the necessary relevant information?

Providers must reveal the--

- **Diagnosis and prognosis**
- **Nature and character of the contemplated treatment**
- **Treatment burden and risks of the treatment**
- **Prospect for success**
- **Place of treatment in sequence of interventions**
- **Similar facts about each alternative treatment**
- **Likely result if the patient remains untreated**

For their part, patients must be able to:

- Be aware of the need to make a decision
- Recognize facts and needed information
- Receive, recall, and comprehend information
- Communicate and digest preferences
- Foresee likely consequences
- Process data rationally
- Make and sustain a decision

These abilities all depend upon capacity

The “big 4” in capacity evaluation

UNDERSTANDING diagnostic and treatment related information, including the ability to attend, encode, comprehend, state and restate words and phrases accurately

APPRECIATION-- determine the personal significance of treatment information, including insight, benefits, and foresight about its potential impact

REASONING—compare alternatives in light of their consequences, including the ability to articulate reasons applicable to the patient’s life situation

EXPRESS A CHOICE—make and communicate a decision and repeat that decision over time

Four often overlooked considerations

1. Capacity-relevant issues can arise both when making **new** treatment requests but also when attempting to **modify** existing requests
2. *REMINDER*: The capacity of the patient and **surrogate** should be assessed
3. **Gender**: men avoid asking questions and often express more understanding than they have to avoid appearing weak. Therefore, extra effort may be needed to verify men's understanding.

4. Providers are prone to question capacity if patients **refuse** a treatment that providers believe is warranted—which may be correct. BUT patients may lack also capacity if they **accept** treatments that providers recommend although may not be in their best interest.
CAPACITY IS INDICATED LESS BY THE CONTENT OF A DECISION THAN BY THE PROCESS OF MAKING IT

To verify patients' understanding, ask:

- What is wrong (the diagnosis)?
- What treatment has been proposed?
- What are the risks and possible complications of this treatment?
- What alternative treatments have been proposed, with their possible risks and complications ?
- What would be the consequences if you refuse the treatment?
- (Franklin & Rosenbloom, 2000).
- Also, please restate your goals for treatment?

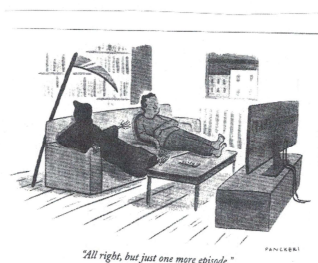
Protocol for the Assessing Patient Capacity to Accept or Refuse Medical Procedures
A. If there are clinical concerns, use tools to assess cognitive functioning with minimally invasive, easily scored instruments (like the MoCA and MMSE). Alert staff to patients whose decision-making capacity may be questionable.
B. Assume that patients have capacity unless there is strong evidence to the contrary. Assess capacity in situations when (1) patient requests a medically questionable procedure, or (2) the patient refuses a medically necessary procedure.
C. Assess the patient's ability to participate in the evaluation: free of delirium, effects of drugs, preoccupation with pain or illness, or experiencing extreme emotional distress. If the patient is unable to participate, attempt to delay assessment until this condition passes. If patient is unable to participate, and an urgent decision is necessary: (1) consult advance directives; (2) contact a surrogate or closely interested parties; (3) search patient's medical record to identify similar decisions in the past; (4) request ethics committee consultation.
D. Choose a private setting free of distractions. Time permitting, learn something about patient's background and culture. Establish rapport and explain the purpose of the evaluation. Evaluate the patient's (1) hearing, (2) vision, (3) linguistic fluency, (4) health literacy, and (5) numeracy. Take any practical steps that can overcome the deficiency. Solicit the patient's consent to the evaluation. If the patient refuses, and a decision is critical, follow protocol in C above.
Carry out the assessment, taking care not to bias the patient's decision-making process:(1) Explain your assessment of the patient's condition and its expected course. (2) Ask the patient to share his or her understanding of the condition, the way it is likely to develop, and which intervention the patient believes would be useful. (3) In as much detail as is appropriate, describe the probable benefits and risks of proposed treatment options including palliative care as an adjunctive or primary method. Use decision aids if helpful. (4) Ask the patient to choose a treatment approach and explain the reasoning that led to the choice including a summary of its potential benefits and harms of each. (5) To verify the patient's understanding of multiple options, request an explanation of the reasons for rejecting the option(s) not chosen, including palliative care. (6) Repeat the choice and its expected benefits and harms and ask patient to verify that you understood his or her decision.
E. If the evaluator is uncertain about patient's capacity, or decides that the patient lacks capacity to make a critical decision with major consequences: (1) consult a qualified peer or mental health professional; (2) request assessment by another evaluator; and/or (3) administer a standardized interview-based instrument, e.g. ACCT or MacCAT-T.
F. Record the results of the assessment in the patient's medical record, using verbatim responses when possible.

Record of Capacity Evaluation		
Patient Name:	Registration #	Date:
Reason for evaluation, by whom requested		
Illness, health status		
Patient status—check if apply: <input type="checkbox"/> Delirious. <input type="checkbox"/> Drug impacted. <input type="checkbox"/> Distracted by pain, etc.		
Explain:		
Could evaluation be delayed?		
If not: <input type="checkbox"/> AD available <input type="checkbox"/> Surrogate contacted <input type="checkbox"/> Medical record review. <input type="checkbox"/> Ethics consult		
Verify patient: <input type="checkbox"/> Hearing. <input type="checkbox"/> Vision <input type="checkbox"/> Language. <input type="checkbox"/> Health literacy. <input type="checkbox"/> Numeracy		
Any accommodation offered?		
Did patient consent to evaluation? Yes. <input type="checkbox"/> No <input type="checkbox"/>		
If no—action taken: <input type="checkbox"/> Relied on surrogate. <input type="checkbox"/> Ethics consult. <input type="checkbox"/> Other		
Description of treatment, options, effects provided:		
Summary of patient responses (see verbatim notes for details). How well did patient show:		
	Key word(s)	Level:
Understanding		High Moderate Low
Appreciation		High Moderate Low
Reasoning		High Moderate Low
Choice expressed <input type="checkbox"/> Yes. <input type="checkbox"/> No. State choice: _____		
Accurately repeated <input type="checkbox"/> Yes. <input type="checkbox"/> No		
List tests administered, with results		
Conclusion		
Discussed with patient <input type="checkbox"/> Yes. <input type="checkbox"/> No. Accept finding <input type="checkbox"/> Yes. <input type="checkbox"/> No		
Discussed with surrogate <input type="checkbox"/> Yes. <input type="checkbox"/> No. Accept finding <input type="checkbox"/> Yes. <input type="checkbox"/> No		
Explain		
Finding entered into patient EMR. <input type="checkbox"/> Yes. <input type="checkbox"/> No		
Evaluator. Print name.	Signature	Date
Observer. Print name	Signature	Date

Time permitting, help build health literacy

1. Ask questions!!!—e.g. "What would this test tell us?" And "How would that information impact my treatment?"
2. Always ask about drug interactions for new rxs
3. Learn how to get the facts, eg. web search skills
4. Prior to agreeing to major procedures, advise seeking 2nd opinions, ideally from a provider working at a different facility
5. Never forget TINSTAFL, eg. Test-to-Treat at drug store

6
FINALLY!!!



Guidelines for Creating an AD

Essence of advance directives

They describe the conditions one considers minimally acceptable standards for *living*

Some people believe the quantity of life matters--life is good in and of itself

Others believe that life below a certain quality is not worth living

Living wills let PATIENTS decide

ADs clarify values, basis of medical orders

Which form to use? Many LW forms are user friendly, but--

1. most are vague
2. and incomplete

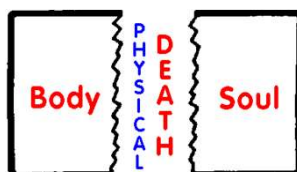
At present, only 6-Steps, CMO, and MOELI offer:

1. conditional orders and
2. access to a full range of options

STEP 1: Clarifying Values

Values are the core structural elements of the way each person finds and assesses meaning in life, dying and death.

Religious and/or spiritual values vary widely.
 For many, not all, body and soul are split at death:
 the way they die impacts the fate of their souls



Step 1. Thinking about Your Values and Preferences

Expressing your values and preferences is an important first step toward your being able to make decisions with which you can be comfortable in the future. The following statements are designed to help you begin to think about your values and preferences for end-of-life care. Please add others that occur to you while considering the choices below.

For each pair of statements below, pick the one closest to your beliefs, even if both have some truth.

X	COLUMN A	OR	X	COLUMN B
	I believe it is my religious and/or spiritual duty to do everything I can to stay alive as long as possible.			My religious and/or spiritual beliefs do not require me to do everything I can to stay alive as long as possible.
	I believe in miracles and I hope that one can cure me if I am dying.			I do not believe that a miracle will cure me if medical care fails.
	I believe my life has value and should be prolonged regardless of its quality.			I do not want my life prolonged if: _____ I lose my identity, cannot think clearly, and cannot communicate with others. _____ I cannot control my bodily functions and must depend on machines or other people. _____ I have very severe pain that cannot be controlled and that prevents my enjoyment of life. Other? _____ _____ _____
	I want to live as long as possible and do not care about the level of suffering and incapacity before my death.			I prefer to die a little earlier if doing so allows me to die with dignity.
	I want all life-prolonging treatments, even if there is less than a 1% chance of success.			I want only those treatments that have a good chance to restore my functioning.
	Economic cost and burden on others, should NOT be considered when planning my end-of-life care.			Economic cost and burden on others, SHOULD be considered when planning my end-of-life care.
	I believe that doctors always know best and I should not question their advice.			I will consider my doctors' advice when I make my own treatment decisions.
	It is too hard for me to decide now so I will leave decisions to my family or others.			I will make these decisions now so I will not burden my family with guessing what I want later.



Step 2. Personal Statement

A **meaningful life** is one that has a sense of purpose, that has significance according to some standard, and makes coherent sense to the person. Finding meaning is a primary motivational force in humans.

(Frankl, 1985, Man's search for meaning...)

Personal statements help pts articulate the meaning of their lives, their values, treatment goals and preferences, and the criteria for each scope of treatment.

Moving to the operational details of an AD.
imagine you are the first EMT on site and you see Harold's POLST with a DNR on the fridge

55 year old Harold's POLST stipulates no CPR because he wants to avoid the rigors of a prolonged painful death. But while gardening, he was stung by eight wasps and suffered anaphylactic shock from which he will die unless resuscitated.

Would you do CPR? Or let him die?

Moral and ethical risks of alternatives?

APPENDIX D: Sample POLST Form

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY			
Washington POLST Portable Orders for Life-Sustaining Treatment A Participating Program of National POLST	LAST NAME / FIRST NAME / MIDDLE NAME/INITIAL		
	DATE OF BIRTH / /	GENDER (optional)	PHONENUM (optional)
This is a medical order. It must be completed with a medical professional. Completing a POLST is always voluntary. IMPORTANT! See page 2 for complete instructions.			
MEDICAL CONDITIONS / INDIVIDUAL GOALS:		AGENCY INFO / PHONE (if applicable)	
A Use of Cardiopulmonary Resuscitation (CPR): When the individual has NO pulse and is not breathing. CHECK ONE <input type="checkbox"/> YES - Attempt Resuscitation / CPR (choose FULL TREATMENT in Section B) <input type="checkbox"/> NO - Do Not Attempt Resuscitation (DNR) / Allow Natural Death			
B Level of Medical Interventions: When the individual has a pulse and/or is breathing. CHECK ONE Any of these treatment levels may be paired with DNR / Allow Natural Death above. <input type="checkbox"/> FULL TREATMENT - Primary goal is prolonging life by all medically effective means. Use intubation, advanced airway interventions, mechanical ventilation, and cardiocirculation as indicated. Includes care described below. Transfer to hospital if indicated. Includes intensive care. <input type="checkbox"/> SELECTIVE TREATMENT - Primary goal is treating medical conditions while avoiding invasive measures whenever possible. Use medical treatment, IV fluids and medications, and cardiac monitor as indicated. Do not intubate. May use less invasive airway support (e.g., CPAP, BIPAP, high-flow oxygen). Includes care described below. Transfer to hospital if indicated. Avoid intensive care if possible. <input type="checkbox"/> COMFORT-FOCUSED TREATMENT - Primary goal is maximizing comfort. Relieve pain and suffering with medication by any route as needed. Use oxygen, oral suction, and manual treatment of airway obstruction as needed for comfort. Individual prefers no transfer to hospital. EMS: consider contacting medical control to determine if transport is indicated to provide adequate comfort. Additional orders (e.g., blood products, dialysis):			
C Signatures: A legal medical decision maker (see page 2) may sign on behalf of an adult who is not able to make a choice. An individual who makes their own choice can ask a trusted adult to sign on their behalf or clinician signature(s) can suffice as witnesses to verbal consent. A guardian or parent must sign for a person under the age of 18. Multiple parent/decision maker signatures are allowed but not required. Virtual, remote, and verbal consents and orders are addressed on page 2.			
Deceased with: <input type="checkbox"/> Individual <input type="checkbox"/> Parent(s) of minor <input type="checkbox"/> Guardian with health care authority <input type="checkbox"/> Legal health care agent(s) by DPOA-HC <input type="checkbox"/> Other medical decision maker by 7.70.065 RCW		SIGNATURE - MEDICIAN/PA-C (mandatory)	DATE (mandatory)
SIGNATURE(S) - INDIVIDUAL OR LEGAL MEDICAL DECISION MAKER(S) (mandatory)		RELATIONSHIP	DATE (mandatory)
PRINT - NAME OF INDIVIDUAL OR LEGAL MEDICAL DECISION MAKER(S) (mandatory)		PHONE	
Individual has: <input type="checkbox"/> Durable Power of Attorney for Health Care <input type="checkbox"/> Health Care Directive (Living Will) Encourage all advance care planning documents to accompany POLST.			
SEND ORIGINAL FORM WITH INDIVIDUAL WHENEVER TRANSFERRED OR DISCHARGED			

The POLST offers dichotomous CPR/DNR option just one of its many short-comings

1. Asks for medical condition that may be unknown in advance and in the same space, asks unstructured question about patient goals
2. Does not validate evaluation of capacity
3. Asks about additional orders with no structure and very little space
4. Does not offer hold blameless clause
5. As mentioned earlier, has a biased title

Medical orders are hallowed: don't create any that are expected to be violated in some circumstances

Also, many pts refuse ADs that have mechanistic stark dichotomies.

Medical Orders for End-of-life Intervention (MOELI)

MOELI is a set of medical orders that guide medical treatment based on a person's current medical condition. ** It is voluntary. **MOELI supplements but does not replace a living will. **Patient and/or legal surrogate must participate in its completion, jointly where possible. ** Patients can accept or refuse treatment as long as they have capacity; MOELI used only when patients cannot decide for themselves. **Before acting in these orders providers must verify the patient's health status, i.e. frailty, diagnosis, and life expectancy.

Patient name Last _____ First _____ Middle _____

Date of birth: _____ Last 4 SSN _____ Gender: ___M___F___ Other (specify) _____

A. Reason for MOELI _____ 80 or older _____ Extremely frail _____ Death likely in 12 months _____
Terminal illness(es) (specify) _____

<p>B. MOELI discussed with:</p> <p>___ Patient _____> Yes ___ No ___ Not assessed</p> <p>___ Spouse _____> Yes ___ No ___ Not assessed</p> <p>___ Domestic partner _____> Yes ___ No ___ Not assessed</p> <p>___ Other (who)? _____> Yes ___ No ___ Not assessed</p> <p>___ Legal guardian _____> Yes ___ No ___ Not assessed</p> <p>___ Parent of a minor _____> Yes ___ No ___ Not assessed</p> <p>Use* for participants who have DPOAH _____</p> <p>If patient did not participate, reason: _____</p>	<p>C. Legal capacity, health literacy, numeracy</p> <p>___ Yes ___ No ___ Not assessed</p> <p>___ Yes ___ No ___ Not assessed</p> <p>___ Yes ___ No ___ Not assessed</p> <p>___ Yes ___ No ___ Not assessed</p> <p>___ Yes ___ No ___ Not assessed</p>	<p>D. Does patient have a living will? _____ Yes ___ No</p> <p>If yes: Date: _____</p> <p>Was it discussed in creating the MOELI? ___ Yes ___ No</p> <p>If living will exists attach it to, and forward with this MOELI.</p> <p>If no, did you encourage patient to create one. ___ Yes ___ No ___ N/A</p>
--	--	--

E. Patient's goal

___ I wish to live as long as possible. Please prolong my life using all reasonably practical means.

___ I wish to live a meaningful life. Please use life supports as long as I am able to communicate and think clearly and my pain is controlled.

___ I wish to experience a natural death. Please do not use artificial means to prolong my life.

F. Cardiopulmonary Resuscitation (CPR)

___ DO resuscitate any time my heart stops beating

___ DO resuscitate only if my heart stopped due to a temporary, correctable event

___ DO NOT resuscitate or use defibrillator under any circumstance; Always allow natural death.

G. Medical Intervention

Full Treatment to prolong life by all medically effective means. Includes transfer to hospital or skilled nursing facility, resuscitation, ventilation, hydration and nutrition by tube, dialysis, all forms of breathing assistance, antibiotics and all other recommended procedures, drugs, and surgery.

___ Always ___ For a trial period of: _____

Limited Treatment to treat medical conditions that avoids burdensome methods. Includes transfer to hospital or skilled nursing facility, resuscitation, fluids and nutrition by tube, and medication including antibiotics and other drugs to relieve pain and symptoms, noninvasive breathing aids, but no surgery.

___ Always ___ For a trial period of: _____

Comfort-focused treatment to maximize comfort. Includes medication to relieve pain and suffering, breathing enhanced with oxygen, suctioning and other means of clearing airways, and positioning for comfort. Does not include resuscitation or other life-prolonging procedures such as fluids and food by tube or dialysis. May include transfer to a hospital or skilled nursing facility if needed for comfort including pain relief.

Additional orders on reverse: ___ Yes ___ No

H. OPTIONAL. I hold blameless any provider who honors the requests herein in a manner that meets the community standard of care, and I direct my healthcare representative to do the same. (Patient's initials) _____

I. Signatures. MOELI is valid only if signed by provider and patient and/or participating surrogate

<p>Name of person who helped patient complete MOELI if other than provider below:</p> <p>Provider _____</p> <p>I verify that this document reports patient's wishes</p> <p>Print Name: _____</p> <p>Signature: _____</p> <p>Physician ___ ARNP ___ NP ___ PA-C _____</p> <p>Date: _____</p> <p>e-mail: _____</p>	<p>Patient</p> <p>Print Name: _____</p> <p>Signature: _____</p> <p>Date: _____</p> <p>Phone: _____</p> <p>e-mail: _____</p>	<p>Surrogate</p> <p>DPOAH? ___ Yes ___ No</p> <p>Legal Guardian? ___ Yes ___ No</p> <p>Signature understands and agrees to represent patient's preferences.</p> <p>Name: _____</p> <p>Signature: _____</p> <p>Date: _____</p> <p>Phone: _____</p> <p>e-mail: _____</p>
--	---	--

SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Photocopies and faxes of signed MOELI forms are legal and valid.
For more information visit: [List contact information for issuing organization](#)

Conditional Medical Order

Please enter in my medical record

Patient _____ Date of birth _____

ID/Record number _____

Patient demonstrated sufficient capacity: ___X___ Yes

Patient health-literacy sufficient to understand decision: ___X___ Yes

As a context, my general goal is—(For clarification, if needed, see my Final Statement and 6-steps Living will dated 1/2/21)

___ To live as long as possible regardless of the quality of my life—therefore I want all potentially helpful treatments.

___X___ I want to try a limited course of treatments only as long as there is a reasonable chance of my being able to live a life I value, be able to function at the college graduate level, able to independently manage my health, function, and able to recognize and converse soberly with others. It is unlikely that I can retain the quality of life I desire. I would like comfort care only.

___ To die naturally—therefore I want comfort measures only to allow natural death. I would rather make the mistake of missing to comfort care too soon than risk waiting to long that my functioning deteriorates below the quality of life I am willing to lead.

Options for Conditional Resuscitation Orders

___ ACPR: DO attempt resuscitation any time I suffer cardiopulmonary collapse.

___X___ DNAR-X: DO NOT attempt resuscitation EXCEPT in the event of cardiopulmonary collapse due to an event that has reversible effects in the opinion of providers at the scene.

___ DNAR: DO NOT attempt resuscitation if I suffer cardiopulmonary collapse regardless of the cause. Comments: _____

Options for Conditional Ventilation Orders

___ AV: DO Always ventilate by any means for any duration recommended

___X___ IMV-C: Use invasive ventilation methods ONLY on the conditions that it is needed for resuscitation or for the treatment of an acute event with reversible effects. OTHERWISE: use non-invasive ventilation as needed.

___ DNI: DO NOT ventilate if the sole purpose is to delay my death from an irreversible terminal illness. Provide oxygen via non-invasive canula only for comfort.

Comments: _____

Options for Conditional Artificial Nutrition and Hydration Orders

___ AANH: ALWAYS administer ANH by any method for any duration as recommended.

___X___ NH-X: DO NOT administer ANH EXCEPT for a short time to achieve a specific goal.

___ DNANH: DO NOT administer ANH. Provide nutrition and hydration orally only, accepting my refusal of either or both.

Additional option that can be chosen along with ANH-X or DNANH

___X___ V-CED: Accept my voluntary cessation of eating and drinking, making me as comfortable as possible while awaiting death. Do not attempt to provide food or liquid orally other than ice chips of lozenge for comfort.

Comments: _____

My wishes regarding Medical Aid In Dying (MAID)

If I suffer from a terminal condition that meets the legal requirements of MAID, I wish to be offered this benevolent service. If the provider(s) treating me do not offer this service, or the institution in which I am being treated does not permit it, I wish to be transferred immediately to a provider or institution that will honor this carefully-considered request.

I hold blameless any provider who honors this order in good faith. YES ___ RRS ___ Initial NO ___ Initial

Physician, RN, ARNP, or PA-C Date _____	Date _____
Patient _____	Date _____
Surrogate _____	Date _____

One more case to test your ideas

The POLST that Alex, age 33, completed stipulates full treatment including CPR. Alex suffered massive head trauma in a rock-climbing accident and is believed to have lost control of all bodily functions including the ability to communicate. He spent his life engaging in high-risk outdoor activities and often said that he goes “nuts” when he is away from the mountains for longer than a day or two. He has no pulse and or respiration. Resuscitation would mean that he could spend decades intubated, pegged, and catheterized, etc., probably with restraints to prevent his reflexive removal of the tubes. **Would you do CPR? Explain your decision.**

Same questions about Edith

75-year-old Marth’a POLST stipulates that she does not want CPR. She has just seen a PCP who prescribed an SSRI to improve her sleep, without realizing that she was already taking two other SSRIs prescribed by different doctors. Her husband called 911 when she collapsed in the bathroom that evening. Seeing the POLST, should the first responder honor the DNR and allow her to die because of a medical error or disregard the POLST and resuscitate?

Explain your decision..

Important to discuss the realities about dying at home

Most people say that they want to die at home, but doing so is often is very different than the Norman Rockwell image,

Incapacitating illnesses often require:

- Invasive management of bodily functions that undermines dignity
- Administration of technically challenging intervention
- Up to 24/7 continuous monitoring
- Exhausting physical assistance

Caregivers often experience

- Severe physical strain and fatigue—the 36 hour day
- Emotional distress
- Lost income
- Considerable expense if home health aides are employed
- Woefully inadequate Medicare funding despite saving vs hospital costs.**

A Drutchas, et al Health Affairs Forefront

2022 DOI: 10.1377/forefront.20220309.591082

Although the wish to die at home may be universal, pts should be encouraged to consider the costs to all concerned.

Patients should also be informed about Palliative Care

- Affirms living and dying as natural processes
- Neither hastens nor postpones death
- Provides relief from distressing symptoms
- Integrates physical, psychological, social and spiritual dimensions of care
- Serves patients and their significant others as a functional system

Major racial and ethnic disparities in access

Study of access to palliative care nationally in SNFs found...

Compared to Caucasians, Blacks and Hispanics were significantly less likely to be offered palliative care, a particular problem b/c Blacks tended to be admitted in considerably worse condition

- Estrada. LV, Harrison JM, Glick AW et al. Examining regional differences in nursing home palliative care for black and Hispanic residents, J Pal Medicine. 2022. Published on line. DOI. 10.1089/jpm.2021,0416

Palliative Care Requirements

Kelley NEJ 2015;373:747-755

Table 2. Palliative Care Domains and Recommendations from the National Consensus Panel Guidelines.*

Domain	Key Recommendations
Structure and processes of care	Interdisciplinary team, comprehensive interdisciplinary assessment, education and training; relationship with hospice program
Physical aspects of care	Pain and other symptoms are managed with the use of best practices
Psychological and psychiatric aspects of care	Psychological and psychiatric issues are assessed and managed; grief and bereavement program is available to patients and families
Social aspects of care	Interdisciplinary social assessment with appropriate care plan; referral to appropriate services
Spiritual, religious, and existential aspects of care	Spiritual concerns are assessed and addressed; linkages to community and spiritual or religious resources are provided as appropriate
Cultural aspects of care	Culture-specific needs of patients and families are assessed and addressed; recruitment and hiring practices reflect the cultural diversity of the community
Care of the imminently dying patient	Signs and symptoms of impending death are recognized and communicated; hospice referral is recommended when patient is eligible
Ethical and legal aspects of care	Patient's goals, preferences, and choices form basis for plan of care; the team is knowledgeable about relevant federal and state statutes and regulations

* Adapted from the National Consensus Project for Quality Palliative Care.²

Differentiate Palliative vs. Hospice Care

Kelley NEJ 2015;373:747-755

Table 1. Palliative Care as Compared with Hospice.*

Characteristic	Palliative Care	Hospice
Model of care	Interdisciplinary team, including physicians, nurses, social workers, chaplains, and staff from other disciplines as needed; primary goal is improved quality of life	Interdisciplinary team, including physicians, nurses, social workers, chaplains, and volunteers, as dictated by statute; primary goals are improved quality of life and relief of suffering (physical, emotional, and spiritual)
Eligibility	Patients of all ages and with any diagnosis or stage of illness; patients may continue all life-prolonging and disease-directed treatments	Patients of all ages who have a prognosis of survival of ≤6 mo, if the disease follows its usual course; patients must forgo Medicare coverage for curative and other treatments related to terminal illness
Place	Hospitals (most common), hospital clinics, group practices, cancer centers, home care programs, or nursing homes	Home (most common), assisted-living facilities, nursing homes, residential hospice facilities, inpatient hospice units, or hospice-contracted inpatient beds
Payment	Physician and nurse practitioner fees covered by Medicare Part B for inpatient or outpatient care; hospital teams are included within Medicare Part A or commercial insurance payments to hospitals for care episodes; flexible bundled payments under Medicare Advantage, Managed Medicaid, ACOs, and other commercial payers	Medicare hospice benefit; standard hospice benefit from commercial payers is usually modeled after Medicare; Medicaid, although coverage varies by state; medication costs are included for illnesses related to the terminal illness

* ACO denotes accountable care organization.

Dementia Advance Directive—

since 50% will die with dementia.

<https://static1.squarespace.com/static/5a0128cf8fd4d22ca11a405d/t/60c51d29f5c2833ef87698d1/1623530793274/dementia-directive.pdf>

NOTE dementia almost always progresses so tiered choice advise

Mild-short-term mem loss, routine tasks difficult, > drive risk

Moderate <communication, < understanding, prob self-care, > agitation, confusion, paranoia

Severe < recognize others, agitation, day/night reversal, angry, disruptive. need 24/7 care

To live as long as I can full effort w CPR

To receive tx to prolong life, but DNR and DNI to allow peaceful death

Comfort-focus only-9-tx pain, anxiety, breath-less, hosp for comfort only

Step 4: Creating a DPOA

Power of attorney: RCW 11.94 and *In re Guardianship of Hamlin*, Washington Supreme Court (1984)

- Appoints an “agent” or “attorney-in-fact” to make specific health care decisions on his or her behalf if pt lacks capacity to act independently at the time
- Pt must have capacity to sign a DPOA
- Durable power that authorizes someone to act if pt lacks capacity to do so independently—and cannot be revoked by an incapable pt.
 - Very powerful: delegates authority to do almost everything pt can do for her/himself except change a will, beneficiary, designations.
 - Includes authority to “pull the plug”
- **REMEMBER: DPOA is supplemental. The individual retains decision making authority and can overrule surrogate.**

Patients with dementia at particular risk

A recent review of research in 12 countries found: **Even if pts had a DPOA** “There was a clear, although unwritten, implication that the primary decisions were made families and health care professionals, rather than patients with reduced agency.”

This is understandable given that many people with dementia wanted trusted family members to make decisions on their behalf, preferred not to discuss dying and death, or acquiesced to avoid conflict with families or doctors.

Birchley G, et al. Dying well with reduced agency. *BMJ Medical ethics*. 2016;17:46

CMO, MOELI to the rescue!

Who Can Make a Substituted Decision?: RCW 7.70.065

Statutory hierarchy of possible decision-makers:

- Patient
- Court-Appointed Guardian
- Attorney-in-Fact or DPOA agent
- Spouse or Domestic Partner
- Adult Children
- Parents
- Adult Siblings

The following may not be surrogates for a given patient:

: Any of the pt's physicians

- Employees of the physicians
- Owners, administrators or employees of the health care facility where the resident resides or receives care --unless he or she is also a relative, such as a spouse, domestic partner, adult child or sibling

Patients should be helped to select surrogates wisely

Not all surrogates and family members are alike. Regarding shared decision-making, they vary in...

how well they know the pt

their ability to understand what they are told

the level of time they will devote to fact gathering & decision-making

their ability to control their own biases

the nature of their attachment to the seriously ill pt

ability to manage the emotional strain ie. resilient

likely reaction to the stress of contributing to discussions of high-pressure decisions (some suffer PTSD).

Only 6-Steps allows pts to designate people they do not want involved

DURABLE POWER OF ATTORNEY FOR HEALTHCARE®

Declaration made this ____ day of _____ (month), 20 ____

I, _____, having the capacity to make healthcare decisions, willfully and voluntarily wish to identify the person and/or people I have chosen to represent me if I temporarily or permanently lose the capacity to make healthcare decisions for myself. If I regain that capacity, I wish to reassert my own right to make decisions pertaining to the treatment that I receive.

1a. I appoint as my **PRIMARY Healthcare Representative**

Name: _____
 Address: _____
 Email: _____ Phone(s): _____
 Relationship to me: _____

1b. If the above named individual is not available to act on my behalf, I appoint the following person as my **ALTERNATE Healthcare Representative**

Name: _____
 Address: _____
 Email: _____ Phone(s): _____
 Relationship to me: _____

1c. If neither of the above named individuals is available to represent me, I authorize my healthcare providers to contact, in order, the following substitute decision-makers as approved for this purpose by the jurisdiction in which I am receiving care i.e. my spouse or domestic partner, my adult children, my parents, and/or my adult brothers and sisters.

Name	Relationship	Phone
1. _____	_____	_____
2. _____	_____	_____

1d. I do not want the following people to participate in planning my end-of-life care.

Name	Relationship
1. _____	_____
2. _____	_____

2. I grant my representative(s) complete authority to make decisions consistent with my stated wishes with regard to starting, refusing, stopping, and/or removing all forms of medical, mechanical, and surgical intervention. I herewith hold my representative(s) blameless for good faith efforts to honor my preferences.

3. If my healthcare representative is unsure about what to decide, I want him or her to please (check ONE):

____ ignore such doubts and act on my Living Will as written OR
 ____ make the best decision he or she can in the face of uncertainty OR
 ____ discuss the situation with my doctor, family members, and/or spiritual advisors named below,
 then use his or her best judgment and after considering their opinions.

Doctor(s) Name: _____
 Family Members Name: _____
 Spiritual Advisor Name: _____

4. I do ____ Do Not ____ (choose ONE) want this decision-making authority to extend to decisions that are made after my death with regard to autopsy, organ donation, and the handling of my remains.

5. I instruct my healthcare providers to release to my representative(s) any information about my medical condition, possible treatments, and prognosis pursuant to the attached HIPAA authorization for release of information.

6. This agreement supersedes and replaces any and all formerly executed Durable Power of Attorney Healthcare documents.

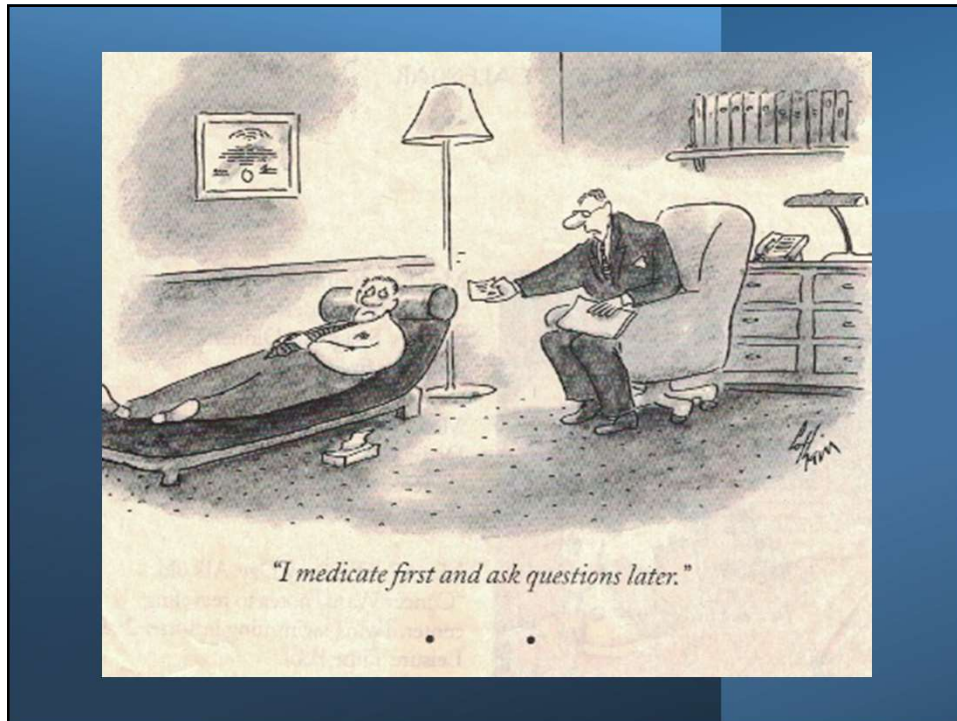
Sign only in the presence of witnesses: Signed this ____ day in the month of _____, 20 ____

Signature: _____ Print name: _____

Page 1 of 2. Please initial.

Questions to verify surrogate's understanding

- **1. What did you hear me request?**
- **2. If you were in my condition which treatment would you choose for yourself.**
- **3. How do the choices you would make differ from those I have made?**
- **4. Did I direct you to limit choices to terms in my AD or do you have the right to present others?**
- **5. How would you respond if a provider or significant other urged you to override my choices?**
- **6. Have you said everything you think it is important for the surrogate or significant others to know, i.e. any loose ends?**



Step 5: Patients' and HCWs' best friend

Typically, first responders will know little to nothing about the patients they are summoned to treat.

Even patients' providers, who may have panels of >2,000 patients and little time for chart review, may recall very little to nothing about the person sitting or lying opposite them. Including tx they provided.

By completing and regularly updating Step 5, and presenting it at each encounter, patients can take a major step toward appropriately individualized, appropriate intervention.

Summary of Important Information to Give to Your Provider
Please place this information in my medical chart.

- Name _____ Date of Birth: _____
- I do have a Living Will, dated _____ Please add my Living Will to my medical record.**
- As a reminder, here are three things I consider to be important for you to know about me:
 - _____
 - _____
 - _____
- My healthcare representative (surrogate) is:

Name: _____ Phone: _____ E-mail: _____

Address: _____
- I am currently: Married _____ Living with a Domestic Partner _____ Living with others _____ Living alone _____
 Name of my spouse or partner: _____ Phone: _____ E-mail: _____
 My partner's address (if not my surrogate): _____
 I Do _____ Do Not _____ (choose ONE) grant this person access to my medical records and discussion of my end-of-life care.
- Listed below are the names and contact information of my alternate healthcare representatives and others I would like to have act on my behalf, in the order listed, if my representative is unavailable.

Name	Relationship	Mailing Address	Phone	E-Mail

Please list anyone that you specifically **DO NOT** want to participate in planning your end-of-life care.

I will hold you blameless for meeting community standards for the requested care, and have asked my representative and loved ones to do the same.

Your Signature: _____ Date: _____

On the next page please list all of the medications that you are **currently taking**.
This information can be a useful reminder for the providers you see regularly,
any new providers you consult, and first responders who answer calls.

Update this information as necessary to make sure it is complete and available in an emergency.

25 **6-STEPS Living Will**

Name: _____ Date: _____

I have the following allergies:

- _____
- _____
- _____
- _____

I have been diagnosed with these critical illnesses:

- _____
- _____
- _____
- _____
- _____
- _____

Medications and other drugs that I TAKE NOW. Include both prescribed drugs and any other over-the-counter drugs, vitamins.

Name of Medication	Dose Level (mg, drops etc.)	How often do you take it? (Times per day)	Who prescribed it?

25 **6-STEPS Living Will**

What I hope you will take away:

ACP IS FOR **EVERYONE** --BEGINNING WITH ALL HEALTHCARE PROFESSIONALS--
AND IT IS NEVER EASY FOR ANYONE

THERE IS ONE RIGHT WAY TO DIE FOR EACH PATIENT TODAY, BUT THAT MAY CHANGE TOMORROW, SO ACP DISCUSSIONS MUST BE ON-GOING

HCPs' ROLES IN ACP

ASK WHO THE PATIENT IS AS A PERSON, INCLUDING VALUES, GOALS, HOW HE/SHE WOULD LIKE TO BE REMEMBERED. Never forget that: *EVERYONE IS A UNIQUE CULTURE AND HAS AN ENTIRELY INDIVIDUALIZED VIEW OF THE ELEMENTS OF A GOOD DEATH*

TELL FACTS, INCLUDING THE DIAGNOSIS AND PROGNOSIS, AS WELL AS IT CAN BE FORETOLD, AND THE PROS AND CONS OF WHAT HEALTH CARE HAS TO OFFER, BALANCED BY CAREFUL ATTENTION TO PATIENTS' EMOTIONS

ASK WHAT THE PATIENT WOULD LIKE TO DO BASED ON THIS INFORMATION and help clarify his/her objectives in operational terms

FACILITATE/MEDIATE SHARED DECISION INVOLVING THE SURROGATE AND SIGNIFICANT ACTORS. CULMINATING IN THE CREATION OF A LIVING WILL, CMO, AND/OR MOELI

ADVISE THE PATIENT AND SIGNIFICANT OTHERS TO DO AS MUCH AS POSSIBLE TO ACHIEVE IMPORTANT GOALS NOW—BEFORE IT IS TOO LATE

An offer

Given that you struggled through 79 slides, you must be either very masochistic or very interested in ACP. Hoping it is the latter....

AT NO CHARGE, I would be delighted to help you or your program or clinic develop and/or deliver ACP services to diverse individuals or groups, via staff development, consultation, or direct contact. If

interested, please contact me at:

rbstuart88@gmail.com

And please use ACP as subject

Today's mantras

Five tasks of the dying: saying I'm sorry, saying, I forgive you, saying thank you, saying I love you, saying goodbye.

Ira Byock

***Only put off until tomorrow
what you are willing to die
having left undone.***

Pablo Picasso

References addressing practical aspects of ACP

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2. Stuart RB, Thielke S.J Standardizing protection of patients' rights: From POLST to MOELI (Medical Orders for End-of-Life Intervention. *Am Med Dir Assoc.* 2017 Sep 1;18(9):741-745. doi: 10.1016/j.jamda.2017.04.022. Epub 2017 Jun 13.PMID: 28623154
3. Step 3 in 6-Steps Living Will. www.6stepslivingwill.org
4. Stuart RB, Thielke SJ. Protocol for the Assessment of Patient Capacity to Make End-of-Life Treatment Decisions. *J Am Med Dir Assoc* 2018 Feb;19(2):106-109. doi
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