

OHSU HEALTH SYSTEM

OFFICE OF CLINICAL INTEGRATION AND EVIDENCE-BASED PRACTICE

GUIDELINE FOR ADVANCE CARE PLANNING

Background: Advance care planning (ACP) is a process supporting patients and their caregivers to understand and share their personal values, life goals, and preferences about current and future medical treatments and caregiving. [1, 2] Ideally, these preferences should be documented, so that this information follows the patient across health care settings to be respected when needed. [3] The goal of ACP is to help patients identify their wishes and values concerning their treatment and caregiving and to communicate those values towards their families and caregivers. [4] In this way, coordinated agreements about treatment can be shared. [2] Studies show that quality of care towards the end-of-life increases through ACP, because of increased coordination between a betterinformed patient and caregivers and the increased use of comfort care strategies. [5-7] However, currently there are no clear, widely accepted national guidelines on how to implement ACP, therefore, OHSU Health is creating a health system guideline to standardize ACP care and create consistency for patients seeking care in our system.

<u>Setting:</u> ACP is appropriate to consider in all health care settings.

Challenges: Patients and their families are open to ACP but experience obstacles during the process. Many health care providers feel unprepared for these conversations or may feel they take too much time. However, when appropriately conducted in a culturally sensitive manner, ACP may benefit patients (increased autonomy, dignity, peace, and intimacy at the moment of death), their families (less intense grieving, less likelihood of developing psychiatric conditions), and the health care system (improved patient safety and health care quality).

Definitions:

Advance Care Planning (ACP): involves discussing and preparing for future decisions about the patient's medical care if patient becomes seriously ill or is unable to communicate his/her/their wishes. [9]

Surrogate Decision-maker (SDM): a substitute healthcare decision-maker who consents or refuses to consent to

some or all medical treatments for the patient who lacks decision-making capacity. SDM is the broadest term for this role as a patient may verbally name any family/friend to this role, but there are specific considerations defined in ORS 127.535. The term may be used differently in other U.S. states. [10]

Health Care Representative: A health care representative is a type of surrogate decision-maker or legally appointed surrogate decision maker authority over the patient's health care that the patient would have if the patient were not incapable, subject to the limitations of the appointment. In Oregon the primary way to declare this specific type of SDM is by completion of a valid Advance Directive [11]

Advance Directive: legal documents that provide instructions for medical care and only go into effect if patients cannot communicate the patient's own wishes. Besides the Oregon Advance Directive, other relationships that serve this function are the living will and Durable Power of Attorney for Health Care "DPOA-HC" [9] Power of Attorney: Some US states have specific Health Care Power of Attorney designations that are named via a legal process. It should be noted that there is a difference between a financial power of attorney and a health care power of attorney.

Serious Illness Conversation: a part of advance care planning that may include prognosis disclosure and focuses on values, goals, and preferences about future care between a clinician and a seriously ill patient. [9] Serious Illness Conversations are a specific strategy for performing what may be referred to as "Goals of Care" conversations.

Portable Orders for Life-Sustaining Treatment (POLST): medical orders completed by a health professional based on the patient's preferences regarding cardiopulmonary resuscitation in the case of cardiopulmonary arrest (do not resuscitate [12] or attempt resuscitation [cardiopulmonary resuscitation]), scope of treatment when not in cardiac arrest (comfort measures only [CMO], selective interventions, or full treatment) [13]

End of Life Care: the support and medical care given during the time surrounding death. End-of-life care can be provided in the hours, days or months before a person dies and encompasses care and support for a person's



mental and emotional needs, physical comfort, spiritual needs, and practice tasks. [14]

Guideline Eligibility Criteria:

ACP can be appropriate for all patients but for the purposes of this guideline the following patients will be considered:

- >/= 65 years old
- Advanced life-threatening illness

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or

- Increased risk of mortality within next 12 months or
- >/= 18 years old with hospitalization or procedure

Guideline Exclusion Criteria:

Pediatric Patients



Clinical Practice Recommendations:

Identifying appropriate patients for advance care planning

The following criteria strongly indicates need for advance care planning, however, ACP should not be considered as limited to this list: (Consensus based on external guidelines) [4, 15-18]

One or more of following conditions:

- · Advanced cancers with life limiting prognosis: Inclusive of solid and hematologic malignancies
- Neurologic Conditions
 - o Dementia or mild cognitive impairment
 - o Amyotrophic Lateral Sclerosis (ALS)
 - Parkinson's
 - o Other progressive neuromuscular disorders
- Stage C/class III or greater heart failure
 - o Heart failure or extensive untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort (NYHA class 3 and 4)
- Advanced liver disease
 - o Cirrhosis with one or more complications in the past year:
 - Diuretic resistant ascites
 - Hepatic encephalopathy
 - Hepatorenal syndrome
 - Bacterial peritonitis
 - Recurrent variceal bleeding
 - Especially if liver transplant is not possible
- Advanced kidney disease
 - o Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health
 - o Kidney failure complicating other life limiting conditions or treatments
 - Stopping or not starting dialysis
- Advanced pulmonary diseases
 - o COPD / home oxygen use / at rest dyspnea
 - o Severe Pulmonary Arterial Hypertension
 - o Idiopathic Pulmonary Fibrosis
 - Cystic Fibrosis with substantially decreased lung function
- Acute stroke /History of stroke
 - $\circ \quad \text{Progressive deterioration in physical and/or cognitive function despite optimal therapy after stroke}$
 - o Speech problems with increasing difficulty communication and/or progressive difficulty with swallowing
 - $\circ \quad \text{Recurrent aspiration pneumonia; breathless or respiratory failure}$
 - Persistent paralysis after stroke with significant loss of function and ongoing disability
- Severe, inoperable peripheral vascular disease
- Critical illness with multisystem organ failure
- Other systemic diseases with life limiting prognosis not captured in the above list

OR

Any general indicators of poor or deteriorating health

- Two or more unplanned hospital admissions in last year
- Performance state is poor or deteriorating, with limited reversibility (eg. The person stays in bed or in a chair for more than half the day due to functional decline)



- Depends on others for care due to increasing health problems; needs help with complex treatment decisions
- Persistent symptoms or worsening despite optimal treatment of underlying condition(s)
- Patients with DNR order
- Any prolonged (Over 7 days) ICU admission
- Clinician would not be surprised if patient died within the next 1-2 years.

Interprofessional Care

Utilize an interprofessional team approach to provide high-quality and individualized care to patients eligible for advance care planning when possible. Interprofessional care is defined as the practice and education where individuals from two or more professional backgrounds interact to develop patient's treatment goals. To ensure effectiveness of this approach, we recommend identifying a trained team member whose role it is to coordinate, navigate, and educate the patient on the different components of ACP care within clinics and care settings where ACP care is delivered. Evidence has shown that nurses, social workers and health educators are effective and trusted patient navigators (Strong Recommendation, Low Quality Evidence). [19-24]

Components of Advance Care Planning

ACP can occur at any time in a lifespan; from healthy people naming surrogate decision makers in case of an unexpected injury to patients with a terminal diagnosis making end-of-life decisions (Consensus). [12]

Figure 1: Continuum of Advance Care Planning [12]



Continuum of Advance Care Planning

Surrogate Decision Maker

The term surrogate decision maker includes a health care representative, legal guardian, friend or family member indicated by patient, or health care advocate (this is a person appointed in accordance with Oregon statute to make medical decisions on behalf of a person with intellectual or developmental disability who does not have a legal guardian or health care representative). Among these categories, legal guardian and health care representative named on a valid Advance Directive supersedes any of the other surrogate decision makers. Please see the OHSU Informed Consent Policy for more details,



including guidance for determining appropriate decision maker for a person without a valid Advance Directive. The term surrogate decision maker may vary by state. (Consensus).

Practice Implication

- For further information, please refer to Surrogate Decision Maker Documentation Job Aid on MCN
- Please refer to Oregon Department of Human Services (DHS) for more information on when health care advocates (HCAs) have no authority or cannot make certain health care decisions.
- Education and training in advanced care planning and serious illness conversations is highly encouraged. Expansion of existing training programs such as Vital Talk and Serious Illness Conversation training is encouraged and are excellent resources for teams. At minimum, providers are encouraged to watch the high quality training videos made available by Ariande labs: Link here. https://www.ariadnelabs.org/serious-illness-conversation-guide-training/

Advance Directive

Advance directives (AD's) are legal documents that provide instructions for medical care and only go into effect if patients cannot communicate their own wishes. AD's should be seen as living documents that are reviewed at least once each year and updated if a major life event occurs. Care teams are suggested to use the <u>Oregon Health Authority template</u>, which recommends reviewing the AD based on the following 6Ds: **(Consensus)**. [9, 25]

- Decade: At each new decade of your life
- **D**eath: When a loved one or a health care representative dies
- Disagreement: When your health care representative does not agree with your wishes
- **D**ivorce: If you separate from a spouse or domestic partner who is your Advance Directive representative, you must complete a new Advance Directive EVEN IF you want them to continue serving as your representative
- Diagnosis: When you are diagnosed with a serious illness or Dementia (in early stage)
- Decline: When your health declines or you can no longer live on your own

Practice Implication

For further information, please refer to Advance Directive Policy on MCN

Goals of Care or Serious Illness Conversation

Goals of care (GOC) conversation is a term that is commonly used to indicate the need for prognosis disclosure and decision making on possible treatments or discontinuation of ineffective treatments. For the use of this guideline, Serious Illness Conversation will be the term used to discuss the overarching aims of health care for a patient. OHSU Health encourages clinical teams to use the Serious Illness Conversation framework for guiding conversations and documenting them as we elicit patients' goals, values, preferences and priorities.

Serious Illness Conversation Guide (SICG) framework is helpful to guide a series of conversations between a health care team and a seriously ill patient and their loved ones. The guide includes prognosis disclosure and explores goals, fears, and critical abilities with standardized questions. The questions reflect on what would be the most important and necessary for the patient, rather than on prolonging life at all costs. Such reflection may help to align decisions with the patient's values. Use of this guide is recommended as standardized tools improve the documentation and communication amongst the interprofessional team (Consensus). [26-32]

We suggest initiating serious illness conversations earlier when patient is not in crisis, and preferably in the outpatient setting. Clinician team must consider different patient needs, preference and priorities, language and cultural factors, and



provide clear opportunities for preferences and concerns to be discussed, at different times (Conditional Recommendation, Low Quality Evidence). [33-35]

Practice Implication

- All providers should be competent in using SICG principles including how to guide conversations and
 document the important components. This includes validated language for documenting when prognosis is
 uncertain. For those interested in further training, <u>VitalTalk</u> is an excellent resource for these important
 skills
- Use system approved documentation templates for SIC documentation to ensure the note content is filed in the Advance Care Planning navigator in Epic. The Navigator is easy to use for both outpatient and inpatient teams and follows patients across hospitals in our system that use the same instance of Epic. (See the Serious Illness Conversation documentation job aid in MCN)
- Care teams that desire additional support for their patients in these discussions or to follow-up on conversations, may consider consulting or referring to palliative care or social work as needed.

POLST

Document in registry for a person with a serious progressive illness, such as advanced heart disease, advanced lung disease or cancer that has spread. It is also for someone who is older and frail and might not want all available medical treatments. A POLST can never be required by a health care professional, care facility or health system, and should be part of the discussion with clinicians. Completing a POLST is an attestation that the conversation was had with the patient or surrogate.

(Consensus). [36]



OHSU Health Office of Clinical Integration and EBP Advance Care Planning Overview

Advance Care Planning

Advance Directive

Which Patients: Anyone >/= 18 years old

How: Complete and scan directive, recommended to use the OHA AD template

Surrogate Decision Maker

Which Patients: Upon admission, patients undergoing surgery, and patients seen in primary care and subspecialty clinics that follow patients regularly and make important treatment decisions

How: Through ACP Navigator in Epic

Serious Illness Conversation

Which Patients: Patient with a life-limiting illness or a condition that puts them

at significant risk for hospitalization or serious complications

How: Serious Illness Conversation Documentation

POLST

Which Patients: Patient with a serious progressive illness or someone who is elderly and frail and might not want all available medical treatment

How: Complete ePOLST



Quality Measures:

SDM:

- Inpatient/Obs: All Adult Admissions
 - Long term goal: 80%
 - Primary Care (Ages 65+)
 - Primary Care: 40%
 - Pre-Operative Medicine Clinic (Ages 18+)
 - 50% of patients seen in Physician/APP clinic sessions

Rate of Yes to CPR POLST < 20%

ePOLST use > 75%

Serious Illness Conversation

• Use of approved SIC documentation templates in the group of patients with identifiable potentially life limiting conditions who also die in the past 12 months before death.



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Guideline Preparation

This guideline was prepared by the Office of Clinical Integration (CI) and Evidence-Based Practice (EBP) in collaboration with content experts across OHSU Healthcare.

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Development Process

DATE: March 2024

This guideline was developed using the process outlined in the CI and EBP Manual (2016). The review summary documents the following steps:

- 1. Review Preparation PICO questions established Evidence search confirmed with content experts
- 2. Review of Existing Internal and External Guidelines Literature Review of Relevant Evidence
- 3. Critically Analyze the Evidence
- 4. Summarize the Evidence by preparing the guideline, and order sets

Evaluating the Quality of the Evidence

Published clinical guidelines were evaluated for this review using the University of Pennsylvania's Trustworthy Guideline Rating Scale. The summary of these guidelines are included in the evidence summary. The rating scale is based on the Institute of Medicine's "Standards for Developing Trustworthy Clinical Practice Guidelines" (IOM), as well as a review of the AGREE Enterprise and Guidelines International Network domains. This scale evaluates a guideline's transparency, conflict of interest, development group, systematic review, supporting evidence, recommendations, external review and currency and updates. The purpose of this scale is to focus on the weaknesses of a guideline that may reduce the trust a clinical user can have in the guideline, and distinguish weaknesses in documentation (e.g. guideline does not have a documented updating process) from weaknesses in the guidance itself (e.g. recommendations are outdated).

The GRADE (Grading of Recommendations, Assessment, Development and Evaluation)

criteria were utilized to evaluate the body of evidence used to make clinical recommendations. The table below defines how the quality of the evidence is rated and how a strong versus conditional recommendation is established. The evidence summary reflects the critical points of evidence.

Recommendation		
STRONG	Desirable effects clearly outweigh undesirable effects or vice versa	



Desirable effects closely CONDITIONAL balanced with undesirable effects Quality Type of Evidence Consistent evidence from well-performed RCTs or High exceptionally strong evidence from unbiased observational studies Evidence from RCTs with important limitations (e.g., inconsistent results, methodological flaws, Moderate indirect evidence, or imprecise results) or unusually strong evidence from unbiased observational studies Evidence for at least 1 critical outcome from Low observational studies, from RCTs with serious flaws or indirect evidence Evidence for at least 1 critical outcome from Very Low unsystematic clinical observations or very indirect evidence

Recommendations

Recommendations for the guidelines were directed by the existing evidence, content experts, and consensus. Patient and family preference were included when possible. When evidence is lacking, options in care are provided in the guideline and the order sets that accompany the guideline.

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Approval Process

Guidelines are reviewed and approved by the Content Expert Team, Office of CI and EBP, Knowledge Management and Therapeutics Committee, Professional Board, and other appropriate hospital committees as deemed appropriate for the guideline's intended use. Guidelines are reviewed and updated as necessary every 2 to 3 years within the Office of CI and EBP at OHSU. Content Expert Teams will be involved with every review and update.

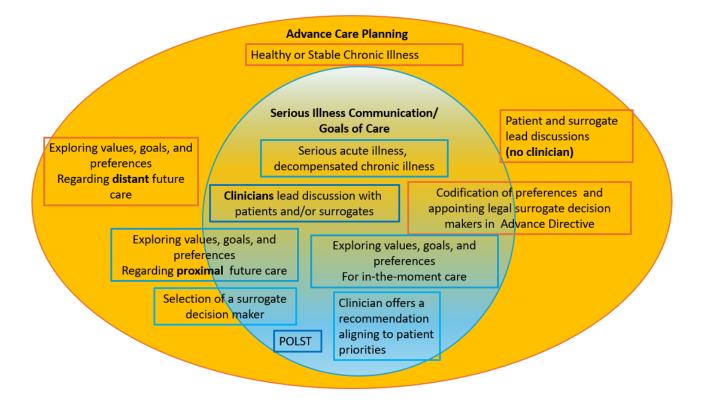
Disclaimer

Guideline recommendations are made from the best evidence, clinical expertise and consensus, in addition to thoughtful consideration for the patients and families cared for within the Integrated Delivery System. When evidence was lacking or inconclusive, content experts made recommendations based on consensus. Expert consensus is implied when a reference is not otherwise indicated.

The guideline is not intended to impose standards of care preventing selective variation in practice that is necessary to meet the unique needs of individual patients. The physician must consider each patient and family's circumstance to make the ultimate judgment regarding best care.



Appendix A: Conceptual Model for areas of distinction and overlap between advance care planning and serious illness communication [32]





Appendix B: Areas of distinction between Advance Directive (AD) and POLST

ACP related Documents		
Who is it for?	Anyone 18 years old and above, who has capacity	Patients who are old or frail or seriously ill AND who may NOT want all possible treatments
What type of document?	Legal document	Medical order
Can I use it to appoint my surrogate?	Yes	No
Who fills it out?	Individual	Health care provider (e.g., doctor) after discussion with patient or SDM**
Who signs it?	Individual, HCR*, and either 2 witnesses or a Notary Public	Health care provider (with individual or SDM**'s input)
Do I need a lawyer?	No	No
Who keeps the form?	Individual, HCR*, and health care provider	Individual, health care provider, and in the electronic Oregon POLST registry
Can I change the form ?	Yes (as long as you have capacity)	Yes
What if there is a medical emergency and I cannot speak for myself?	Your HCR* speaks for you and honors your wishes	Medical care team obtains the POLST and follows the instruction
Can Surrogates create/sign the form?	No	Yes, with a health care provider
Can emergency responders use it?	No	Yes
*HCR: Health care representative **SDM: Surrogate decision maker	Not always easy to find the document in different health care settings (Needs to provide copies for each HCP in different settings)	Upon hospital admission CODE status will be discussed. DNR on POLST is not automatic DNR in a hospital setting