INTRODUCTION TO ELICITING VALUES, GOALS, AND PREFERENCES WHEN PATIENTS HAVE A SERIOUS ILLNESS

Training for Nurses, Social Workers, Psychologists, and Chaplains

Sponsored by:

National Center for Ethics in Health Care
Office of Care Management and Social Work Services
Office of Geriatrics and Extended Care, Hospice and Palliative Care Program
Office of Nursing Services
Office of Primary Care Services
National Chaplain Center
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Objectives

Following this learning activity, participants will be able to

• Describe the rationale for conducting proactive goals of care conversations with high risk patients
• Identify steps required to ensure that goals of care conversations occur with high-risk patients
• List the elements of a goals of care conversation
• Identify ways to document patients’ goals and preferences in the electronic health record
Veterans at Risk

• Joe Veteran – 72, advanced heart failure, mild dementia

• Jane Veteran – 46, stage IV breast cancer

• Jim Veteran – 58, advanced COPD

• Jenny Veteran – 83, multiple medical problems
Understanding and honoring patients’ values, goals, and preferences supports personalized, proactive, patient-driven care
Ensuring that patients’ values, goals, and preferences are honored: 

**ICARE values in action**

- Integrity
- Commitment
- **Advocacy**
- Respect
- Excellence
To successfully honor patients’ goals and preferences, we must:

- Proactively identify high risk patients
- Prepare for a conversation about what matters
- Elicit patient’s values, goals and decisions
- Document this information in CPRS
- Honor patients’ values, goals, decisions

Goals of Care Conversations
Goals of Care Conversation

• To elicit the patient’s values, goals of care, and thoughts/questions/decisions about services and life-sustaining treatments

• Intended for patients at high risk of a life-threatening clinical event in the next 1-2 years* (or those who want to limit life-sustaining treatment)

• May take more than one visit, and involve more than one clinician

• May be conducted with the patient’s surrogate if the patient does not have decision-making capacity
Proactive Goals of Care Conversations with High Risk Patients

May include:

• Identifying the patient’s authorized **surrogate**, and determining whether the patient would like to name a different surrogate
• Confirming the patient’s **understanding** of diagnosis and prognosis
• Eliciting the patient’s **values and goals** related to their health care
• Providing **information** about available services and treatments to support the patient’s goals
• Making **shared decisions** about services and treatments (within clinician’s scope of practice)
• Reviewing or assisting with **documents** reflecting the patient’s wishes
• Establishing **next steps**
Proactive Goals of Care Conversations with High Risk Patients

Clinical Settings:

- Primary Care & Home Based Primary Care
- Outpatient Specialty Care (oncology, pulmonology, cardiology, renal, etc.)
- Inpatient Units
- CLC/Hospice Units
POLL #1

Have you worked with at least one patient with a serious illness in the last year?

- Yes
- No
- Not sure

For example…

COPD
Cancer
Heart Disease
Dementia
Organ Failure
POLL #2

If you have worked with patients with a serious illness, in what setting(s) did you provide the care?

- Inpatient Unit
- CLC/Hospice Unit
- Primary Care Clinic
- Home Based Primary Care
- Outpatient Specialty Medicine Clinic
- Outpatient Mental Health Clinic
- Other
Why is change needed?

• Conversations about goals and LST decisions often initiated too late – after the patient has lost decision-making capacity or during a medical crisis

• Difficult to locate CPRS documentation of the patient’s goals of care and LST decisions

• VA orders pertaining to LST have been limited to CPR – no orders have been available to document other LST decisions (mechanical ventilation, feeding tubes, dialysis, others)

IMPACT ON PATIENTS, FAMILIES, TEAM MEMBERS:

STRESS     CONFUSION     CONFLICT

PATIENTS MAY NOT RECEIVE CARE THAT IS ALIGNED WITH THEIR GOALS AND PREFERENCES
Why aren’t advance directives enough?

- Many patients don’t have advance directives

- May have been completed…
  - A long time ago, before the patient got sick
  - Without discussing goals of care and likely outcomes of treatment choices

- May be vague or not specifically related to the current medical condition

- Preferences, not orders – require interpretation by surrogate decision-maker
Life-Sustaining Treatment Decisions Initiative

National quality improvement initiative to promote personalized, proactive, patient-driven care for Veterans with serious illness

 Desired Outcomes
The values, goals, and life-sustaining treatment decisions of Veterans with serious illness are proactively elicited, documented, and honored
Life-Sustaining Treatment Decisions Initiative

• Promotes proactive, high quality **goals of care conversations** with high risk patients
• Promotes **improved documentation** of goals of care and life-sustaining treatment decisions
LST Decisions Initiative
Demonstration Sites

Implemented, tested, and improved LST processes and tools

- Lovell Federal Health Care Center, North Chicago
- VA Black Hills Health Care System, Ft. Meade and Hot Springs, SD
- VA Salt Lake City Health Care System
- William S. Middleton Memorial VA Hospital, Madison
Tested at Demonstration Sites

- New VHA Handbook

- New CPRS tools to document goals of care and LST decisions

- Resources and training

In final stages of national concurrence

To be released with new LST Handbook
VHA Handbook 1004.03 (LST Handbook)

• Standardizes processes related to:
  • **Conducting** goals of care conversations with high risk patients
  • **Documenting** goals of care and LST decisions in CPRS
  • **Honoring** LST decisions

• Also addresses:
  • Establishing LST plans for patients who lack decision-making capacity and do not have a surrogate
  • Resolving conflicts regarding LST treatment
  • Conscientious objection
  • VA prohibition against assisted suicide and euthanasia

• Following publication, facilities will have **18 months** to establish facility policy and implement new practices

Release Date TBD
Steps to ensure that care is aligned with high-risk patients’ goals

1. Proactively identify high risk patients
2. Prepare for a goals of care conversation
3. Conduct a goals of care conversation
4. Document values, goals and decisions in CPRS
5. Honor the patient’s values, goals, and decisions

Quality improvement activities help identify and fix gaps in processes.
Success Depends on Teamwork

- Multiple disciplines involved in:
  - Proactively identifying high risk patients
  - Preparing patients and surrogates for goals of care conversations
  - Discussing the patient’s choice of surrogate
  - Discussing the patient’s values and goals of care
  - Providing information about services and treatments
  - Discussing the patient’s preferences
  - Managing documents that reflect the patient’s wishes

- Attending physicians, residents, APRNs, and PAs: responsible for confirming LST plan and writing related LST orders
Proactively Identify High Risk Patients

At HIGH RISK of a life-threatening clinical event

- Advanced Heart Disease
- Advanced Kidney Disease
- Alzheimer’s Disease
- Advanced Cancer
- Chronic Liver Disease
- Chronic Lung Disease
- Cerebrovascular Disease
- Frail with multiple comorbidities

Serious life-limiting condition associated with a significantly shortened lifespan
Proactively Identify High-Risk Patients

Use Clinical Judgment

Ask yourself the “surprise question:

Would I be surprised if this patient experienced a life-threatening clinical event or lost decision-making capacity in the next 1-2 years?

Clues that the patient may be at high risk:

- Multiple hospitalizations within the last year
- New or changed diagnosis
- At risk for loss of decision-making capacity
- Dependent on others for care
- Daily symptoms affecting quality of life or function
- LAST FOUR SYNDROME: you know the last four digits of the patient’s SSN without having to look it up
Proactively Identify High-Risk Patients

- Care Assessment Need (CAN) scores
  - Indicates risk of hospitalization or death
  - Available to Primary Care teams through the Primary Care Almanac and the Patient Care Assessment System (PCAS)

Coming Soon:
- Goals of Care filter in Patient Care Assessment System (PCAS)
  - One click to see a list of patients who may be appropriate for a goals of care conversation
  - Can add patients to the list, assign tasks to team members
Prepare YOURSELF

• Review the patient’s record
• Get perspectives from others on the team
• If the patient lacks decision-making capacity, identify their authorized surrogate

VA Surrogate Hierarchy:
• Health care agent (named in a Durable Power of Attorney for Health Care)
• Guardian (named by a court of law)
• Next of kin (18+ years of age, in the following order: spouse, child(ren), parent(s), sibling(s), grandparent(s), grandchild(ren)*)
• Close friend

*Individuals at the same level of the hierarchy have equal standing as the patient’s surrogate
Prepare THE PATIENT (or surrogate)

- Educate about goals of care conversations
  - Team member who knows the patient best might be the right person to do this
- Provide patient education materials
  - Setting Health Care Goals: A Guide for Patients with Health Problems
  - Information for Patients and Families about Life-Sustaining Treatments
    - Feeding Tubes
    - Dialysis
    - Mechanical Ventilation
    - CPR
Prepare THE PATIENT (or surrogate)

- Assess readiness
  - Explore understanding of medical condition/prognosis
    - “What have your doctors told you about your health?”
    - Link patient with practitioner if there are significant gaps in understanding
  - Readiness to discuss goals of care
    - Even if the patient is not ready to make decisions, encourage discussion of values and goals
  - Recommend websites that help patients prepare through interactive exercises, videos
    - Prepare for Your Care [https://prepareforyourcare.org/page](https://prepareforyourcare.org/page)
Prepare THE PATIENT (or surrogate)

• Determine who should be invited – discuss with the patient (or surrogate)
  • Patient
  • Authorized surrogate
  • Health care team members
  • Others in the patient’s trusted support system

• Schedule a time to meet
  • How this is accomplished will vary depending on the setting
Discuss Goals and Preferences

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</table>
Discuss Goals and Preferences

Throughout the conversation:

- Use strong communication skills
  - Open-ended questions
  - Simple and complex reflections
  - Affirmations
  - Exploring
  - Expressions of empathy
- Watch for and respond to emotional cues
- Watch for and respond to spiritual concerns
Discuss Goals and Preferences

STEP 1: Introduce the Conversation

• Orient patient/surrogate to the conversation
• Create a safe and open space for discussion
• “It’s important to make sure we are providing care that lines up with what matters most to you. To do that, it’s helpful to understand what you hope for with your health care. Today, we’ll talk about how we can best support your goals and preferences. We’ll take today’s visit at your pace, and we can meet again if we need more time.”
Discuss Goals and Preferences

STEP 2: Identify Authorized Surrogate

• “Have you thought about who should make health care decisions on your behalf if you are too sick to speak for yourself?”

• Make sure the patient understands who would be authorized to serve as the patient’s surrogate if they lost decision-making capacity
  
  • If they don’t want this person to serve, offer to help complete a Durable Power of Attorney for Health Care

• If talking to the surrogate, clarify the surrogate’s role

• Obtain surrogate’s contact information
Discuss Goals and Preferences

STEP 3: Assess Understanding of Health

- Explore understanding, concerns, hopes
- Fill in knowledge gaps (within scope)
- Significant knowledge gaps lead to poorly-informed decisions
  - Write down Veteran’s questions
  - Recommend a discussion with the provider
  - Revisit a discussion about goals, preferences, services after the patient has a better understanding of medical condition and prognosis
Discuss Goals and Preferences

STEP 4: Elicit Veteran’s Values and Goals

- “What’s most important to you as you think about your health and the future?”
- “Is there anything that would be helpful for me to know about your religious or spiritual beliefs?”
- “What do you hope for with your medical care?”
- “What worries or concerns do you have about the future with your [heart problems/lung problems/cancer/etc.]?”

VALUES

GOALS OF CARE

Helps define what the patient wants to avoid
Discuss Goals and Preferences

STEP 5: Support Veteran’s Goals

- Summarize goals and ask for confirmation
- Topic 1: Discuss services available through VA and in the community to support the patient and family if more help is needed
- Topic 2: Provide or review information about life-sustaining treatments and explore patient’s preferences, questions
Discuss Goals and Preferences

STEP 5: Support Veteran’s Goals

• Topic 1: Services
  • Home Based Primary Care
  • Home Telehealth
  • Mental Health Care
  • Chaplain Services
  • Caregiver Support Services
  • Homemaker Support
  • Home Health Care
  • Adult Day Health Care

• Respite Care
  • Veteran Directed Care
  • Medical Foster Home
  • Community Living Centers
  • Community Residential Care
  • State Veterans’ Homes
  • Palliative Care
  • Hospice Care

Find information about many of these programs at www.va.gov/geriatrics

If you are not an expert in available services, refer to the appropriate team member for additional information.
Discuss Goals and Preferences

STEP 5: Support Veteran’s Goals

Topic 2: Life-Sustaining Treatments

- Mechanical Ventilation
- Artificial nutrition/hydration
- Dialysis
- CPR

- Assess understanding, provide general information (within scope), explore concerns and questions
  - Use the LST Booklet for Patients and Families
- **Refer to the provider** for discussion of risks/benefits given the patient’s medical condition, and for shared decision making about the LST plan
Discuss Goals and Preferences

Step 6: Review next steps with the patient

- Follow-up appointment if needed
- Referrals
  - Appointment with provider to discuss LST plan (can be done by phone)
  - Social Worker
  - Chaplain
  - Mental Health
  - Other specialists
  - Services
- Completion of documents reflecting the patient’s wishes
  - Advance directives
  - State-authorized portable orders
  - CPRS notes, orders
Document the Discussion in CPRS

- Upon release of VHA Handbook 1004.03, facilities will be required to create a note title for these discussions conducted by nurses, social workers, psychologists, chaplains

- Recommended title: 
  **Goals & Preferences to Inform Life-Sustaining Treatment Plan**

- Recommended that this note appear in CWAD/Postings so it will be easy for other team members to retrieve

*Don’t forget to add the patient’s primary care provider and other key team members as additional signers.*

*Practitioners complete Life-Sustaining Treatment Progress Notes and Life-Sustaining Treatment Orders*
Life-Sustaining Treatment Progress Note

REQUIRED FOLLOWING RELEASE OF THE LST HANDBOOK

- Written by attending physicians, residents, APRNs, PAs, and residents to document the patient’s life-sustaining treatment plan
- Accessible from CPRS Cover Sheet
Life-Sustaining Treatment Progress Note

REQUIRED AFTER RELEASE OF THE LST HANDBOOK

Accessible from the CPRS Cover Sheet
Life-Sustaining Treatment Orders

REQUIRED AFTER RELEASE OF THE LST HANDBOOK

- Written by attending physicians, APRNs, PAs, and residents
- Address all LST decisions - not just CPR
- At the top of the list on the CPRS Orders tab in ‘Default’ view
- Can be written for patients in any care setting
- Durable – do not auto-discontinue when patient changes location of care
Life-Sustaining Treatment Orders

- Default to the top of the CPRS Orders tab
- Durable – do not auto-discontinue when patient moves between clinical settings

<table>
<thead>
<tr>
<th>Service</th>
<th>Order Description</th>
<th>Start / Stop</th>
<th>Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Support</td>
<td>DNR: Do not attempt CPR in the event of cardiopulmonary arrest</td>
<td>06/10/15 07:09</td>
<td>Dr. Smith</td>
</tr>
<tr>
<td></td>
<td>&gt;&gt; No invasive mechanical ventilation (e.g., endotracheal or tracheostomy tube) in</td>
<td>06/10/15 07:09</td>
<td>Dr. Smith</td>
</tr>
<tr>
<td></td>
<td>circumstances other than cardiopulmonary arrest</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt;&gt; No artificial nutrition (enteral or parenteral).</td>
<td>06/10/15 07:16</td>
<td>Dr. Smith</td>
</tr>
<tr>
<td></td>
<td>&gt;&gt; No transfers to the ICU except if needed for comfort.</td>
<td>06/10/15 07:16</td>
<td>Dr. Smith</td>
</tr>
<tr>
<td>Nursing</td>
<td>&gt;&gt; OOB as able</td>
<td>07/12/99 15:30</td>
<td>Dr. Smith</td>
</tr>
<tr>
<td>Diet</td>
<td>&gt;&gt; Elevate head of bed</td>
<td>07/12/99 15:30</td>
<td>Dr. Smith</td>
</tr>
<tr>
<td>Lab</td>
<td>ALBUMIN SERUM WC QMONTH LAB LB #521</td>
<td>06/18/99 08:00</td>
<td>Dr. Smith</td>
</tr>
</tbody>
</table>
**What are the differences?**

<table>
<thead>
<tr>
<th>VA LST Orders</th>
<th>Advance Directives</th>
</tr>
</thead>
<tbody>
<tr>
<td>For high risk patients</td>
<td>For any adult</td>
</tr>
<tr>
<td>Written by practitioners with the oral consent of the patient (or surrogate)</td>
<td>Written by patients</td>
</tr>
</tbody>
</table>
| Medical orders for current treatment | 1. To guide health care decisions after patient loses decision-making capacity  
2. To name a Health Care Agent (surrogate) |
State- Authorized Portable Orders (SAPO)

- Community LST/DNR orders
- Vary from state to state
  - POLST, MOLST, MOST
- Written by practitioners who meet state requirements
- Must align with VA LST orders
Honoring Goals and Decisions

- Revisit when the patient experiences a change in condition

  Find out if goals or preferences have changed

- Review LST Progress Notes and LST Orders when the patient experiences a medical crisis

  Honor the patient’s decisions
Establishing Goals and LST Plans When the Patient Lacks Decision-Making Capacity and Has No Surrogate

• **Core treatment team** reviews the patient’s medical condition, collects and discusses information about the patient’s values, goals, preferences, life plan

• **Licensed independent practitioner** identifies goals, proposes LST plan based on patient’s known wishes or, if these are unknown, patient’s best interests

• Reviewed by **multidisciplinary committee**

• Reviewed by **Chief of Staff** *(if limits to LST are proposed)*

• Reviewed by **Facility Director** *(if limits to LST are proposed)*
Upcoming webinar October 24, 2016
1:00 – 2:00 pm ET

• Team-Based Approaches to Eliciting Values, Goals, and Preferences When Patients have a Serious Illness

• Objectives:
  • Describe three team-based models for conducting goals of care conversations with high-risk patients
  • List steps for implementing proactive goals of care conversation in health care clinics
  • Identify resources to help teams build skills, educate patients, and improve practices related to communicating about goals of care and serious illness

• Register in TMS – enter “30029” in the Search box
Goals of Care Conversations
Skills Training Programs

• **For RNs, Social Workers, Psychologists, Chaplains**
  • Train-the-trainer program beginning in 2017
  • Interactive, practice-based communication skills training
  • Multidisciplinary team implementation planning

• **For MDs/APRNs/PAs**
  • Train-the-trainer program resuming in 2017
  • Interactive, practice-based communication skills training
Life-Sustaining Treatment Decisions Initiative

Ensuring that Veterans with serious illness receive care that is consistent with their values, goals, and preferences

http://vaww.ethics.va.gov/Education/LST.asp