Advance Care Planning 101

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Disclosures

No relevant financial relationships to disclose
Objectives

The engaged participant will:

• Be able to describe the concept of advance care planning (ACP)

• Understand the basics of ACP in practice

• Utilize practical tools and resources to assist in ACP conversations
Background

• The majority of people die in facilities.
• Many more are admitted to hospice within days of death.
Background

• Patients and providers are not communicating.

• Wishes and concerns are not being recorded.
Advance care planning promotes compliance with patients’ wishes and improves satisfaction.
ACP impact on knowledge of and compliance with patient wishes


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ACP impact on patient and family satisfaction

Residents dying in the hospital before and after ACP program implementation


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Bonus: Advance care planning reduces health care costs, admissions, and readmissions.
Per patient costs following ACP implementation


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Vision for California

Treatment will be personalized.
People get the treatments that they need and no less, and the treatments that they want and no more.

Families and loved ones are supported throughout the process.

People know what high-quality end-of-life care looks like and will reliably receive it.
What We’re Aimming For

- WISHES EXPLORED
- WISHES EXPRESSED
- WISHES HONORED
What We Need to Get There

COMPETENT COMMUNITIES

COMPETENT PROFESSIONALS

COMPETENT SYSTEMS

PUBLIC POLICY & COMMON VISION

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Our task

Promote high-quality care for the seriously ill by transforming the culture of health care
Reflection

• Do you have concerns about care YOU might receive at end of life?
• Are you aware of situations where ACP was helpful?
• Have you seen challenges as a result of no ACP having been done?
What is your role?

- First, plan for yourself and with your family
- Be an ACP Champion
- Advocate for quality care
- Support expanded access to palliative care in your area
- Educate others
- Share resources, lessons, and best practices
- Empower and engage your colleagues
Benefits of ACP

From the patient’s perspective:

• Increases likelihood that wishes will be respected at end of life
• Achieves a sense of control
• Strengthens relationships
• Relieves burdens on loved ones
• Eases sharing of medical information (HIPAA)
• Provides opportunities to address life closure
Benefits of ACP

From the healthcare perspective:

- Patient-centered care
- Avoid unwanted or unnecessary care
- Improved family and caregiver relations
ACP across the life span

All Adults
- Talk with family about wishes
- Identify surrogate / spokesperson
- Complete advance directive

At diagnosis of serious or chronic illness or in advanced age
- Same as above, plus discuss role of POLST
- Now values and preferences have some medical context

In advanced illness or at end of life
- Same as above
- Complete POLST
ACP across the continuum

Age 18

Complete an Advance Directive

Update Advance Directive Periodically

Diagnosed with Serious or Chronic, Progressive Illness *(at any age)*

Complete a POLST Form

Treatment Wishes Honored

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What is an Advance HealthCare Directive?

Tool to make healthcare wishes known when a patient is unable to communicate

Allows a person to do either or both of the following:

1. Appoint a surrogate decision-maker, healthcare agent (Durable Power of Attorney for Health Care)

2. Give instructions for future healthcare decisions (Living Will)
What else can go into an advance directive?

- Goals
- Values
- Treatment preferences
- Directions on leeway
ACP documents in California
California: Which document do I use?

No single form for California

Several to choose from:

• Statutory form
• Simple versions
• Five Wishes
• From healthcare system
• DPAHC only
Choosing a surrogate

- Willing and able
- Knows values and preferences
- Can make difficult decisions
- Available
- Will speak for you despite their interests, beliefs

*May or may not be the “closest” family member*
Names & terms for surrogates

- Surrogate
- Healthcare Agent or Agent
- Conservator – appointed by court order
- Closest available relative
- Surrogate Decision-maker
- Spokesperson
Activity

Choose your Surrogate!
Scope of agent’s authority in California:

- Choose healthcare providers
- Approve or refuse medical treatment
- Agree to testing
- Review medical records
- Donate organs
- Authorize autopsy
- Direct disposition of remains
Who cannot be a surrogate

- Patient’s supervising healthcare provider(s)  
  *Unless related to patient*

- Any employee of the healthcare institution where the patient receives care  
  *Unless related to patient*

- Any operator or employee of facility where the patient lives  
  *Unless related to patient*
When is surrogate’s authority effective?

- When patient lacks capacity
- If the patient so designates or as stated in advance directive
Requirements for making an advance directive legal in California

• Individual/owner’s signature
• Date of execution
• Witnesses or Notary

You do not need an attorney for this.
Who cannot be a witness?

Neither witness can be:

- Patient’s healthcare provider or employees of patient’s healthcare provider
- Operator or employee of community care facility or assisted living facility
- The agent named in the advance directive

One of the witnesses cannot be:

- Related to patient by blood, marriage, adoption
- Entitled to a portion of the patient’s estate
For California skilled nursing facility residents:

When executing a new advance directive, one witness must be the long-term care ombudsman.
Duration of effectiveness

In California, advance directives do not expire unless:

• Document states otherwise, or
• If multiple documents exist, then the one with the most recent date will be followed
California recognizes...

- Advance directives executed in another state in compliance with that state’s requirements
- Military advance directives
California POLST
Physician Orders for Life-Sustaining Treatment

- Physician’s Medical Order
- Provides instructions regarding specific medical treatment
- Legally binding across healthcare sites in California
- Valid only if appropriately signed
Indications for POLST form

- Serious illness
- Medically frail
- Chronic progressive condition
# Advance directive vs. CA POLST

<table>
<thead>
<tr>
<th>Advance directive</th>
<th>POLST</th>
</tr>
</thead>
<tbody>
<tr>
<td>General instructions for <strong>FUTURE CARE</strong></td>
<td>Specific orders for <strong>CURRENT CARE</strong></td>
</tr>
<tr>
<td>Needs to be retrieved</td>
<td>Stays with the patient</td>
</tr>
<tr>
<td>Many different forms</td>
<td>Single, standardized form</td>
</tr>
<tr>
<td>Signed by patient &amp; witnesses or notary</td>
<td>Signed by patient (or HC Agent) and physician</td>
</tr>
</tbody>
</table>

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POLST Best Practices-summary

• POLST is *always voluntary* for patients
• POLST is not indicated for all patients*
• POLST should be re-visited when there is unexpected or significant change of condition
• POLST can be voided by patient *at any time*
• Surrogate decision-makers can void or change a POLST *when circumstances change*
  *(Provider should be involved in discussions)*
When to review and update documents

- Important life changes
  * Marriage, birth, separation, divorce, death
- Change in health status, new diagnosis
- Change in treatment preferences
- Every 5-10 years

This is a living document.
What if I change my mind?

- Anyone can revoke their healthcare directive or appoint a new healthcare agent or state new treatment preferences at any time.
- Best practice is to execute a new document.
Care model

- Curative Care
- Palliative Care
- Hospice Care
- Bereavement Care

Focus of Care:
- Advanced Illness
- Terminal Illness
- Death

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Focus for Care Planning

Healthy adults
- Advance Care Planning & AHCD

Diagnosis or aging
- Care Planning in Serious Illness
- Conversations for QoL

Terminal illness
- Anticipating End of Life
- POLST
- Grief Support

Focus of Care
- Curative Care
- Palliative Care
- Hospice Care
- Bereavement Care

Advanced Illness

Terminal Illness

Death
Process recap

• Gather and share information on goals, values
• Select a spokesperson/healthcare agent
• Discuss wishes with agent, loved ones, providers
• Complete advance directive document, DPOA-HC
• Give copies to agent, loved ones, doctor
• Periodically review and make changes
• POLST form when appropriate, if desired
Conversations: Low cost & high value

American College of Physicians

“Communication about goals of care for patients with serious illness is one of five most important low-cost, high-value interventions.”

• Value of conversation is greatest when patient is facing serious illness, but not at time of catastrophic hospitalization—communicate at the right time in the right way for greatest impact

• Create realistic expectations

• Allow patients and families to make individualized, informed decisions

American College of Physicians Advice on High Value Care 2014
Language makes a difference

• Use language that is comfortable, comprehensible for the patient and family

• Language that focuses on outcomes and quality of life

• Clarify or avoid non-specific terms that rely on interpretation—e.g. “heroic measures”, “vegetable”, “miracle”
Anticipate Barriers

- Avoidance—“I don’t want to talk about that.”
- Not me—“I don’t need this now.” “My doctor will make those decisions.” “I’m not sick.”
- Language barriers
- Cultural differences
- Barriers due to setting or logistics
- Access to resources for ACP
Making decisions now that will impact future decisions

- Personal goals and expectations change over time; anticipate more than one conversation
General Communication Skills

- Preparation
- Active listening
- Open-ended questions
- Reflective statements
- Identifying emotional cues
- Empathic responding
- Using silence or time out
All Conversations Are Cross Cultural
Questions for open minds

• **What** do you call the problem?
• **What** do you think will happen?
• **What** do you worry about most?
• **How** do you think the illness should be treated?
• **How** do you want us to help you?
• **Who** do you turn to for help?
• **Who** should be involved in decision-making?

Adapted from Arthur Kleinman’s Explanatory Model
Examples of Conversation Tools

- AHCD document or Planning Booklet
- Story, media, news, video, movie
- Framework or paradigm
- Mnemonic
- Key phrase or question
- Use of particular skills: Silence, empathy, inquiry, etc.
Some Tools for early ACP conversations

• Finding Your Way booklet, CCCC
• Conversation guidelines and tips, CCCC
  http://coalitionccc.org/tools-resources/advance-care-planning-resources/
• The Conversation Project Tool Kit
  http://theconversationproject.org/
• Five Wishes
  https://agingwithdignity.org/
<table>
<thead>
<tr>
<th>Phrases &amp; formats that help</th>
<th>Example</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tell me more</strong></td>
<td>Can you tell me more about .....?</td>
<td>For when you need more information or time…</td>
</tr>
<tr>
<td><strong>Ask-tell-ask</strong></td>
<td>Help me understand what you are asking. How much do you want to know? What information would be most helpful?</td>
<td>Avoids giving too much information at once Allows honest discussion of patient needs Respects their need to be &amp; feel heard Helps gather more information</td>
</tr>
<tr>
<td><strong>“I wish” statements</strong></td>
<td>I wish I could tell you the treatment was always successful.</td>
<td>Align with patient but acknowledges reality</td>
</tr>
</tbody>
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Adapted from work by Anthony Back, James Tulsky, others
Discussing serious news: SPIKES Acronym

<table>
<thead>
<tr>
<th>Step</th>
<th>Overview</th>
<th>What you do</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Setting</td>
<td>Consider culture/location/posture/eye contact</td>
</tr>
<tr>
<td>2</td>
<td>Perception</td>
<td>What does the patient know? What did others say?</td>
</tr>
<tr>
<td>3</td>
<td>Invitation</td>
<td>Permission, style, format of information given</td>
</tr>
<tr>
<td>4</td>
<td>Knowledge</td>
<td>Give the information, with warning if needed, pause</td>
</tr>
<tr>
<td>5</td>
<td>Empathy</td>
<td>Anticipate emotion, respond, proceed when patient is ready</td>
</tr>
<tr>
<td>6</td>
<td>Summary</td>
<td>Summary, next steps, concrete plan, support</td>
</tr>
</tbody>
</table>
Managing Emotional Responses

Respond with empathy and understanding
Give time for processing

Photo courtesy of: http://imagebase.net/
## N-U-R-S-E: Acronym for Articulating Empathy

<table>
<thead>
<tr>
<th></th>
<th>Example</th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Naming</strong></td>
<td><em>I see this is frustrating news to hear.</em></td>
<td>State what might be happening</td>
</tr>
<tr>
<td></td>
<td><em>Some people feel upset when …</em></td>
<td>Turn it down a notch</td>
</tr>
<tr>
<td><strong>Understanding</strong></td>
<td><em>This helps me know how you might be feeling…</em></td>
<td>Indicate that you understand</td>
</tr>
<tr>
<td><strong>Respecting</strong></td>
<td><em>I see you have tried hard to follow the plan.</em></td>
<td>Show respect for the efforts they put in</td>
</tr>
<tr>
<td><strong>Supporting</strong></td>
<td><em>We will face this together.</em></td>
<td>Non-abandonment, support</td>
</tr>
<tr>
<td></td>
<td><em>I will be here for you.</em></td>
<td></td>
</tr>
<tr>
<td><strong>Exploring</strong></td>
<td><em>Please say more about that.</em></td>
<td>Asking a focused question can create a more natural flow</td>
</tr>
<tr>
<td></td>
<td><em>Tell me what you mean when you say….</em></td>
<td></td>
</tr>
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</table>
When to review and update documents

• Important life changes
  Marriage, birth, separation, divorce, death

• Change in health status, new diagnosis

• Change in treatment preferences

• Every 5-10 years

This is a living document.
Take Action

List three things you will do as a result of being here today.