



Advance Care Planning 101

Lael C. Duncan, MD
CCCC Medical Consultant

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

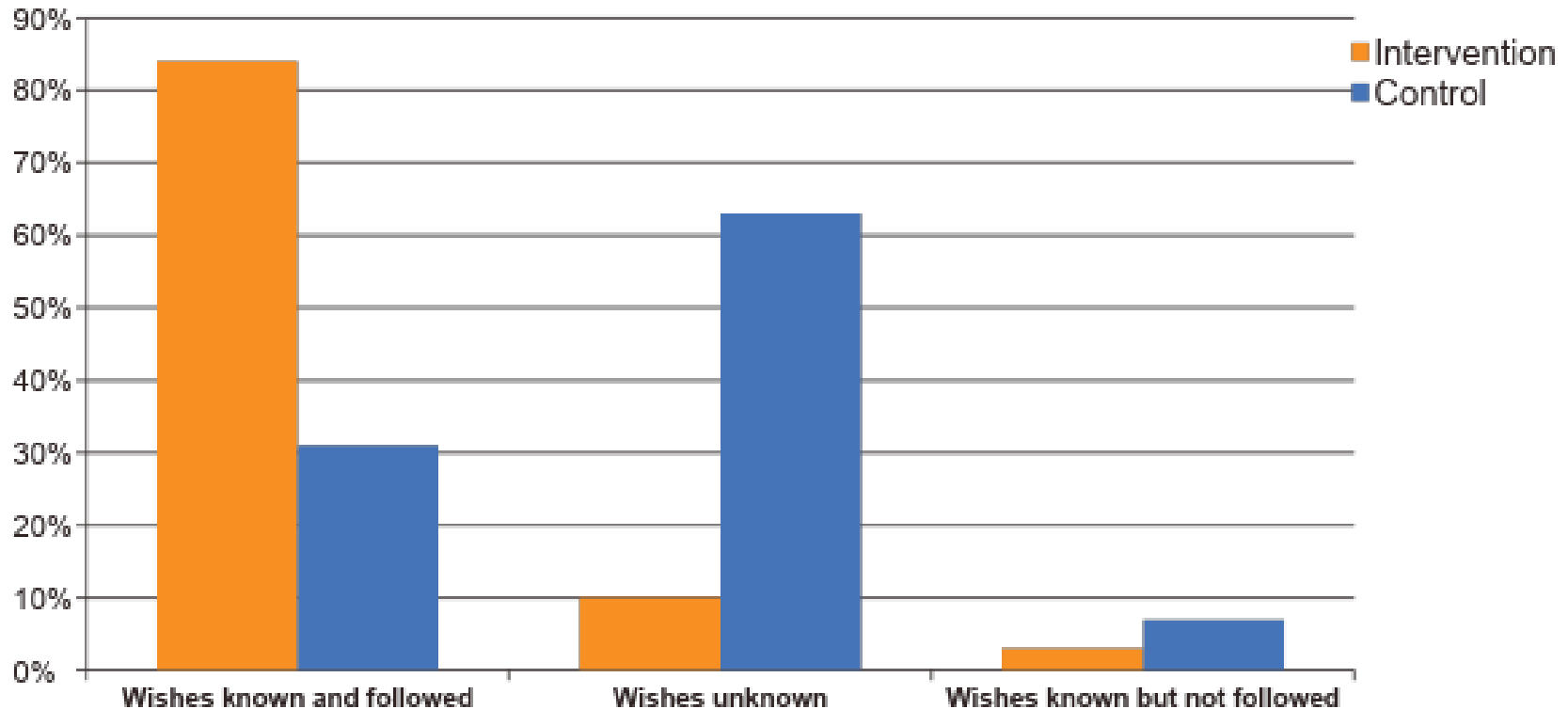
- The majority of people die in facilities.
- Many more are admitted to hospice within days of death.

Background

- Patients and providers are not communicating.
- Wishes and concerns are not being recorded.

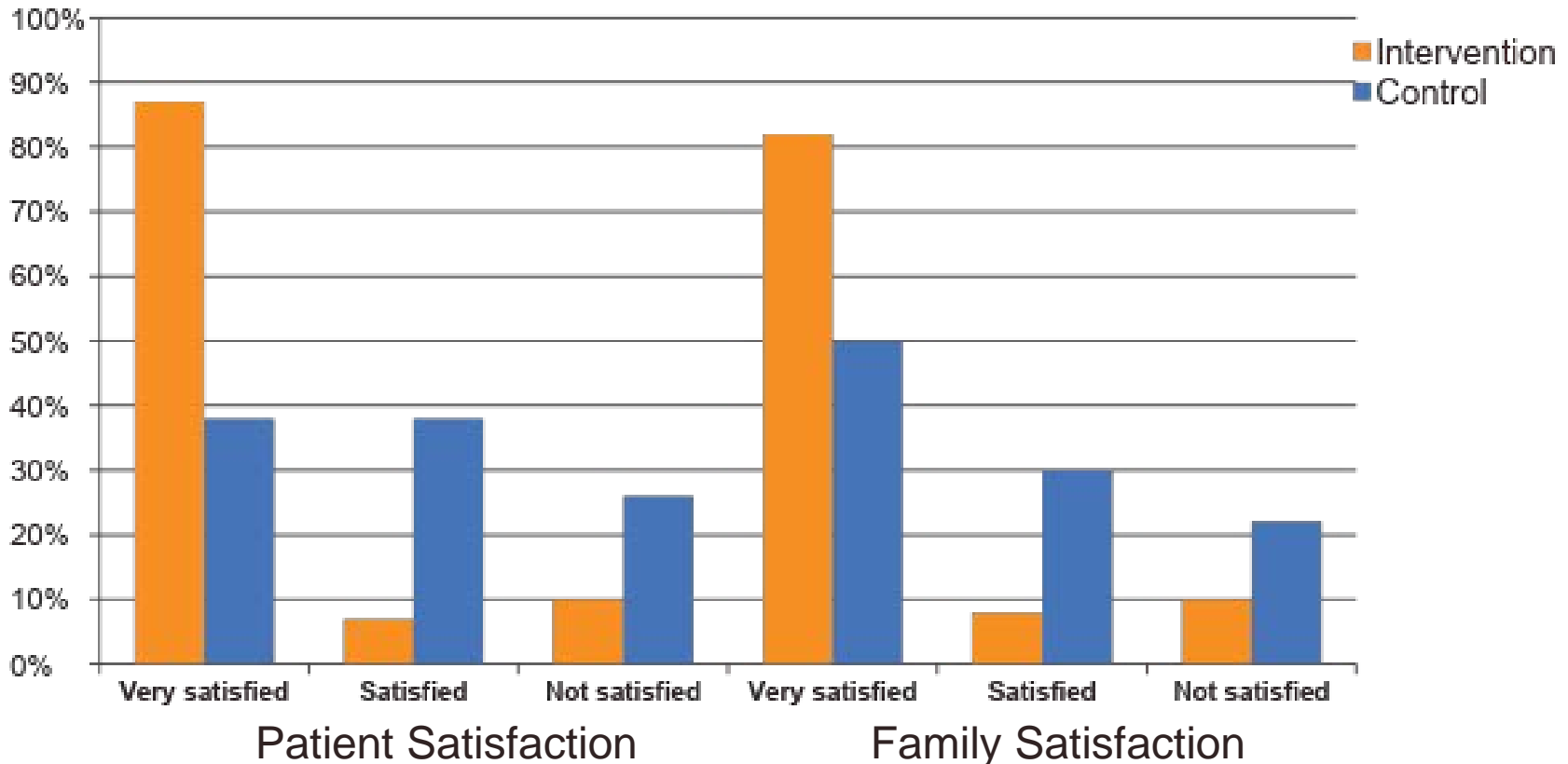
Advance care planning
promotes compliance with
patients' wishes and
improves satisfaction.

ACP impact on knowledge of and compliance with patient wishes



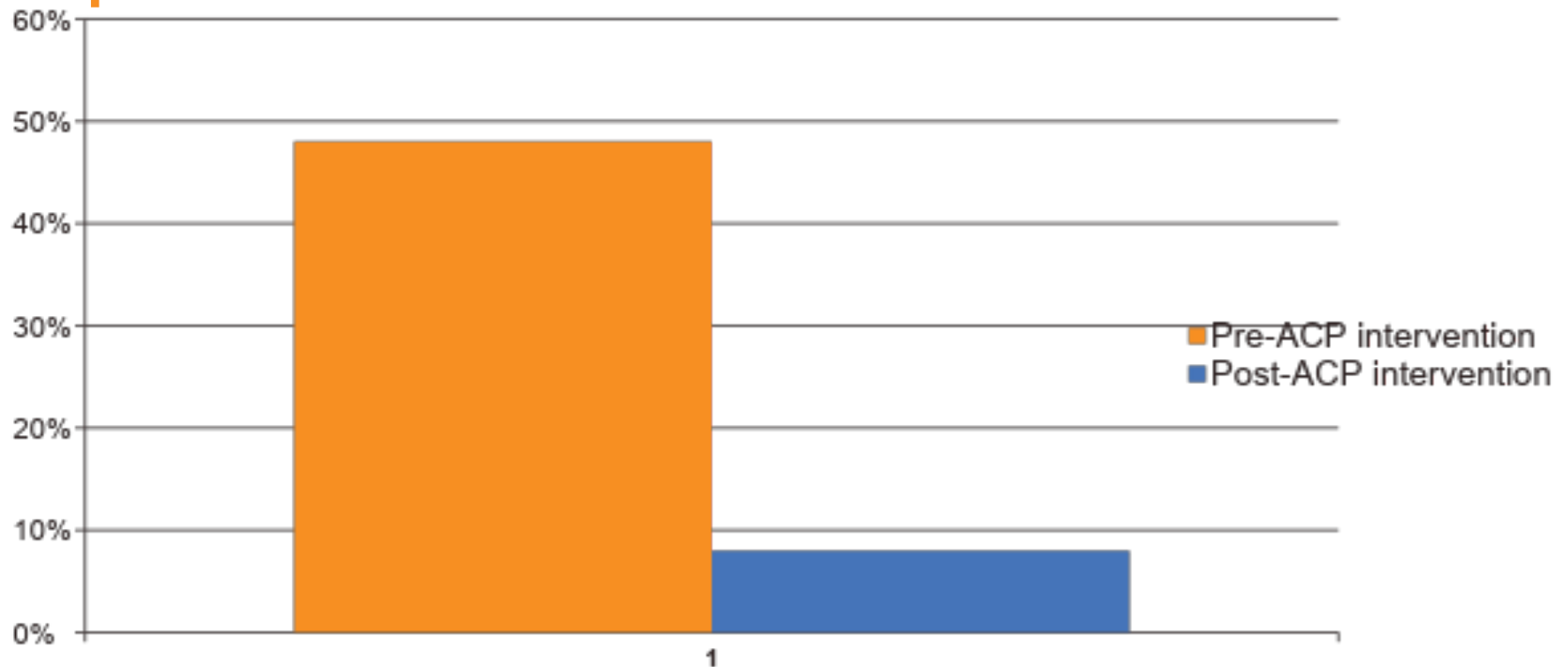
Morrison RS, Chichin E, Carter J, et al. The effect of a social work intervention to enhance advance care planning documentation in the nursing home. *J Am Geriatr Soc* 2005; 53(2): 290–294.

ACP impact on patient and family satisfaction



Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomized controlled trial. BMJ 2010; 340: c1345.

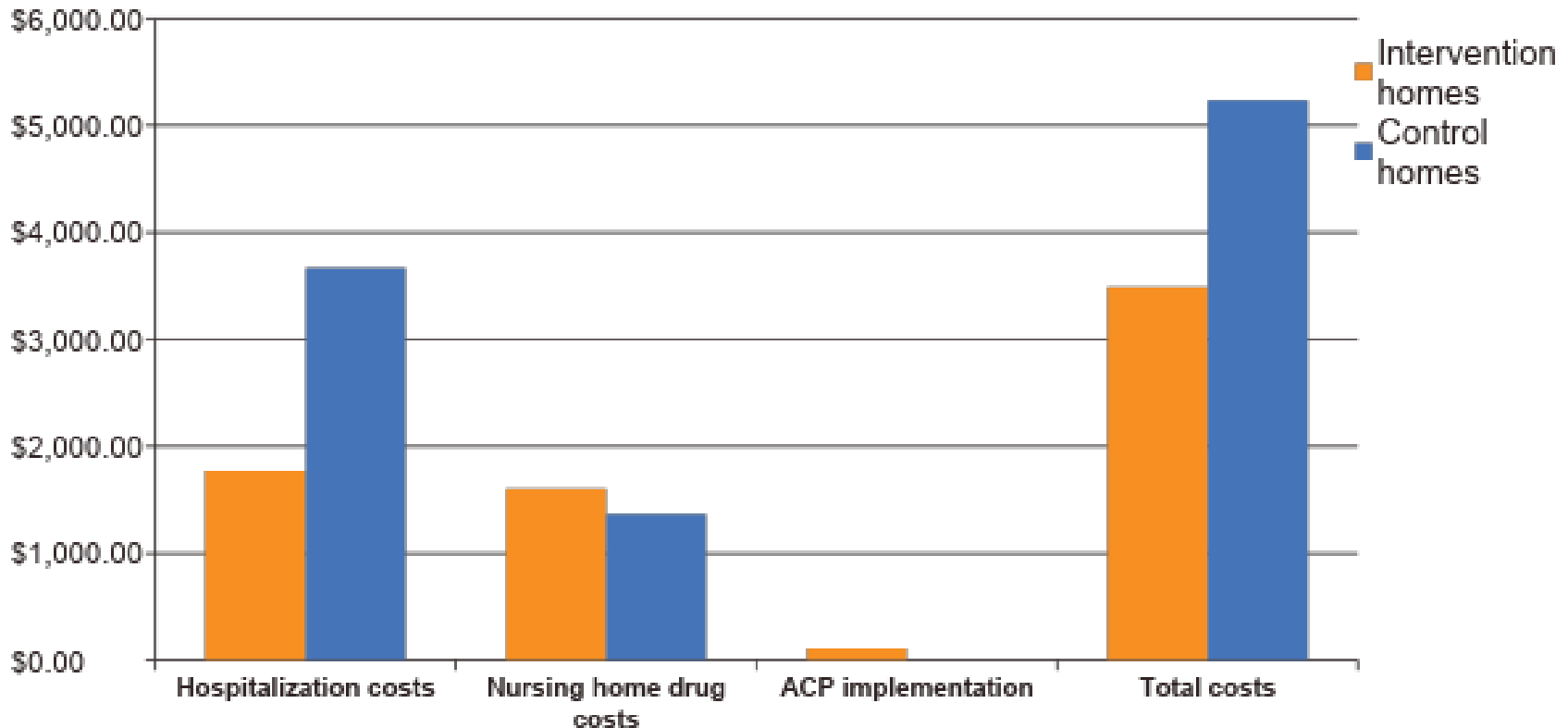
Residents dying in the hospital before and after ACP program implementation



Levy C, Morris M and Kramer A. Improving end-of-life outcomes in nursing homes by targeting residents at high risk of mortality for palliative care: program description and evaluation. *J Palliat Med* 2008; 11(2): 217–225.

Bonus:
Advance care planning
reduces health care
costs, admissions, and
readmissions.

Per patient costs following ACP implementation



Molloy DW, Guyatt GH, Russo R, et al. Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial. *JAMA* 2000; 283(11): 1437–1444.

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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 Aiming For



What We Need to Get There



**COMPETENT
COMMUNITIES**



**COMPETENT
PROFESSIONALS**



**COMPETENT
SYSTEMS**



**PUBLIC POLICY
& COMMON VISION**

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



ADVANCE CARE PLANNING KEY CONCEPTS

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

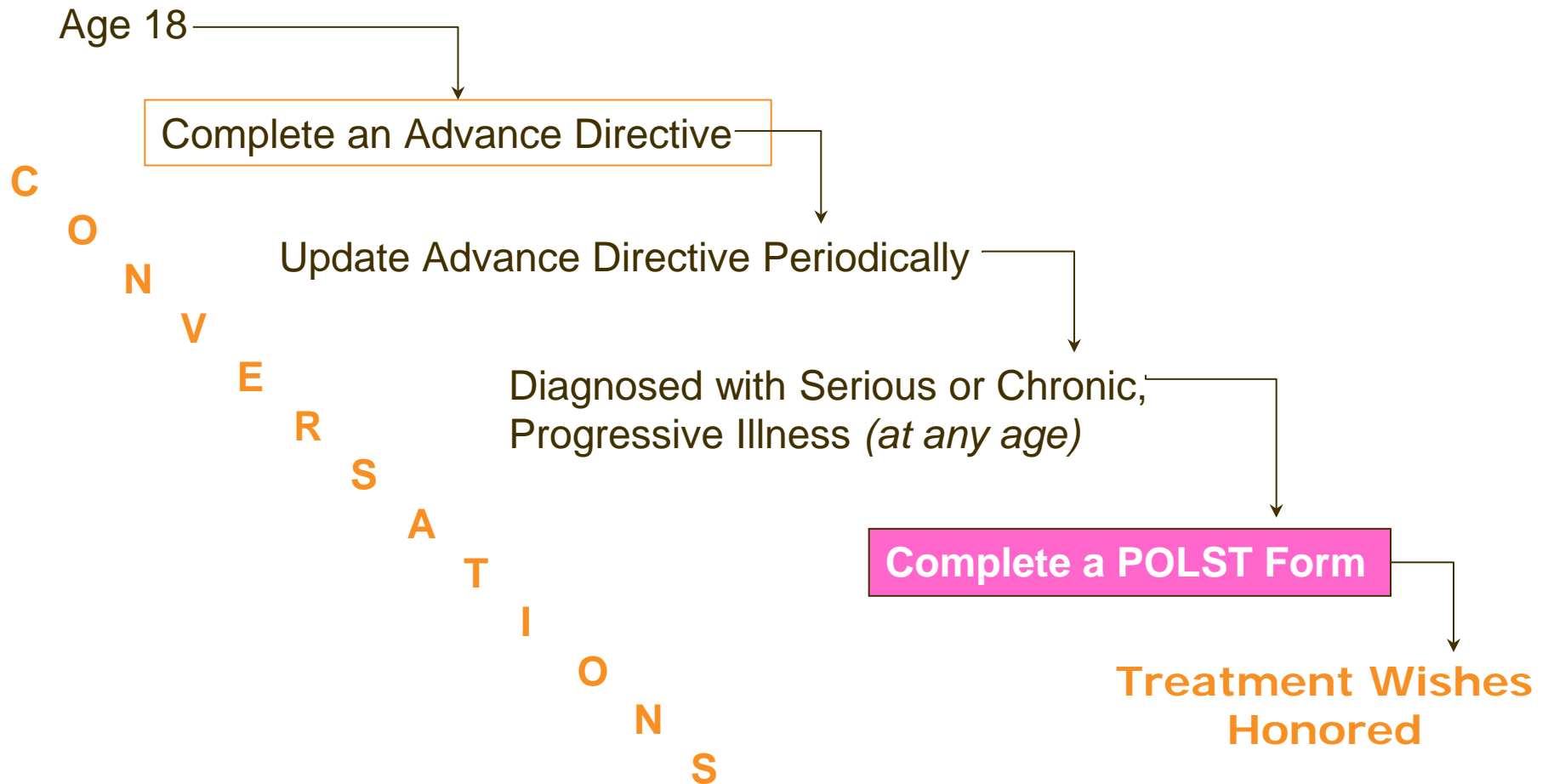
At diagnosis of serious or chronic illness or in advanced age

- 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



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 Advance Health Care Directive


This form lets you have a say about how you want to be cared for if you get very sick.

This form has 3 parts. It lets you:

- Part 1: Choose a medical decision maker, Page 3**
A medical decision maker is a person who can make health care decisions for you if you are too sick to make them yourself.
- Part 2: Make your own health care choices, Page 6**
This form lets you choose the kind of health care you want. This way, those who care for you will not have to guess what you want if you are too sick to tell them yourself.
- Part 3: Sign the form, Page 11**
The form must be signed before it can be used.

You can fill out Part 1, Part 2, or both.
Fill out **only** the parts you want. Always sign the form in Part 3.
2 witnesses need to sign on Page 12, or a notary on Page 13.

Your Name _____



PREPARE
FOR YOUR CARE

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Advance Health Care Directive

With the increasing ability of medical science to sustain our lives, people are living much longer than ever before. Unfortunately, as we grow older and experience poor health, we may find ourselves in a position where decisions need to be made as to how we wish to be treated in a variety of medical situations at the end of our lives. Further, sometimes we find ourselves in a condition where we can no longer express our preferences. Advance health care directives allow us to deal with these situations. Without such directives, your family may find it necessary to obtain court orders to deal with your medical situation.

State laws vary concerning the appropriate documents to cover these situations. All fifty states and permit you to express your wishes as to medical treatment in terminal illness or injury situations, and to appoint someone to speak for you in the event you cannot speak for yourself. Depending on the state, these documents are known as "living wills," "health care proxies," or "advance health care directives." Some states have a standardized document for this process, while other states leave the language up to individual lawyers and their clients.

What if an illness or an accident leaves you in a coma? Would you want to have your life prolonged by any means necessary, or would you want to have some treatments withheld to allow a natural death? What if you are dying from a painful terminal illness? Would you want to receive medical procedures to prolong your life?

An advance directive allows you to give instructions to your health care providers and your family on these topics. You can give them instructions about the types of treatments you want or don't want to receive if you become incapacitated. Usually, directives will only go into effect in the event that you can't make and communicate your own health care decisions. Up until then, you can continue to give directions to your health care provider even though you have an advance directive.

Hospitals and other health care providers are required under the federal Patient Self-Determination Act to give patients information about their rights to make their own health care decisions. That includes the right to accept or refuse medical treatment. If you have executed a Living Will, Health Care Power of Attorney, or Advance Health Care Directive, your health care provider may ask you for a copy.

Types of Advance Directives

A living will is your written expression of how you want to be treated in certain medical conditions. Depending on state law, this document may permit you to express whether or not you wish to be given life-sustaining treatments in the event you are terminally ill or injured, to decide in advance whether you wish to be provided food and water via intravenous devices ("tube feeding"), and to give other medical decisions that impact the end of life. "Life-sustaining treatment" means the use of available medical machinery and techniques, such as heart-lung machines, ventilators, and other medical equipment and techniques that will sustain and possibly extend your life, but which will not by themselves ease your condition. In addition to terminal illness or injury situations, most states permit you to express your

11

FIVE WISHES[®]

MY WISH FOR:

- The Person I Want to Make Care Decisions for Me When I Can't
- The Kind of Medical Treatment I Want or Don't Want
- How Comfortable I Want to Be
- How I Want People to Treat Me
- What I Want My Loved Ones to Know

DATE SIGNATURE

DATE SIGNATURE

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

The image shows a sample of a POLST form. The form is titled "Physician Orders for Life-Sustaining Treatment (POLST)". It includes sections for "GENERAL INFORMATION", "MEDICAL INTERVENTIONS", "ADDITIONAL MEDICINE NEEDS", and "INFORMATION AND SIGNATURES". The form contains checkboxes for various medical interventions such as "Cardiopulmonary Resuscitation (CPR)", "Artificial Airway", and "Mechanical Ventilation". The form is designed to be filled out by a healthcare provider and a patient or their surrogate.

Advance directive vs. CA POLST

Advance directive	POLST
General instructions for FUTURE CARE	Specific orders for CURRENT CARE
Needs to be retrieved	Stays with the patient
Many different forms	Single, standardized form
Signed by patient & witnesses or notary	Signed by patient (or HC Agent) and physician

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

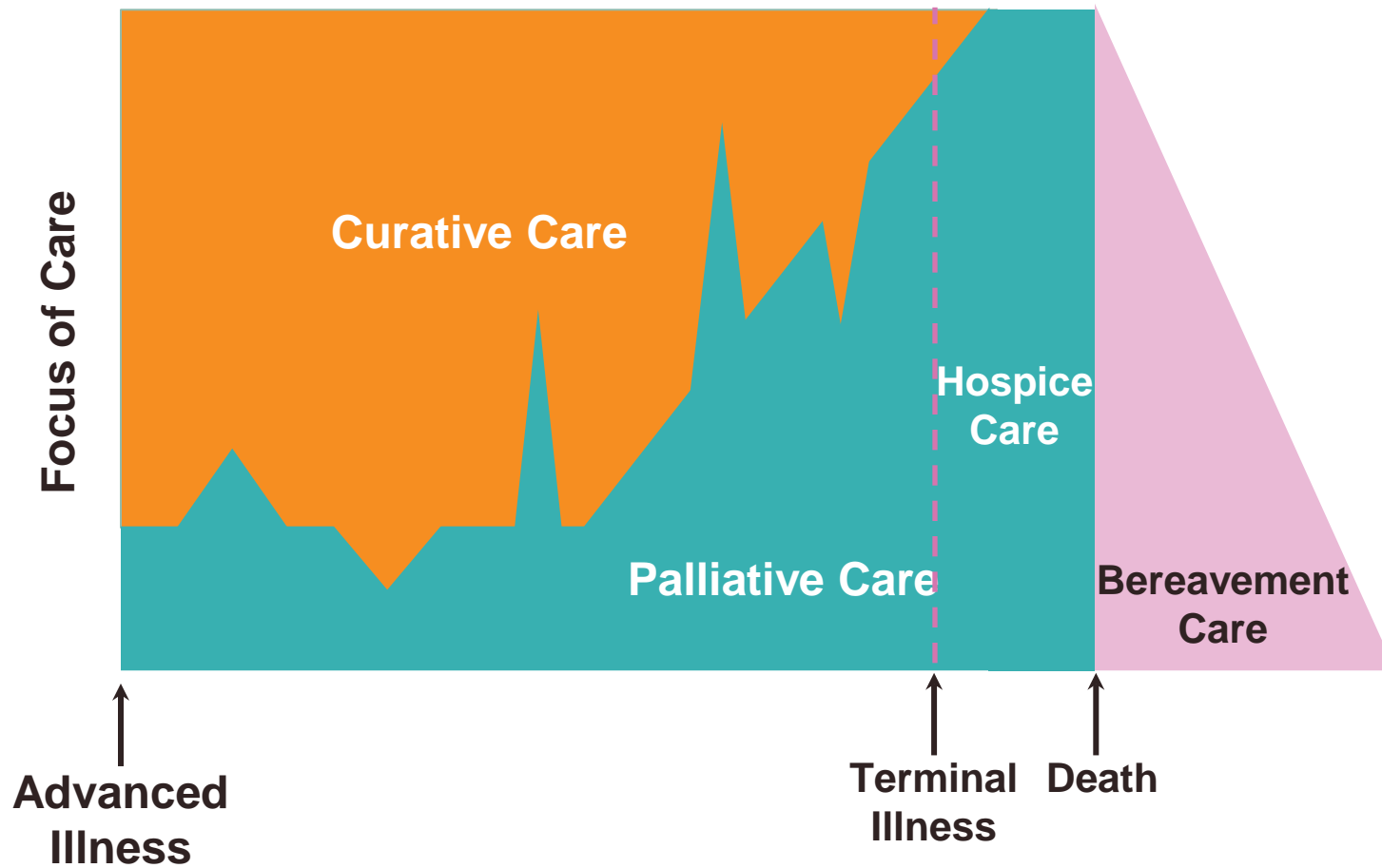
- Important life changes
Marriage, birth, separation, divorce, death
- Change in health status, new diagnosis
- Change in treatment preferences
- Every 5-10 years

This is a living document.

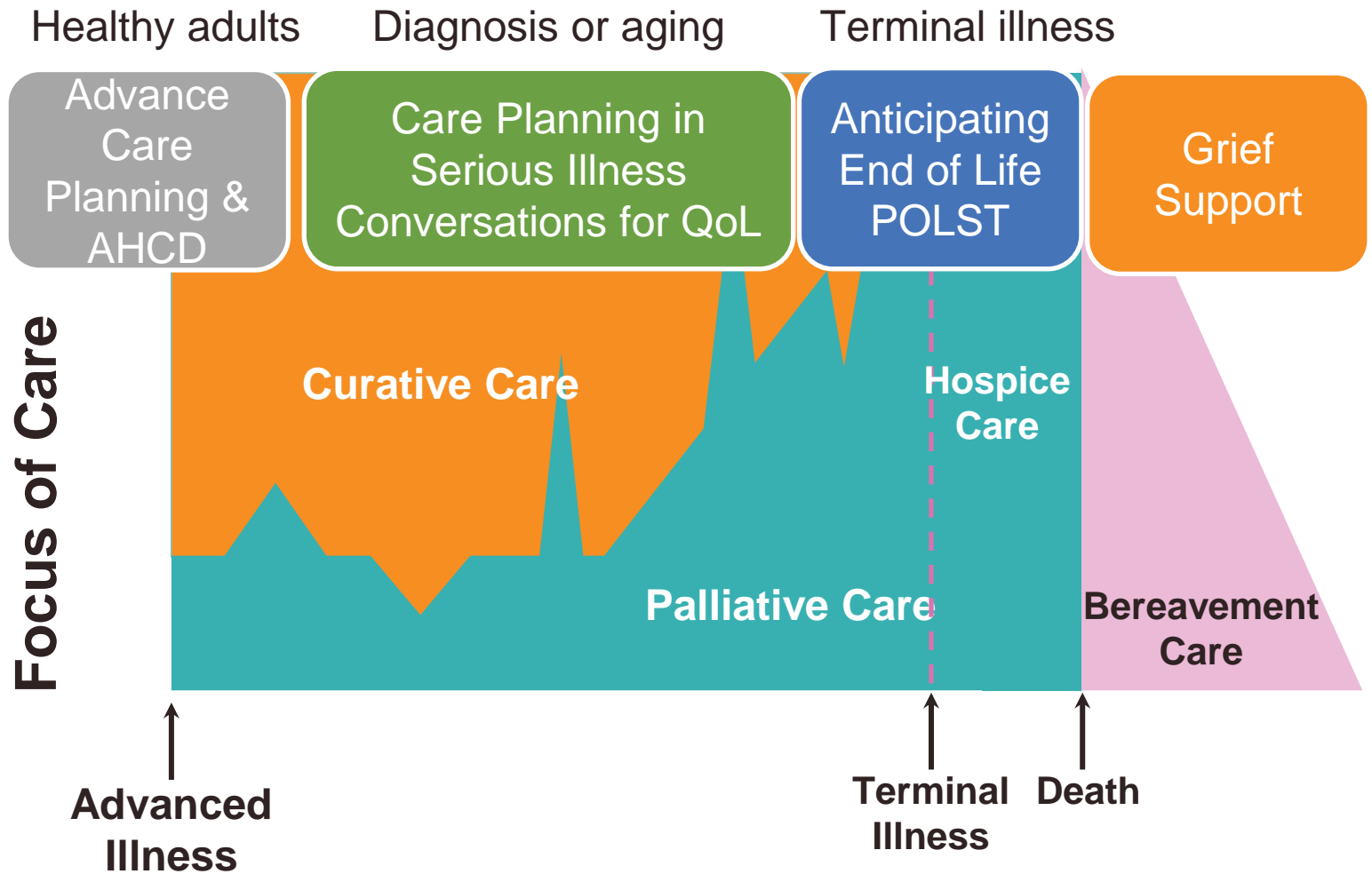
What if I change my mind?

- 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



Focus for Care Planning



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



CONVERSATION SKILLS FOR ACP

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

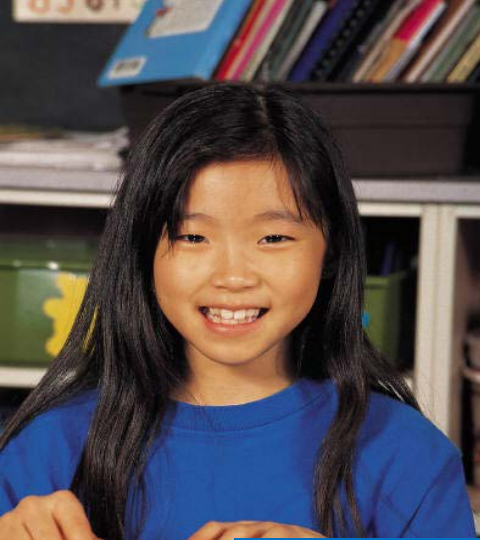
- Avoidance—“I don’t want to talk about that.”
- Not me—“I don’t need this now.” “My doctor will make those decisions.” “I’m not sick.”
- Language barriers
- Cultural differences
- Barriers due to setting or logistics
- Access to resources for ACP

Making decisions now that will impact future decisions

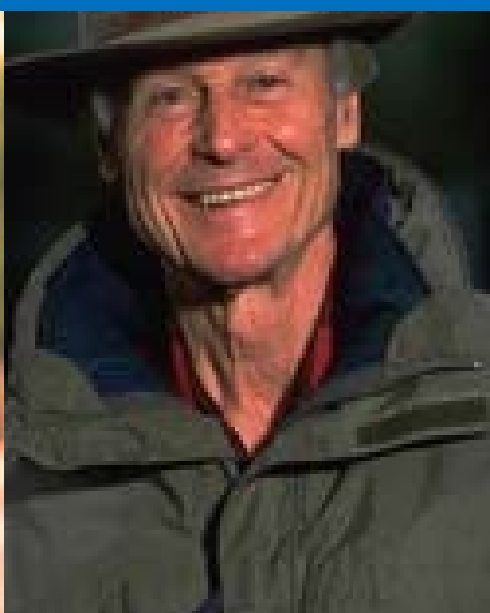
- Personal goals and expectations change over time; anticipate more than one conversation

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 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/>

Phrases & formats that help

	Example	Notes
Tell me more	Can you tell me more about?	For when you need more information or time...
Ask-tell-ask	Help me understand what you are asking. How much do you want to know? What information would be most helpful?	Avoids giving too much information at once Allows honest discussion of patient needs Respects their need to be & feel heard Helps gather more information
“I wish” statements	I wish I could tell you the treatment was always successful.	Align with patient but acknowledges reality

Adapted from work by Anthony Back, James Tulsky, others



Discussing serious news: SPIKES Acronym

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

Buckman R. *Breaking Bad News: A Guide for Health Care Professionals*. Baltimore: Johns Hopkins University Press, 1992:15. [Oncologist](#). 2000;5(4):302-11.

SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer.
[Baile WF](#)¹, [Buckman R](#), [Lenzi R](#), [Glober G](#), [Beale EA](#), [Kudelka AP](#).

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

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



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- Important life changes
Marriage, birth, separation, divorce, death
- Change in health status, new diagnosis
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Take Action

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



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