



Quality of Life Conversation On Advance Care Planning

Information Packet



About the Integrated Healthcare Association

The nonprofit Integrated Healthcare Association (IHA) convenes diverse stakeholders, including physician organizations, hospitals and health systems, health plans, purchasers and consumers committed to high-value integrated care that improves quality and affordability for patients across California and the nation.

The Quality of Life Conversation

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The Quality of Life Conversation

Invitation to Participate



To: Employer Organizations

The Integrated Healthcare Association (IHA) invites your organization to participate in the IHA Quality of Life Conversation – a vital initiative to improve awareness of advance care planning with their workforce.

IHA teamed up with the Coalition for Compassionate Care of California – a statewide partnership of regional and statewide organizations, state agencies, and individuals working together to promote advance care planning and high-quality, compassionate end-of-life care for all Californians. The Coalition brings great expertise, leadership and training experience and tools to this initiative.

There are compelling reasons to involve your organization’s employees in advance care planning. It’s integral to providing patient-centered care for everyone, and many of us have personal experience that underscores the importance of this topic on improving quality of life for ourselves and loved ones.

We hope you’ll join the IHA initiative and start this essential conversation!

The Quality of Life Conversation

Introduction

The Integrated Healthcare Association (IHA) and its member organizations are focused on patient-centered care. It's part of our mission. The ultimate measure of such care is whether patient values and preferences are honored, from date-of-birth to the end-of-life. For a variety of reasons, these preferences are not always known. That's why we'd like to start the conversation, beginning with you and your workforce.

IHA developed a voluntary initiative we hope you'll join. The Quality of Life Conversation is an awareness campaign on advance care planning and a call to action to expand the use of advance directives. We invite you implement an internal program focused on your workforce. Employees will be asked to start a conversation with family members about a topic important to all of us, as individuals and as healthcare organizations.

IHA also plans a limited public awareness campaign on the issue within the California community. This effort coincides with National Healthcare Decisions Day every year in April, and includes more than 1,000 organizations across the country.

The Quality of Life Conversation is a positive campaign and uses messaging and strategies already proven effective and sensitive to issues. We know this is a challenging topic for everyone. IHA leveraged the expertise and work of those already engaged with advance care planning in California and across the country. This includes some of our own members who have launched their own programs for employees or patients.

IHA's Board approved this voluntary initiative in September 2012. This information packet is meant to help you and your organization make a decision on participation. We think there's a compelling case to join and start with your workforce.

If you have any questions or would like additional information as you consider participation, please contact info@iha.org.

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Background

Patients often do not receive care that is aligned with their preferences, particularly at the end of life.

A major driver of this problem stems from deficiencies in the country's advance care planning framework. Advance care planning (ACP) refers to the process of discussing and documenting patients' preferences for the care they receive at the end of life. This helps ensure that preferences can be followed in the event one is no longer able to communicate, and that heroic efforts are not made to prolong the lives of patients against their own wishes.

What is the size of this problem?

There are significant opportunities for improvements in the quality of care delivered at the end of life with enhanced advance care planning. First, there is an unmet need for ACP conversations between patients and providers. A significant percent of adult Californians have not discussed advance care planning with their doctors and report that they would like to do so.

When these conversations do not take place, unnecessary or inappropriate care can result. For example, although patients prefer to die at home, most Americans die in hospitals. Engaging patients in end-of-life planning discussions can enhance patients' experience of care: it gives them a greater understanding of their treatment options, the ability to influence their care, the feeling that their physicians have a greater understanding of their wishes and lower levels of fear and anxiety.

Patients' wishes may not be written down or communicated with care providers.

Only a quarter of adult Californians report having put their end-of-life medical treatment wishes in writing; even fewer have had their doctor ask them about their preferences for end-of-life treatment. There are many reasons for this. End-of-life conversations can be challenging to navigate or awkward to bring up for both patients and providers. Physicians can be time-pressed or face competing, seemingly more important issues, and may feel the discussion can happen later when the need arises. Also, physicians are not reimbursed by Medicare or other payers for advance care planning discussions, which may require substantial time to talk through options with patients and their surrogates.

What is "Advance Care Planning" and why is it important?

Advance care planning is a process to ensure that the healthcare individuals receive at the end of their lives is aligned with their wishes. The goals of advance care planning are to:

1. Ensure clinical care is consistent with patient preferences, including when patients no longer have the capacity to express them;

2. Improve the decision-making process to a shared one with a proxy assigned to speak on behalf of the patient and flexibility that allows changes based on real-time patient status and preferences;
3. Improve patient well-being by reducing the frequency of over- or under-treatment; and
4. Reduce patient concerns about the burden placed on family members and others.

The Advance Directive

The existence of an advance directive – a form used to specify preferences for end-of-life care and designate a surrogate decision-maker – may not translate into patients’ preferences being honored. Advance directives come in many versions and can vary in detail from very general to very specific. There is no single gold standard. According to a series of AHRQ-funded research papers, 65-76% of physicians whose patients had an advance directive were unaware of the directive. Even when physicians were aware, advance directives did not necessarily translate into documentation in a medical chart, or could not be used in making decisions for reasons such as non-specific language. (See Attachment E for a sample advance directive.)

Physician Orders for Life Sustaining Treatment (POLST)

Physician Orders for Life Sustaining Treatment is a clinical paradigm designed to improve the quality of care for people who have advanced, progressive illness and/or frailty. Central components include the clarification and communication of patient treatment goals and wishes, documentation in the form of medical orders on a distinctly recognizable form, and an obligation of health care professionals to honor these preferences across all care settings.

In contrast to an advance directive, the POLST form reflects the patient’s here-and-now goals for medical decisions that may confront him or her today and converts these goals into specific medical orders. Differences between the POLST and an advance directive are outlined in Table One.

Table One: Differences between POLST and Advance Directive

Characteristic	POLST	Advance Directive
Population	Advanced progressive chronic conditions (situations where a clinician can answer ‘no’ to the question “would you be surprised if this patient died within a year?”)	All adults
Time Frame	Current care	Any future care
Where Completed	Medical setting	Any setting
Portability	Provider responsibility	Patient/family responsibility
Periodic Review	Provider responsibility	Patient/family responsibility

Source: Charles P. Sabatino and Naomi Karp, “Improving Advanced Illness Care: The Evolution of State POLST Programs.” AARP Public Policy Institute, 2011. p.4.

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Reasons to Get Involved and Join the Initiative

Advance care planning is vital to improving quality of care and patient experience for everyone, no matter their age or health status, and can minimize anxiety and strife for family members. California healthcare organizations are well positioned to make a difference. The diversity of organizations and workforce strength offer the potential to engage many individuals and their families. California is so often ahead of the curve on healthcare issues, but this is an area where we can do so much better. We need your help.

Many of the reasons listed below to participate are stated in terms that talk about patients. However, we know that satisfaction with healthcare services offered by an employer often carry over to how employees feel about where they work. This is certainly the case for healthcare organizations. And, there is an element of pride about working for an organization dedicated to making sure that all services provided – whether to employees, their families or other members – respect individual preferences for care at all stages of life, including end-of-life.

Advance care planning may enhance patient experience

Engaging employees in planning discussions can enhance patient empowerment and patient experience of care. It offers greater understanding of treatment options, the ability to influence their care, the feeling their physicians have a greater understanding of their wishes, and may lower levels of fear and anxiety.

California healthcare employers should take the lead

California healthcare organizations have a responsibility to lead on an issue that affects everyone who receives healthcare services, starting with our workplace. Our leadership can lay the foundation to have all California adults understand the need for quality of life conversations, and how it ultimately improves care.

Californians do want to discuss end-of-life care with their doctors

47% of patients surveyed by the California HealthCare Foundation say they would “definitely” like to talk to their doctors about their end-of-life wishes and 48% reported they would “probably” or “maybe” like to have an advance care planning conversation.

Personal preference and values are not honored in advance care

Patients prefer to be in the comfort of their own homes, yet most Americans die in hospitals.

Only 23% of adult Californians report having a written document stating their medical treatment wishes

And only 7% have ever had their doctor ask them about their preferences for end-of-life treatment. Reasons vary, including the challenge of discussing the issue, time

constraints, perception that other issues are more pressing, and lack of Medicare and payer reimbursement.

Less than 50% of severely or terminally ill patients have an advance directive in their medical record

Although these patients may have completed an advance directive, their stated wishes may not be acted upon if the document is not available when healthcare decisions are made. The record may not follow transitions to different care settings such as from a physician office to a nursing home.

Accidents are the 5th leading cause of death in California and nationally

Most advance care planning efforts have focused on those who are older, have a serious illness or are hospitalized. This misses the opportunity to help individuals and families plan ahead – not every situation that may require healthcare services can be anticipated. Surveys show people are concerned about placing a decision burden on family members.

Increased workforce awareness should benefit members

Encouraging your employees to have a discussion with their own families should benefit members, too. Clinical staff responsible for having advance care discussions with patients may gain valuable insight and experience from having the conversation with their own family members.

Unique opportunity to shift the conversation

Most awareness campaigns have focused primarily on the elderly and terminally ill. As healthcare organizations, we have an opportunity to redirect the focus and change behavior. With our example and working with others, we can help reframe the discussion to one that all adults should have.

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Initiative Overview

The IHA Quality of Life Conversation is an education and awareness campaign focused on employees of participating organizations. It is not aimed directly at health plan member or patient audiences.

The initiative includes an employee awareness campaign on advance care planning and a call to action to complete an advance directive. IHA is providing the resources you need to implement an effective employee program. We provide the contact information of experts to train designated employees, provide a baseline employee survey and develop a comprehensive communications and implementation toolkit.

This is a challenging and sensitive issue. That's why we've talked to those already deeply engaged in the issue in California, and nationally. We're fortunate that groups including The SCAN Foundation, California HealthCare Foundation and California Coalition for Compassionate Care (CCCC), and other national organizations have already done significant work. Each of these groups has completed surveys, research, message development, and developed engagement strategies and written material.

Most people associate this topic with death, so it's not surprising they avoid discussing it. Many may think there's time in the future to discuss the issue when they "need" to. Unfortunately, accidents are the 5th leading cause of death in California and nationally. So, to make it more approachable, "re-branding" has reframed the issue by talking about values and preferences for living life – right up to the very end. Such planning has been recast as having a "kitchen table" conversation. SCAN, for example, has developed positive key words based on polling for their advance care planning program to include "active" "friends" "community" and "independent." Surveys have also determined where there may be cultural differences on the issue among African Americans, Hispanic and Asian Pacific Islander populations.

This work helps us advance strategies and messaging that is positive and proactive. It is reflected in the ideas and material you receive from IHA.

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Program Elements

IHA's awareness and call to action program includes the following:

1. Seek Executive Approval and Support

We know your organization has approvals and authorizations to complete before launching a company-wide or regional program aimed at employee education. We invite you to share this information packet with your human resources, legal, and employee communications or training executives to help them understand the initiative and goals to empower patients and improve quality of life.

2. Designate an Implementation Team

Your organization will need to designate an internal implementation team and lead. IHA strongly recommends creating a two-track approach for clinical and non-clinical staff. For this reason, we recommend selecting at least one clinician (e.g., physician or nurse) and one non-clinician from human resources or training departments.

The team's designated lead should be either a physician or executive champion. If the team lead is not a physician, you might include a physician as another clinical team member.

Each team should have at least two fully trained facilitators – including at least one clinician. Once trained, these employees may facilitate employee meetings, lead educational workshops and make presentations on the initiative. We estimate the time required for this role will range from a few hours to one or two days per month for several months depending on your company's size and program. The team may also decide to customize material provided by IHA to meet your organization's individual needs.

3. Communicate to Employees

Organizations develop and distribute communications to employees that will introduce the Quality of Life Conversation on advance care planning.

4. Baseline Awareness Survey

To develop the most effective employee program and aid informal evaluation, IHA has developed a short confidential survey of approximately 6 core questions. You may want to add a few questions of your own. (*See sample survey questions in Attachment B.*)

The survey can be completed online. Results may help determine how to structure your program – where to focus and what information may be most helpful.

A follow-up survey assesses whether the initiative has enhanced awareness of advance care planning, led to more family discussion, and/or increased the use of advance directives.

5. Train-the-Facilitators

IHA partnered with the California Compassionate Care Coalition (CCCC) on training. Their experts are available to conduct training for participating organizations. CCCC is available for consulting and implementation services. Members of the implementation team will learn to lead workshops, give presentations, answer questions and serve as a resource for employees.

(See Attachment C for more information on training.)

6. Comprehensive Implementation and Communications Toolkit

IHA has provided the tools needed to implement an effective internal program and “start the conversation” on advance care planning. The tools offer ideas for engaging employees on the issue as well as user-friendly written material. There are a variety of template communication materials you can use in different settings. These include, but are not limited to:

- Email or memo announcing the initiative to your employees
- Fact sheets
- Frequently Asked Questions (FAQ)
- Presentations – power point slides, speeches and webinar scripts
- Articles to use for employee newsletters, Intranet copy
- Website copy and social media component (if there is sufficient demand)
- Copies of two different types of advance directives to use in California
- Resources list – where to go for additional information (web-based)
- Suggestions on activities to engage employees on the issue including group meetings, brown bag lunch sessions, health fairs and more
- Suggestions on how individuals can begin thinking about their values and prompts for having difficult conversations with their families

The toolkit is flexible for organizations to use “off the shelf,” pick and choose only a few communication tools, or customize to fit their organization’s style and messaging. Sample communications are included as attachments to this information packet.

The Quality of Life Conversation is about empowerment and respecting choices about care and treatment. Without advance care planning or advance directives, the patient’s voice may be lost at the most critical times of care. Communications should be framed in a sensitive nature that express choice and promote a quality of life conversation at a time when the individual has sound mind and judgment to make their wishes known.

7. Conduct Employee Meetings

Organizations will confirm the schedule for employee meetings, designate specific implementation team members that can be approached by employees for follow-up questions, understand legal requirements for completing an advance directive, and may identify and possibly compensate notary publics that are available within the organization to notarize advance directives. Employee educational sessions may be conducted in-person, via webinars, health fairs, training sessions, or “brown bag” luncheons.

8. Informal Evaluation

Using the initial survey as a baseline, a follow-up survey is recommended to review how the awareness campaign and call to action changed perception and whether it increased the number of employees with an advance directive.

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Sample Timeline

Project Plan	Date
Decision to participate	Week 1
Designate Implementation Team and Executive Champions	Week 1
Decision on number and type of training sessions for team members	Week 1
Implementation teams and facilitators attend formal training sessions	Week 2
Communicate Quality of Life Conversation initiative to employees	Week 3
Distribute baseline survey to employees	Week 4
Launch campaign communications and conduct employee education sessions	Weeks 5-8
Re-distribute survey to employees to measure improved awareness	Week 8

Launch: Once your organization decides to implement the IHA initiative and gains approval from management, you should designate a project lead. Participating organizations will also need to designate an implementation team and lead. The lead should be a physician or executive champion. Members should include clinicians (physician, nurse) and non-clinicians (human resources or training).

Training: Representatives that have been identified by their organization to be part of their “implementation teams” or a “facilitator” begin formal training sessions with professional trainers to learn how to facilitate employee workshops on discussions of advance care planning and advance directives.

Implementation: Implementation team “facilitators” conduct training sessions for employees on “having the conversation” and filling out advance directives (professional trainers will be present for first one or two sessions).

- Coordinate employee baseline survey
- Organizations may choose to identify notary publics within organization to assist with advance directives; and determine notary compensation for this campaign
- IHA develops/forwards a comprehensive implementation and communications toolkit
- Schedule and arrange presentations featuring:
 - ✓ 20 minute power point; 10 minute Q&A
 - ✓ Hand-outs: Fact Sheet; Advance Directive samples
 - ✓ Additional resources: webpage, implementation team contacts

Attachment A: Sample Employee Email

Today we're announcing a new awareness and call to action program for all of our employees. It's about starting a conversation with your families about your values and preferences in how you live your life and think about your healthcare.

These conversations – that include advance care planning and advance directives – are those we also have with our patients/members.

We're participating in this program sponsored by the Integrated Healthcare Association, along with other healthcare organizations in California including health plans, hospitals and medical groups.

We often talk about quality of care and patient-centered care. It's part of our mission and our job. We want to make sure these principles apply to each of you and your families, too. That means thinking about what you value and prefer when you receive healthcare services. You already make decisions every day about your life and your healthcare. This is about planning for future medical needs.

Our campaign will encourage everyone to start a conversation with their family on what's important to them and what they think about different types of care, including at the end-of-life. We'll also give you the tools to help document those preferences. Honoring your values and preferences at all stages of your care is important for you and your family.

We know these are not easy topics to think about or discuss with family members. Surveys of Californians show that a majority of people want to talk about these issues but don't. Ultimately, having a kitchen table conversation with loved ones can bring peace of mind. Planning ahead is always a good idea.

To help you tackle this important planning for the best possible life, we'll have resources to share with you in the coming months. There will be handouts, a website and project team members you can talk to. We're also planning group meetings, brown bag lunches and webinars, etc. where you can learn more and ask questions. We'll also have a confidential questionnaire so we can find out what everyone already knows about this topic and what information would be most helpful.

All of you are involved in healthcare, no matter what your job is here. You know from experience at work and likely in your own life, how important it is to let your family and doctor know about what you value in your care. From your own experience, you probably also realize these discussions and decisions are not just for those who are very old or may have a serious illness. These are conversations we should all have as adults as we discuss our healthcare needs.

We hope you'll want to learn more about this important topic and that you'll join the conversation and start your own.

If you have any questions, comments or have ideas to share, please contact <team facilitator>.

Attachment B: Sample Employee Survey

Email text:

To: All Employees (or Regional or Select Group of Employees)
From: Executive or Physician Champion
Subject: Quality of Life Conversation about Advance Care Planning

Did you know that you have the power to direct your healthcare choices, even when you are unable to speak for yourself? This patient empowerment and choice is activated when you talk about advance care planning, or what we are calling, “The Quality of Life Conversation.” This initiative is about patient empowerment and respecting choices about care and treatment.

Please take the next five minutes to take a **confidential survey** on advance care planning. Your responses will allow us to tailor an educational campaign to give you the power to have your voice heard when you need it most.

To take the survey, click on the following link:

[Survey](#)

Survey questions:

1. What is your current awareness of advance care or end-of-life planning?
2. Do you know what an Advance Directive is?
3. Have you had a conversation with your family regarding advance care planning?
4. How comfortable are you with discussing this topic with your family?
5. Do you have an Advance Directive? If yes, does your doctor have a copy?
6. What would you like to know about this topic?
7. How can we help you get started?

Closing page:

Thank you for taking this important survey. Patient empowerment and respecting choices about individual care and treatment is very important to us. You will hear more from us on the Quality of Life Conversation in the next few weeks.

Regards,
Executive/Physician Champion

Attachment C: Training Information

Coalition for Compassionate Care of California Quality of Life Conversation Training

Led by Judy Citko, JD, Executive Director, the Coalition for Compassionate Care of California (Coalition) is a statewide partnership of regional and statewide organizations, state agencies, and individuals working together to promote high-quality, compassionate end-of-life care for all Californians.

IHA partnered with the Coalition experts to conduct initial training for member organizations that participated in the Quality of Life Conversation initiative.

The Coalition is available for consulting and implementation services, to train facilitators, and support the facilitators from each organization with their employee training.

The Coalition training sessions are designed for those who will be facilitating advance care planning workshops for staff within their organizations. The trainings include additional information about the legal and clinical aspects of advance care planning and advance healthcare directives and how to “have the conversation.” Workshops are interactive and include role plays and small group discussions.

The training will address such issues as why you should think about this issue now rather than later and how to begin the process. Participants will also learn about the steps involved in advance care planning: considering your personal values about quality of life, choosing someone to speak for you, talking with your decision-maker, talking with your doctor, and completing an advance directive.

As part of the training, participants work on a sample program and receive materials to use with staff in their organizations, including “Go Wish Cards”, “Consider the Conversation” video, 5 Micro-Documentaries on advance care planning (2 minute shorts on why it’s important), plus other selected brochures and factsheets to facilitate understanding.

For more information on the Coalition for Compassionate Care of California, and their consulting fees and availability, see: <http://coalitionccc.org/>

Attachment D: Advance Care Planning Resources

California Coalition for Compassionate Care

<http://coalitionccc.org/>

The SCAN Foundation

<http://thescanfoundation.org/>

National Healthcare Decisions Day (April 16)

<http://www.nhdd.org/>

California Health Care Foundation

Advance Care planning videos. <http://www.chcf.org/projects/2012/end-of-life-care>

Respecting Choices

Evidence based program established in 2000 by Gunderson Lutheran Medical Foundation in La Cross, Wisconsin; includes training and certification in advance care planning via online learning modules, webinars, and onsite training options.

<http://respectingchoices.org/>

Costs for training vary and can be found on the Respecting Choices website at:

<http://respectingchoices.org/>

Five Wishes

Living Will with instructions for completion, available in 26 languages:

<http://www.agingwithdignity.org/five-wishes.php>

The Institute for Healthcare Improvement - The Conversation Project

Website with “Starter Kit” to guide families in a Conversation -

<http://theconversationproject.org/>

American Bar Association

Consumer’s Tool Kit for Health Care Advance Planning

http://apps.americanbar.org/aging/publications/docs/consumer_tool_kit_bk.pdf

Caring Connections

Sponsored by the National Hospice and Palliative Care Organization

<http://www.caringinfo.org>

Project Grace

“One Slide” campaign to get people talking about advance care decision making and preferences <http://www.engagewithgrace.org/Download.aspx>