Expanding the Volunteer Role to Include Advance Care Planning Knowledge

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Expanding the Volunteer Role to Include Advance Care Planning Knowledge

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NURS 670: Internship

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Expanding the Volunteer Role to Include Advance Care Planning Knowledge

Abstract

Problem: Transition patients at the end-of-life are those patients who are not mentally ready or physically eligible for hospice thus not enrolled in a Palliative or Hospice Program. Only one-third of the Transition patient census had completed and filed advance care plans. Healthcare providers are obligated to perform life-saving measures unless documented otherwise. A lack of advance care planning can create complicated scenarios and cause discordant care incidents.

Context: End-of-life care is a delicate subject to navigate conversations with patients. With holistic care being a large component of hospice and palliative care, it is important to have updated and accurate advance care plans for all patients, including Transition patients.

Intervention: A training program was developed and conducted with volunteers to assist patients to better identify and document their end-of-life wishes, care goals, and values.

Measures: Competency quizzes conducted online before and after training were collected to determine the program’s efficacy and retainment of knowledge. A score of 80 percent was considered a passing rate, and the aim was an overall average increase of knowledge by 15 percent across all the volunteers. Long-term measures include 100 percent of patients having received a follow-up and having completed and electronically filed advance care plans.

Result: No volunteer reached the 80 percent competency rate with the pre-test. However, all volunteers increased their knowledge as indicated with a better score greater than or equal to 15 percent than the pre-test. The average post-training score was 93 percent.

Conclusion: Advance care plans support patient autonomy and preserve patients' ability to be informed and involved in their care. Training volunteers to follow-up and educate Transition-
enrolled clients about advance care planning will benefit the patient, the patient’s family, and the healthcare system.

*Keywords: advance care plan, training, education, end-of-life care, hospice, palliative care*
Personal Leadership Statement

The nurse leader is in a pivotal role where they can use their responsibilities’ expectations and their position’s influence to enact positive changes in health care. A clinical nurse leader in quality improvement is responsible for the design and implementation of improved patient care outcomes through coordination, delegation, and supervision of their healthcare team (American Association of Colleges of Nursing [AACN], 2007). The intersectionality of personal faith beliefs and mission in nurse leadership are the driving factors of where nursing should be.

From a Christian perspective, being spiritual in practice means to live in love, with the company of others and God, and with the purpose of being a gift to the Earth. The love of God and the love of neighbors/others become a driving factor. The nursing paradigm, as suggested by Domingo-Osle & Domingo (2020), consists of three elements: care, relationship, and practice. There is not one without the other, and the domain of nursing is the extension of caring and relationships.

The hospice organization is a secular space, not affiliated with any specific religion or spirituality. However, the core essence of nursing practice remains the same in building deeper and holistic relationships between members of the healthcare team and the patient and their families. The microsystem’s commitment to compassionate, culturally aware, respectful, and competent care overlaps with my values to care for others.

Introduction

Health care is holistic in caring for an individual at every life stage. This includes hospice and palliative care, which seek to improve the quality of life at the last stage of life. There are many approaches to ensure that client healthcare-related wishes are accurately represented and completed (Hickman et al., 2015). The Physician Orders for Life-Sustaining
Treatment (POLST) and California Advance Healthcare Directive (CAHCD) are among the advance care plans utilized in a hospice setting.

Advance care plans support the idea of patient autonomy and preserve patients' ability to be informed and involved in their care. To equip the hospice volunteer team who work with Transition patients with advance care planning knowledge can help reduce costs and increase patient safety and satisfaction with care. A nurse leader with relational strengths is in an integral position to build an influential team and create positive quality improvement changes.

**Problem Description**

Advance care plans have the potential to provide crucial information related to preferences in care options that align with the patient’s values. This hospice setting conducts biweekly meetings with the interdisciplinary care team to discuss patient updates. Nurses routinely check in with patients to provide teaching, gather assessments, perform medication reconciliation, and be the communication bridge between the patient and the rest of the care team. The frequency of nurse visits depends on the patient’s symptoms and level of care. A nurse has a constantly changing schedule with various responsibilities. It would be hard to add more responsibilities.

In its current state, the volunteer’s primary role is companionship at the bedside. Some volunteer responsibilities include listening without judgment, identifying activities that define and promote quality of life, and joining the patient on outings. Previous rotations of volunteers have been educated and trained to teach patients about advance care planning. However, current volunteers lack training or assigned responsibility regarding advance care plans. It is in the organization’s best interest to further expand the volunteer role, who already are at the bedside and have established rapport with clients, to include advance care planning completion and
follow-up regarding quality of care and the patient’s needs as their condition changes (see Appendix A for Gap Analysis). Equipping the volunteer team with advance care planning knowledge can help reduce costs and increase patient safety and satisfaction with care.

**Specific Project Aim**

With the implementation of a hospice and palliative care volunteer-based advance care planning education program, the aim is to increase volunteers’ knowledge of advance care planning forms (ex. POLST, CAHCD) and resources by an average of 15 percent, compared to the pre-knowledge. (See Appendix B: Project Charter.)

**Available Knowledge**

**PICOT Question**

A PICOT question is an approach used to guide and summarize research for evidence-based quality improvement initiatives. The PICOT question: For volunteers in a hospice and palliative setting, how will an advance care planning education program, in comparison to no education, affect volunteer knowledge immediately after implementation of the program?

**Search Strategy**

An electronic search was conducted to review evidence regarding the influence of advance care plans and the role of a volunteer in a hospice or palliative clinical setting. Databases such as CINAHL, PubMed, and various online journals were searched for research studies, systematic reviews, and literature synthesis papers using a varied combination of the following keywords: volunteer, volunteer role, hospice, palliative care, health outcomes, advance care plan/planning, advance health directive, and POLST form. Limitations were set to include research written in English published after 2015. The Johns Hopkins Nursing Evidence-Based
Practice Appraisal Tool was used to determine the quality and the level of evidence for each article (see Appendix C: Evaluation Table).

**Synthesis of Literature**

Of the six articles reviewed, four were research evidence falling between levels two to three. The only level two article was a survey with 501 participants that analyzed the components and the complexity of advance care planning, including the barriers and readiness of individuals (Sudore et al., 2017). A level three piece of evidence used a nonexperimental method of prediction as their research design to look into the role of a nurse leader and their influence in promoting change initiatives (Ducharme et al., 2017). The other level three evidence articles were systematic reviews; one of advance care planning educational resources (Gazarian et al., 2019) and the other of 20 observational studies looking into the intersection of patients and their POLST status and healthcare outcomes (Vranas et al., 2021). The two other pieces of literature were at a level five scoping review regarding different models of a volunteer-based advance care planning program and its risks and benefits (Sellars et al., 2019) and an integrative review about the factors that lead to an incomplete advance care plan and ways to approach conversations with older adults regarding care plans (Frechman et al., 2020). These evidence pieces vary in level and quality. However, most of them are related to advance care plans, and all relate to this improvement initiative, whether it is to help explain the status quo, how and why change should be implemented, and the expected outcomes of training volunteers to understand and assist patients with advance care planning.

**Rationale**

Roger’s Five-Step Theory, also known as the Innovation Diffusion Theory, was developed in 1995. It helps explain how knowledge of an innovation or intervention can be
decided to be adopted or rejected. A distinctive aspect of this theory is that if a project is not successful with the desired outcomes, it can always be postponed if it is better applicable in the future time frame in a more appropriate manner. Roger emphasizes the importance of including key stakeholders, maximizing the organization’s strengths, and facilitating the different factors that could inhibit change (Willcox et al., 2018). The five stages in theory include knowledge, persuasion, decision, implementation, and confirmation (Willcox et al., 2018). The change process begins with exposure and knowledge building of an innovation (or change agent), followed by the decision and implementation of a change and the confirmation to continue or suspend the innovation (Willcox et al., 2018).

Watson’s Theory of Human Caring was developed between 1975 and 1979 to complement medical science. Nursing practice is rooted in science, and Watson wanted to create a philosophical and ethical basis in the nursing discipline unique to the values, knowledge, and practices of nursing care (Smith & Parker, 2020). In this shift from medical and clinical nursing, Watson transitions to include humanity and the holistic experiences of the healing process. The ten “curative factors” also known as the ten “caritas” expand the views of self and promote oneness and connectedness of all within nursing as a healing model (Smith & Parker, 2020).

The original ten “caritas” are: “formulation of humanistic-altruistic system of values; instillation of faith [and] hope; cultivation of sensitivity to one’s self and to others; development of a helping, trusting, and human caring relationship; promotion and acceptance of the expression of positive and negative feelings; systematic use of a scientific problem-solving caring process; promotion of interpersonal teaching [and] learning; provision for a supportive, protective, and/or corrective mental, physical, societal, and spiritual environment; assistance with
gratification of human needs; and the allowance for existential [and] phenomenological forces” (Smith & Parker, 2020, pp. 315-316).

In consideration of the quality improvement initiative, both Roger’s Change Theory and the Watson Caring Theory can cohesively explain how and why the role of a palliative care volunteer can and should be expanded to include advance care planning follow-ups. With the acquisition of previous teaching materials and current research regarding advance care planning, change can be integrated using a pilot program guided by Roger’s Five-Step Change Theory. Structuring change around Watson’s Caring Theory can allow for better follow-up with patients and their goals, leading to better outcomes, and a more holistic and involved approach. Roger’s and Watson’s frameworks can help identify variables of the change process and how implementation can be considerate of the human end-of-life experience.

Context

Microsystem Assessment

Purpose/Patients

This hospice agency is a local, independent nonprofit organization that gives the end-of-life process a team-oriented and holistic approach. They provide support, services, and care coordination to patients and families. The organization serves patients with terminal illnesses and chronic conditions across the end-of-life spectrum with different programs depending on the needs and goals of care. The prioritization of quality of life is essential to the core values and mission of the hospice organization.

Professionals

If a patient is enrolled in hospice, the members of their care team, consisting of a physician, nurse, case manager, social worker, and clergy, as applicable, visit at regular intervals.
Volunteers, who are provided with a 26-hour training course, are provided at patient request and volunteer availability. The volunteers become an integral part of the care team as a bedside presence.

**Process**

Upon initial intake, the client undergoes an acuity assessment, and follow-up occurs with the different members of the care team. If a patient is enrolled in the hospice program, follow-up will happen at a minimum of weekly intervals, varied by different team members. An interdisciplinary group (IDG) meets every two weeks to discuss patient goals and care plans to determine needs and if any changes in care are required.

Patients who are not mentally ready or physically eligible for hospice are enrolled in the Transitions Program. At no cost to the patient, the Transitions Program provides nursing evaluation and consultation, social work support, and volunteer services to individuals with life-limiting illnesses who continue to receive treatment. Follow-up happens every few months by a nurse or social worker depending on staff availability.

**Patterns**

There is no pattern within the Transitions Program regarding who gets a follow-up and how often. Patients enrolled in the program understand that they may contact the hospice organization at any time for questions or service requests (such as volunteer services). Patients are followed up if hospitalizations or call requests occur. Otherwise, it can be months up to a year before a patient is followed up.

Leadership at the executive level is open to change and wants to have better processes for patient care follow-ups and volunteer training for advance care planning. Patients and families are greatly involved in patient care and discussions with the healthcare team at the hospice
program levels, but conversations are lacking at the Transition level. There is a desire to better utilize the Transitions program, the time of current staff in their roles, and further develop the volunteer role to utilize the overwhelming number of volunteers.

**SWOT Analysis**

A strengths, weaknesses, opportunities, and threats (SWOT) analysis was completed to assess the external and internal factors that might impact the quality improvement initiative. One of the organization’s strengths is using a community-based approach with a variety of competent staff and well-trained volunteers to serve the needs of patients and families. However, not every patient gets the proper follow-up due to the time limitation of staff. There is an opportunity here to expand the volunteer role to provide relief to staff and better increase patient outcomes and care satisfaction supported by the agency’s strong management and leadership team. An improvement in care could lead to more funding and donations from the community, and retention of patients and services, limiting the threat of losing patients and families to competitors. End-of-life conversations can be challenging, and patients and their caregivers might be resistant, but the volunteer is already in an ideal role to have those conversations. (See Appendix D, SWOT Analysis.)

**Communication Plan**

Throughout the quality improvement project, stakeholders were updated based on the power interest grid (see Appendix E). The Director of Compliance, Quality, and Education and the Events and Community Education Manager were asked for input at every stage due to their high power, high interest, and the proximity of who and what services they regularly oversee. Members of the board and the senior administrative team have high power but have limited interest. Therefore, they are to be kept satisfied with the goals and results of the quality initiative
project. Other members of the clinical staff, such as nurses and physicians will be contacted as needed as they have low power and low interest regarding the project. Volunteers and social workers will be affected by the quality improvement project and need to be kept updated at every stage. And those with high power and high interest, such as the Director of Palliative Care and Transitions Program and the Director of Volunteer Services, were in direct collaboration and closely involved with the implementation. Active communication between the educator and the Directors of the Transitions Program and Volunteer Services gave frequent updates to key stakeholders on the project's progression and managed volunteer availability to find the best time to organize teaching sessions.

**Intervention**

The nature of hospice and the sensitivity of advance care planning conversations can be a barrier to starting discussions with patients. The many roles and responsibilities of a registered nurse or case manager combined with the limitation of their time have become why patients enrolled in the microsystem’s Transitions Program have not been followed up more frequently. A volunteer-based approach is an intervention that can provide personalized, timely, and accurate information about advance directives and starting those initial end-of-life conversations.

A two-session education program targeted volunteers who have already completed the direct care volunteer curriculums set up by the hospice organization but wish to take their skills further and learn the intricacies of advance care planning and how to hold conversations about it. This training was resourced from a previous education program created by the hospice organization to train the general public about advance care planning. In-depth training in advance care planning provided by this education program is unique to the volunteer who has the passion, availability, and mental and emotional space to provide thorough follow-ups and help initiate and
broaden discussions about patient and family goals of care. The work of the volunteer will aid the patient and the healthcare team in a smoother transition if and when hospice or palliative care is necessary.

The role expansion of a volunteer and additional responsibilities alongside the training are outlined in the volunteer job description (see Appendix F) and competency checklist (see Appendix G). The education program (see Appendix H) included an overview of the hospice organization’s policies and procedures, the role and responsibilities of the Transition Program volunteer, advance care plans (ACP) background and importance followed by an ACP toolkit (see Appendix I), and further resources (see Appendix J). The implementation will follow the project timeline as outlined in Appendix K.

Financial Analysis

The advance care plan (ACP) education program is aimed at decreasing the incidence of unwanted lifesaving measures, therefore, reducing the cost of emergency services and inpatient stays (see Appendix L for a full breakdown of the financial analysis). Creating a standard of advance care plan knowledge for Transitions volunteers allows for better follow-ups and the accurate representation of client wishes if and when transferred to a palliative or hospice program. If the client’s wishes are not expressed correctly, this could result in unwanted lifesaving procedures and an inpatient stay. A short three-day inpatient stay will range from emergency care to initial intake and assessments to variable therapies such as ventilators, IV therapy, and nutritional supplementation, depending on patient need. With all these procedures and equipment, the cost for a single patient for three days in a hospital can amount to around $36,608.
With the implementation of an educational program for volunteers at the cost of $2,496, there is a substantial net savings of $34,112 when subtracting the cost of implementation from the cost avoidance. This cost avoidance is representative of avoiding an adverse event with a singular patient, and net savings will only increase if more than one patient receives unwanted care. This teaching session can be implemented on a yearly basis for reinforcement, and the healthcare system can continue to net a sizable return on investment.

**Study of the Intervention**

For outcome measurement, the educator compared the results of volunteer knowledge with pre- and post-training quizzes originally developed from information found in the training material (as outlined in Appendix M: Volunteer Competency/Evaluations Forms). The overall progress of the program and intended outcomes will be subject to chart review to compare the number of advance care plans completed and how many patients were followed up with. The quiz was issued before the education sessions and immediately after to create a basis of comparison to measure training efficacy as part of the volunteer competency checklist found in Appendix G but detailed in Appendix M. A score of 80 percent was considered a passing rate. The aim was an overall average increase of knowledge by 15 percent across all the volunteers.

The initial chart review showed that about one-third of the current census had completed advance care plans, whereas the remaining two-thirds required follow-ups. A long-term goal to be met within the first year is to have half of the Transitions Program patient census with completed and filed advance care plans.

**Ethical Considerations**

The University of San Francisco (USF) has approved this quality initiative as an evidence-based project. The criteria for the Non-Research Determination Form (see Appendix N)
have been met due to the entirety of the project being non-research-based and not needing approval by the Institutional Review Board (IRB).

Expanding the volunteer role and training hospice volunteers in advance care planning relates to USF’s Jesuit values of *cura personalis* which means “care for the whole person” and the call to social service as “people for others” (University of San Francisco, 2023). USF’s mission to serve others is exemplified in this project to promote quality healthcare that considers all persons and their unique values. Ensuring that every patient enrolled in the Transitions Program gets a proper follow-up preserves patient autonomy and upholds beneficence and justice all of which fall under three principles from the American Nursing Association’s (ANA) Nursing Code of Ethics. Under the fifth provision to the ANA’s Code of Ethics, it is the nurse’s responsibility to promote health and safety and preserve integrity and unity of character in themselves and their patients (Gaines, 2023; American Nursing Association, 2015) as exemplified through this quality initiative.

**Outcome Measure Results**

None of the eight volunteers reached a competency rate of 80 percent on the pre-test. The lowest score was 20 percent, and the highest was 73 percent. The average pre-test score was 43 percent. There was no expectation of any person to score a passing competency rate on the pre-test, understandably that some of the questions were very specific and required more than one correct answer to get the full point. The two most missed questions were opened ended responses to correctly order the listed options of the four steps in advance care planning and to define the POLST acronym. In turn, these became very important teaching points to emphasize. All eight volunteers increased their post-test score by more than 15 percent, with only one individual
missing the 80 percent competency passing rate by one question. The post-test average score was 93 percent.

The results were as expected. The hospice volunteers noted a small amount of guesswork with the questions regarding advance care planning statistics. The one question every single person got incorrect, asked for three characteristics of a healthcare agent, to which everyone put applicable responses of understanding, communicative, knowledgeable, and truthful, however the correct answers were very specific to the role of a healthcare agent such as calm in a crisis, strong advocate, and will respect your wishes.

Summary

Volunteers with an interest and who might have experience in hospice care should not be expected to have complete knowledge about advance care plans. While some might have a better understanding than others, there are specific data points that should and need to be taught in order for volunteers to gain the best picture. The option to expand their role and responsibility and enroll in a training was a voluntary process for the direct care volunteers. This desire to do more might have contributed to a volunteer’s engagement in the learning process and to the overall success of the education program. After being trained and educated about the different types, aspects, and steps of an advance care planning process, all the individuals were able to express that they were knowledgeable in the subject matter by being able to correctly answer specific questions about the process and hold mock conversations with patients about advance care plans.

Conclusions

Advance care planning is a lengthy conversation with many nuances that may change between each state and different stages of life. Nevertheless, it is important to get the
conversation started no matter what as it can detail patient healthcare-related preferences to help ensure the quality of life and promote client autonomy. While this pilot training program is for volunteers to expand their role within the organization and empower them to hold follow-up conversations with end-of-life patients regarding advance care plans or simply getting the process started with education, this training can bring familiarity for the patients about the topic so that they may continue the conversations within their sphere of close family and friends. It is not expected that the average person outside of the healthcare industry will know a lot about end-of-life care and advance care planning. However, enabling individuals to know more about their health and the options they have, regardless of the stage of life, is a good starting point.

The emphasis on patient autonomy can sometimes get overlooked in the overwhelming end-of-life conversation. Advance care planning can help preserve the patient’s right to determine the care they need to be delivered in the way they want. Volunteers at this specific hospice organization already get a closer look at the holistic and person-centered care that can happen, but this is an opportunity for them to be active participants in that process.
References


https://doi.org/10.1111/jgs.17447

### Appendix A: Gap Analysis

<table>
<thead>
<tr>
<th>Area under consideration:</th>
<th>End of life care/health goals assessment and documentation, Volunteer staff education</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aim Statement:</strong></td>
<td>To better identify and document patient care goals with completed and accurate advance care plans (ACP), education will be provided to volunteer staff in a hospice microsystem with a goal to increase of knowledge by 15% within six months of implementation.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Desired State</strong></th>
<th><strong>Current State</strong></th>
<th><strong>Action Steps</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Expanded volunteer role to include care planning conversation and follow-up with patients.</td>
<td>Previous volunteers have been educated on advance care plans/POLST forms. Current direct care volunteers do not have any training or further role regarding advance care plans. One third of patients enrolled in the Transitions Program have a completed POLST and Advance Directive.</td>
<td>1. assess before: a) volunteer knowledge of advance care plans/POLST b) census patient chart review of how many completed ACPs c) cost implications of incomplete/inaccurate advance care plans/POLST forms 2. provide education regarding accuracy and importance of completion of advance care plans/POLST forms and how to follow-up about care 3. assess after: b) volunteer knowledge of advance care plans/POLST b) completion audits via chart review c) cost analysis of completed advance care plans/POLST forms</td>
</tr>
</tbody>
</table>
Appendix B: Project Charter

**Project Charter:** Advance Care Plans Educational Program for Hospice-Transitions Program Volunteers

**Global Aim:** To create and implement a program for direct care volunteers in palliative and/or hospice care setting to help patients understand and utilize advance care planning documents.

**Specific Aim:** With the implementation of a hospice and palliative care volunteer-based advance care planning education program, the aim is to increase volunteers knowledge on advance care planning forms (ex. POLST, CAHCD) and resources by an average of 15 percent, compared the pre-test.

**Background/Rationale:** Advance care planning allows a client in any clinical setting to consider and communicate the preferences in health care treatment that aligns with their wants and values (Sellars et al., 2019). In a palliative and/or hospice care setting, the Physician Orders for Life-Sustaining Treatment (POLST) or the California Advance Health Care Directive (CAHCD) are used to communicate patients’ wishes for end-of-life care. In collaboration with the patient and the healthcare team, using advance care plans can promote overall patient safety, improve healthcare outcomes, prevent discordant care, reduce unnecessary usage of medical resources, and reduce costs (Vranas et al., 2021; Sellars et al., 2019).

**Sponsors**
- Director of Palliative Care and Transitions
- Director of Compliance, Quality, and Education

**Interventions:** To create a program model to train and educate direct care volunteers regarding advance care planning in a palliative/hospice setting

1. Develop an advance care planning (ex. POLST, CAHCD) training and education program
   a. Creation of pre and post-knowledge quizzes
   b. Creation of job summary, job description, and competency checklist
2. Identification of volunteers and usage of knowledge to complete advance care plans with clients
3. Create a plan for annual follow-ups
   a. Follow up with volunteers, on knowledge competency
   b. Follow up with patients, on advance care plans and completion

**Measures:** outcome, process, balancing; strategy and description

<table>
<thead>
<tr>
<th>Measure</th>
<th>Data Source</th>
<th>Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Test Score, in knowledge of advance care planning</td>
<td>Post-training test</td>
<td>80%</td>
</tr>
<tr>
<td>% of Volunteers with a passing rate</td>
<td>Post-training test</td>
<td>80%</td>
</tr>
<tr>
<td>% of Patients, with completed advance care plan</td>
<td>Chart review</td>
<td>50%</td>
</tr>
<tr>
<td><strong>Process</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Volunteer Training/Education | Sign-in, schedule, pre-post test | 90%
---|---|---
Annual Follow-up | Chart review | 90%

**Measure Strategy**

**Data Collection Method:** Various data will be gathered from the pre- and post-training tests given to the volunteers, chart review for advance care planning completion, and follow-up audits.

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Definition/Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre- and post-test score</td>
<td>To create a basis of comparison for training efficacy.</td>
</tr>
<tr>
<td>Test Passing Rate</td>
<td>In the post-test, a score of 80% if considered a passing rate/competency rate.</td>
</tr>
<tr>
<td>Satisfaction Audit</td>
<td>To assess patient satisfaction of care after advance care plan completion and involvement in care</td>
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</table>

**Measure Description**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Measure Definition</th>
<th>Data Collection Source</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Test Score</td>
<td>N=minimum passing score on post-test</td>
<td>Post-training test</td>
<td>80%</td>
</tr>
<tr>
<td>% Test Score (Increase)</td>
<td>N=average increase of score between pre- and post-test</td>
<td>Pre- and Post-training test</td>
<td>15%</td>
</tr>
<tr>
<td>% of Volunteers</td>
<td>N=# of volunteers that scored the minimum passing post-test score</td>
<td>Post-training test</td>
<td>80%</td>
</tr>
<tr>
<td>% of Transitions Patients</td>
<td>N=# patients with completed advance care plan</td>
<td>Chart review</td>
<td>50% in the first year, 75% by the second year</td>
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</tbody>
</table>

**Team Members**

- Preceptor/ Director of Palliative Care and Transitions
- Director of Volunteer Services/Volunteer Coordinator
- Direct Care Volunteers

**References**


**Appendix C: Evaluation Table**

**PICOT Question:**
For volunteers in a hospice and palliative setting, how will an advance care planning education and training program in addition to volunteer orientation affect volunteer knowledge after implementation?

<table>
<thead>
<tr>
<th>Study</th>
<th>APA citation</th>
<th>Design</th>
<th>Sample</th>
<th>Outcome/Feasibility</th>
<th>Evidence rating</th>
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</thead>
<tbody>
<tr>
<td>Frechman, E., Dietrich, M. S., Walden, R. L., &amp; Maxwell, C. A. (2020). Exploring the uptake of advance care planning in older adults: An integrative review. <em>Journal of Pain and Symptom Management, 60</em>(6). <a href="https://doi.org/10.1016/j.jpainsymman.2020.06.043">https://doi.org/10.1016/j.jpainsymman.2020.06.043</a></td>
<td>Integrative review and synthesis of literature</td>
<td>Of 1081 studies, 78 met the inclusion criteria</td>
<td>This review takes a look into the complexity of advance care planning, barriers to why advance care plans (ACPs) aren’t being filled out properly, and models in approaching ACP conversations with older adults.</td>
<td>L V</td>
<td></td>
</tr>
<tr>
<td>Gazarian, P. K., Cronin, J., Dalto, J. L., Baker, K. M., Friel, B. J., Bruce-Baiden, W., &amp; Rodriguez, L. Y. (2019). A systematic evaluation of advance care planning patient educational resources. <em>Geriatric Nursing, 40</em>(2), 174–180. <a href="https://doi.org/10.1016/j.gerinurse.2018.09.011">https://doi.org/10.1016/j.gerinurse.2018.09.011</a></td>
<td>Systematic Review</td>
<td>20 educational resources</td>
<td>Not one resource will be comprehensive enough to provide ACP teaching in all situations. But the different resources were listed and notes the features of each one and matches resources to the different levels of change preparedness based on the Transtheoretical Model (TTM).</td>
<td>L II</td>
<td></td>
</tr>
<tr>
<td>Reference</td>
<td>Study Type</td>
<td>Population</td>
<td>Summary</td>
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<td>Sellars, M., Simpson, J., Kelly, H., Chung, O., Nolte, L., Tran, J., &amp; Detering, K. (2019). Volunteer involvement in advance care planning: A scoping review. <em>Journal of Pain and Symptom Management, 57</em>(6). <a href="https://doi.org/10.1016/j.jpainsymman.2019.02.031">https://doi.org/10.1016/j.jpainsymman.2019.02.031</a></td>
<td>Scoping Review</td>
<td>11 studies identified</td>
<td>This review takes a look into the volunteer role and how it can be improved and rationales as to why their roles should expand to include advance care planning. It also looked into different ACP models of integration and the potential risks of involving volunteers with ACP.</td>
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<tr>
<td>Vranas, K. C., Plinke, W., Bourne, D., Kansagara, D., Lee, R. Y., Kross, E. K., Slatore, C. G., &amp; Sullivan, D. R. (2021). The influence of POLST on treatment intensity at the end of life: A systematic review. <em>Journal of the American Geriatrics Society, 69</em>(12), 3661–3674. <a href="https://doi.org/10.1111/jgs.17447">https://doi.org/10.1111/jgs.17447</a></td>
<td>Systematic Review</td>
<td>104,554 patients across 20 observational studies</td>
<td>This review took a look at patients and their POLST status and how treatment limitations (due to POLST) had any effect on patient outcomes and care satisfaction at end of life (EOL). There were knowledge gaps identified that should be addressed in order to maximize the use of POLST and reduce risks.</td>
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</tbody>
</table>
## Appendix D: SWOT Analysis

Problem: Infrequent follow-ups regarding Advance Care Plans for Transitions Program Patients

<table>
<thead>
<tr>
<th>Internal (attributes of the organization)</th>
<th>Favorable/Helpful</th>
<th>Unfavorable/Harmful</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strengths</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Community-based approach</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Home health approach and resources to serve client needs (after-hours care)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Variety of staff and volunteers (NPs, social workers, spiritual workers, RNs)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Systems in place to address patient needs (acuity assessment)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Willing management and supportive leadership</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Weaknesses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Education/training of staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Time conflicts for multiple training sessions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Time it takes to audit POLST/ACP forms</td>
<td></td>
<td></td>
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<tr>
<td>• Resistance to change</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• More work and time for the staff</td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>External (attributes of the organization)</th>
<th>Opportunities</th>
<th>Threats</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Opportunities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Train and educate volunteers and staff on therapeutic communication and accurate information to complete a POLST</td>
<td></td>
<td></td>
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<tr>
<td>• Create opportunity for client wishes to be accurately represented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Improvement in care could lead to more funding/donations</td>
<td></td>
<td></td>
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<tr>
<td><strong>Threats</strong></td>
<td></td>
<td></td>
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<tr>
<td>• Patients and families not willing to have open discussion regarding palliative/hospice/transition care</td>
<td></td>
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<tr>
<td>• Staff emotional exhaustion regarding end of life topic</td>
<td></td>
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<tr>
<td>• Patient satisfaction of care not met (competition)</td>
<td></td>
<td></td>
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</tbody>
</table>

### Appendix E: Power Interest Grid
(Communication Plan)

<table>
<thead>
<tr>
<th>Level of Power</th>
<th>Keep Satisfied</th>
<th>Manage Closely</th>
</tr>
</thead>
</table>
| High Power, Low Interest | o Board Members  
| | o Senior Leadership/ Administrative Team | o Director of Palliative Care and Transitions Program  
| | | o Director of Volunteer Services |
| | | o Director of Compliance, Quality, and Education  
| | | o Events and Community Education Manager  
| | | o Board Members previously involved with the previous ACP initiative  
| Low Power, Low Interest | o Patients and their families  
| | o Clinical Staff  
| | o Nurses  
| | o Physicians, Care Teams/ Interdisciplinary Group (IDG) | o Volunteers  
| | | o Social Workers  
| | | o Community Ambassador Volunteers |

<table>
<thead>
<tr>
<th>Level of Interest</th>
<th>Monitor</th>
<th>Keep Informed</th>
</tr>
</thead>
</table>
| Low Power, Low Interest | o Board Members  
| | | o Senior Leadership/ Administrative Team |
| | | o Director of Palliative Care and Transitions Program  
| | | o Director of Volunteer Services  
| | | o Director of Compliance, Quality, and Education  
| | | o Events and Community Education Manager  
| | | o Board Members previously involved with the previous ACP initiative |
| Low Power, High Interest | o Volunteers  
| | o Social Workers  
| | o Community Ambassador Volunteers |

Appendix F: Job Description and Summary

Transitions Program Volunteer

Summary of Position

In addition to the competencies and knowledge gained from the Direct Care Volunteer Training Program, Transitions volunteers will be trained on advance care planning and its importance and how to hold spaces and conversations to follow-up with Transitions patients. Under the direction of the Director of the Transitions Program, volunteers will be assigned patient(s) in where follow-up phone calls or in-person visits will be made at monthly intervals. The work of the volunteer will aid the patient and the healthcare team in a smoother transition if and when hospice is necessary.

... 

Job Description

The hospice microsystem is an organization that strives to provide a tailored continuum of care.

As a branch of the Direct Care Volunteers, Transitions volunteers are further trained in advance care planning and will provide follow-up sessions with assigned Transitions Program patients.

At no cost to the patient, the Transitions Program provides nursing evaluation and consultation, social work support, and volunteer services to individuals with life-limiting illness but continue to receive treatment. This program is designed for patients who are not yet physically or emotionally ready for hospice.

This role is unique to the volunteer who have the passion, availability, and mental and emotional space to provide thorough and comprehensive follow-ups, help initiate and broaden discussions about patient and family goals of care. The work of the volunteer will aid the patient and the healthcare team in a smoother transition if and when hospice is necessary.

As a Transitions Volunteer, you will:

- Provide emotional and social support
- Provide companionship
- Provide a calm, non-anxious presence
- Listen impartially and without judgement
- Strengthen the patient’s sense of being in control
- Help the family normalize the dying experience
- Report the patient’s pain level
- Report possible abuse and/or falls to the Director of the Transitions Program
- Refer patients and families to members of the care team to answer questions a volunteer is not qualified to provide an answer
- Provide additional advance care plan education
- Help start and expand discussions about goals of care and advance care plans
- Share observations with staff regarding the patient’s care plan
- Gain competency in advance care plans to teach other volunteers

Qualifications

No experience is required. Volunteers must be emotionally and physically able to serve. The hours and schedule will be flexible, depending on the volunteer’s personal schedule, format of follow-up, as well as the needs of the patient and/or their family.

Direct Care Volunteers report to, and are annually evaluated by, the Volunteer Coordinator. A Transitions volunteer is a voluntary position that will also report to the Director of the Transitions Program.

Like all other volunteers, Transitions volunteers will have access to mentoring and other support as necessary. No one will be asked to do anything that will bring an individual out of their physical or emotional comfort zone.

Training and Evaluation

The hospice organization provides volunteers with 26 hours of required training to prepare for direct care settings in hospice. Transitions volunteers will incur an additional 10 hours of required training on advance care plans and follow-ups with patients.*

Annual Direct Care Volunteer competencies will apply in addition to the advance care planning competency training.

In addition, Continuing Education / Support Meetings are provided on the first Saturdays and third Thursdays of each month. These are recommended but not required, unless otherwise announced.

*Summer 2023 will serve as the pilot education and training program for Transitions volunteers. The hope is for volunteers to be able to train fellow volunteers in advance care plans and follow-ups in an annual competency for current and previous volunteers and training for new Transitions volunteers.
Appendix G: Transitions Volunteer Competency Checklist

Advance Care Plan Training Content

- Hospice-Transitions program processes, policies, and procedures
- The roles and responsibilities of Transitions Volunteers
- Advance Care Planning background and importance
- Advance Care Planning Toolkit
  - Think
  - Talk
  - Choose
  - Write
- Extra resources

Goals for the Workshop

- Recognize the importance of advance care plan
- Understand the role of an Advance Directive and other documents (POLST, CAHCD) used to record health care wishes
- Equipped with tools to:
  - Explore values and beliefs and how they influence end of life choices
  - Start conversations about ACP to those around you, community members, fellow volunteers
  - Follow up with patients regarding their care and goals
- Explore important considerations in choosing a health care agent
- Feel ready to begin these critical conversations
- Feel prepared to teach other volunteers about advance care planning

Advance Care Plan Volunteer Education Program Policies and Procedures

The education program is designed to equip volunteers to go out into the community and educate clients about the importance of advance care planning and follow-up about the patient’s plan of care and if health goals are being achieved. Transition Program patients are followed-up at sporadic intervals, and with a trained volunteer to relay information at a more regular rate, the patient can better meet their specific needs and move more seamlessly into the hospice or palliative care programs.

Requirements

1. All Transitions volunteers must complete the Direct Care Volunteer curriculum (26 hours) followed by the Transitions Program Advance Care Plan education course.
2. It is preferred that a volunteer must have completed a Direct Care assignment.
3. All Transitions Program volunteers will participate in at least two simulated calling/follow-up sessions with the Volunteer educator or mentor before making calls or follow-ups on their own.

4. Volunteers will participate in quarterly support/debriefing sessions based on availability and/or one-to-one calls with volunteer manager and/or volunteer mentor.

Procedures

1. Volunteers will receive call/patient information from the Director of the Transitions Program and/or Volunteer Coordinator.
2. Telephone calls/in-person follow up visits will be made no later than two weeks from when patient information is received.
3. When a volunteer receives information that requires action, that information will be communicated to the Director of the Transitions Program and/or the Volunteer Coordinator no later than 36 hours maximum.
4. Calls not requiring action may be submitted with all documentation, no later than one week.

Supervision

1. The general supervision of Transitions volunteers will be the responsibility of the Director of the Transitions Program.
2. Volunteers will participate in competency assessment and evaluation following education course, prior to performing any new duty and annually thereafter.
3. Volunteers will be notified of continuing education opportunities specific to their duties.

Confidentiality

1. All volunteers must maintain confidentiality concerning hospice patients and families. There should be no discussion of patient cases or mentioning of patients’ names other than in direct contact with other members of the hospice team. Since there will be patient/family information in the volunteer’s home, volunteers are expected to take the necessary precautions to assure confidentiality of the information. All volunteers will understand and sign the Volunteer Code of Ethics/Confidentiality Statement.

2. Volunteer staff needing information from the home care chart can request the information from the social worker or case manager. It is important to remember that charts are reviewed by team members on a need-to-know basis and not for curiosity sake. Charts can be reviewed for specific (rather than general) information.
Appendix H: Education Program

Take charge!

Critical Conversations
About Advance Care Planning

About

It's about life.

An independent nonprofit founded in 1979, provides
patients and their families in the San Mateo and Santa Clara County area with quality, compassionate end-of-life care and education.

Who We Are

• Volunteer

• We are not medical or legal experts

• However like many, we have personal stories that brought us to this work

Philosophy

It's about life.

We believe that death is a human experience that touches every one of us, and that we each deserve care at the end of life that is aligned with our beliefs, wishes and values.

We help patients live life to the fullest, and support their loved ones so they can make the most of their time together. Our holistic, team-oriented approach includes physical, emotional and spiritual care throughout the last phase of life.
Overview Of Services

- Patients and families in San Mateo and Santa Clara counties
- Hospice care in homes, hospitals and other institutions
- A Hospice home in Redwood City
- Transitions and Palliative Care
- Bereavement support
- Continuing education for medical professionals
- Public education

Take charge!

Goals For This Workshop

By the end of these two sessions we hope that you will:

1. Recognize the importance of advance care planning
2. Have tools you can use to:
   - explore your values and how they might influence your end of life choices
   - start conversations with those important to you
3. Understand the role of an Advance Directive and other documents used to record your health care wishes
4. Explore important considerations in choosing a Health Care Agent
5. Feel ready to begin these critical conversations

Take charge!

Welcome!

Introduce yourself, and if you are comfortable, tell us what brought you to this workshop

Take charge!

What Is Advance Care Planning?

- A process by which you can TAKE CHARGE of the care you will receive by:
  - Thinking about what matters most to you
  - Recording your wishes in advance to be used in the event that you cannot speak for yourself
  - Communicating your wishes to healthcare professionals and loved ones
- It is for everyone: young or old, healthy or unwell
  Don’t wait until you are forced to plan!
  Be Proactive, Do it now

Take charge!
Why Is Advance Care Planning Important?

We are all going to die....

And most people have strong feelings about how they would like to go. We say things like:

“I want to go quickly.”
“I just want to die in my sleep”
“I’m going down fighting!”

Take charge!

The Reality Is

While a California survey of attitudes toward death and dying cited as primary concerns:
• “Making sure I am not a financial burden to family” (67%)
• “Being comfortable and without pain” (69%)
• “Would prefer to die at home” (70%)

Research suggests that the reality is different ...
• 70% die in institutions
• 50% of Americans die in pain
• 30% of families lose most of their life savings while caring for a dying loved one

(Does not include the cost of lost wages by family members)

Take charge!

However... Few Make Their Wishes Known To Those Who Need To Know

• 90% of people say that talking with their loved ones about end of life care is important....
• But only 27% have actually done so. (Caregiver Project-National Survey 2012)

• 60% of people say that it is extremely important that their family is not burdened by tough decisions about their care
• But 56% have not communicated their end-of-life wishes to their family. (California Health Care Foundation Survey 2012)

Take charge!

Most Important Factors At End Of Life

Take charge!
Under Current Law And Norms Of The Medical Profession

In the absence of any other information about your wishes, physicians are trained to pursue all means necessary to prolong your life.

*If this is not what you want, you need to Take charge!*

Activity: Why Do We Avoid These End-of-Life Conversations?

- Denial: It’s not going to happen to me.
- My spouse, my kids, already know what I would want.
- The subject of death is uncomfortable for me and my family.
- I’m not sure how I feel. I’ll decide when it becomes an issue.
- I trust my doctor to do what he/she feels is right.

*Take charge!*

What Is Advance Care Planning?

- A process by which you can TAKE CHARGE of the care you will receive by:
  - Thinking about what matters most to you
  - Recording your wishes in advance to be used in the event that you cannot speak for yourself
  - Communicating your wishes to healthcare professionals and loved ones.

- It may change over time... as circumstances in your life change.

- It’s a gift you give to your loved ones.

*Take charge!*

Take charge! : Your Advance Care Planning Toolkit

*Take charge!*

- Take these four steps to help get the care you need — based on what matters most to you.
- Talk about who makes you happy.
- Tell your story with your family and friends.
- Choose your words on your own.
- Help to know, and share your plan.
Take charge! : Coalition Partners

Take charge! : A Four-Step Process

Take these four steps to help get the care you want – based on what matters most to you.

- Think about what matters most to you.
- Talk about your wishes with your family and friends.
- Choose your health care agent.
- Write it down – and share your plan.

Getting Started: What Matters To You At The End Of Your Life?

1. Turn to page 4 in Your Conversation Starter Kit.
2. Take 5 minutes to capture your initial thinking by answering 1-5 on the “Where I Stand” scales on pages 4-6.
3. If you have time while others are finishing, think about your answers to the open-ended (box) questions on those same pages.

https://www.thecommunicationproject.org/
Table Or Pairs Discussion

Did you find these questions easy or difficult to answer?
Why do you think that was true for you?
Which questions were hardest for you to answer? Why?
Which were easiest to answer? Why?

Take charge!

It’s Different For Each of Us

- Some questions are easy for some and the same one hard for others
- Often times our decision-making is influenced by religious or spiritual beliefs, cultural norms, past experiences and family values
- There are no “right” answers...and answers may differ within a family or couple. That’s why it is so important to explore for yourself what matters TO YOU!
- You may find that you don’t have strong opinions about certain issues. That can be a valuable thing to share too!
Each of us needs to figure out what matters most to us!

Take charge!

Another Tool: What Matters Most At The End Of Your Life?

The Coda Alliance is dedicated to helping you comfortably deal with one of life’s most difficult situations — starting your end-of-life conversation.
http://codaalliance.org/go-wish/

Take charge!

Another Tool: What Matters Most At The End Of Your Life?

1. Review “Go Wish” cards and select 10 that seem most important to you.
2. From the 10 you chose, pick 3 that you would consider most important.
3. Working with a partner, share what went into making the selections that you did. Your partner should get the conversation started by asking one of these questions about one of your top 3 cards:
   - “Tell me about what (statement on card) means to you.”
   - “Tell me why (statement on card) is important to you?
4. Alternate so that both partners have time to share their thinking about at least two cards.

Take charge!
Power Of The “Go Wish”

Playing “Go Wish” may:
- Create a safe way to initiate a difficult conversation
- Alert you to things you may want to do NOW….(or encourage a loved one to get started on)
- Guide some of the medical care decisions you will document in an Advance Directive
- Guide things you may want to be sure to communicate to your loved ones (in addition to specific medical treatments)

Take charge!

Two Critical Issues To Consider Now…..

- Decisions about the medical treatment you might want … or not want … at the end of your life
- Who you would like to speak for you about your wishes regarding medical care if you are unable to speak for yourself (Your “Health Care Agent”).

Take charge!

Advance Care Planning Can Involve Thoughts About:

- Where you want to be and with whom at the end of your life
- How and to whom you want your situation to be communicated
- What it means to you to “be ready” to go...
- Arrangements for funerals or memorials
- The question of organ donation…
- Anything that is important to you….

However, for the remainder of this workshop we are going to focus on two key elements of Advance Care Planning:

Take charge!

Determining Choices For Care

As part of your Advance Care Planning, you will want to consider health care options as you near the end of your life:

1. I want all measures to be taken to prolong my life as long as possible.
   OR

2. Do not take measures to extend my life if they have no power to cure my illness and may restrict the quality of my life.

Take charge!
The Benefits/Burden Trade-off

<table>
<thead>
<tr>
<th>Treatments such as...</th>
<th>Potential Benefit</th>
<th>Potential Burdens</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPR</td>
<td>Stabilizes the Patient and Postpones Death</td>
<td>Discomfort</td>
</tr>
<tr>
<td>Feeding Tube</td>
<td></td>
<td>Pain</td>
</tr>
<tr>
<td>Breathing Machine/ Ventilator</td>
<td></td>
<td>Isolation from friends and family</td>
</tr>
<tr>
<td>Dialysis</td>
<td></td>
<td>Communication challenges</td>
</tr>
<tr>
<td>Surgery</td>
<td></td>
<td>Requires constant professional support or hospitalization</td>
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</tbody>
</table>

The Central Question Regarding Medical Care

Prolong my life as long as possible vs.
I do not want my life to be prolonged if there is little chance of a cure and/or the burdens of treatment outweigh the benefits.

What Matters Most To You?

Film clip: Extremis

The Question Is NOT...

Do all you can vs.
Do nothing
The Question Is ...

How Important is My (Our) Quality of Life?

Consider The Facts And Your Options

- Questions that need answering
  - What do you understand about the prognosis?
  - What concerns you about what lies ahead?
  - What trade offs are you willing to make?
- How do you want to spend your time if health worsens?

It's about managing anxiety: about death, loved ones, finances... There are many worries and real terrors.

Take charge!

Consider Two Questions

When should we continue to pursue a “cure”? And when should we not?
Why does society consider continued pursuit of an unattainable goal a fight, and acknowledgment that we cannot a failure?

How should we respond?
- Ask for all the facts and options

Take charge!

What Does Being Alive Mean To You?

- How much are you willing to go through to “have a shot” at being alive?
- What kind of “being alive” is tolerable to you?
  - Would you want to stay alive but be mentally or physically impaired?
  - Would you want to stay alive but not be able to care for yourself?
  - Would you want to stay alive but be hooked up to equipment required to keep you breathing or your heart pumping?
- What is the cost (physical, emotional, financial, other) to you and your loved ones?

Take charge!
Palliative Care And Hospice Care

Both these forms of care:

- Maximize the quality of life over the quantity
- Emphasize relief of symptoms (with special attention to pain and discomfort) using medical expertise and medications
- Use a team approach to assist with additional non-medical issues such as spiritual and social supports

Take charge!

Availability Of Palliative Care

- Palliative Care is a relatively new medical specialty and serves patients with a serious illness
- You may request services in addition to other on-going medical treatment(s)
- Services are available through hospitals and in some community clinics
- Level of coverage may depend on your insurance policy

Take charge!

Medical Choices and Care

Availability Of Hospice

- Hospice services are available when the patient is considered by medical professionals to be in the last 6 months of life
- Hospice services are covered by Medicare and most insurance policies for those not yet eligible for Medicare
- Hospice services are delivered wherever the patient is (homes, hospitals and other institutions)
- Hospice services are offered by many organizations – you may request Hospice Care from any organizations that serves the area where you live

Take charge!
Benefits Of Palliative Care And Hospice

- Patients live as long or longer with better reported quality of life
  - In a survey of 4500 patients over four years, mean survival rate of hospice patients was 29 days longer than non-hospice patients. (Cancer. 2014, 120, 1-10)
  - In a study of patients with non-small cell lung cancer, median survival was longer among patients receiving early palliative care (11.6 months vs. 8.9 months). (JAMA Intern Med. 2014)
- Families are more likely to be highly satisfied with quality of care
- Patients report fewer unmet pain management or emotional needs

Take charge!

Integration Of Palliative Care Into Standard Oncology Care

Earlier involvement of Palliative Care also leads to more appropriate referral to and use of hospice, and reduced use of futile intensive care.

No trials to date have demonstrated harm to patients and caregivers, or excessive costs, from early involvement of PC.” (Journal of Clinical Oncology)

Take charge!

Integration Of Palliative Care Into Standard Oncology Care

“...substantial evidence demonstrates that Palliative Care—when combined with standard cancer care or as the main focus of care—leads to better patient and caregiver outcomes. These include:

- Improvement in symptoms,
- Improvement in quality of life and patient satisfaction, and
- Reduced caregiver burden.

(Journal of Clinical Oncology)

Take charge!

Palliative Care and Hospice

Ask about these services! Even if your doctor doesn’t bring it up!

Comfort care means you will continue to be treated in order to maximize the quality of your life.

Take charge!
“Usually people think about (choices for care at the end of life) as having a better death. But its really about how you live as well as you possibly can in the face of impairment at the very end.”

Atul Gawande author of Being Mortal as cited in “What it Means to be Ok” Harvard Magazine Jan/Feb 2019

Remember:  

Take charge!

It’s about the conversation

Who Needs To Know About Your Wishes?

- Your family and loved ones
- Your doctors
- Your Health Care Agent

STEP 2 Talk about your wishes with your family, friends, and doctor.

Now that you’ve thought about what matters most to you - Who needs to know?

Take charge!
Critical Conversations: Getting Started With Friends And Family...

“I need your help with something...”
“Remember how (someone in the family) died? I would like my death to be different/similar. I need your help.
“I was thinking about what happened to (name) and it made me realize...”
“I need to think about the future. Will you help me?”
“I just answered some questions about how I want the end of my life to be. I want you to see my answers so you understand what is important to me.”

(Your Conversation Starter Kit, page 8)

Take charge!

Talking with Your Doctor

• 67% of the public believe it's important to talk with their doctor about advance care planning

• 7% have

• 89% of doctors responded they are not comfortable starting the conversation

Take Charge & Do This For Yourself

Critical Conversations: Sharing Your Thoughts About End of Life

• What’s most important to you? How would you like this phase to be?
• Do you have any particular concerns about your health?
• What personal affairs do you need to get in order?
• Who do you want (or not want) involved in your care?
• Who would you prefer to be actively involved in decisions about your care?
• Would you prefer your doctors to decide what is best?
• Are there any disagreements or family tensions that you are concerned about?
• Are their important milestones you’d like to be there for if possible?

(Your Conversation Starter Kit, page 8)

Take charge!

It’s About The Conversation

https://www.plos.org/doi/10.1371/journal.pone.0169507

Take charge!
**STEP 3** Choose your health care agent—someone you’d want to make decisions about your care if you are unable.

**A Good Health Care Agent/Proxy**
- Can talk to you about your wishes, knows you and your values
- Has demonstrated they are concerned with your happiness and well-being
- Is not afraid to ask doctors questions and advocate for you
- Is calm in a crisis
- Can make difficult decisions even when emotions are involved
- Can talk to your family and loved ones in a compassionate supportive way
- Will respect your wishes even if they are different from their own

**Take charge!**

**Naming A Health Care Agent/Proxy**
- Your agent is the person who will help ensure that your wishes for medical care will be respected if you become unable to speak for yourself.
- Your health care agent will have legal authority to make health decisions for you.
- If you have NOT selected a health care agent and you become unable to communicate your wishes,
  - your friends and family may disagree about the medical care you should receive
  - decisions about your care will be made by doctors with hospital administrators, or judges when needed.

**Prepare Your Health Care Agent To Carry Out Your Wishes!**

“Several studies have shown that surrogates are not well-acquainted with patient preferences, but patients believe that their loved ones already know their wishes.”

**Strategies for communicating with health care agents:**
- Play a round of Go Wish
- Share any concerns you may have about potential family conflicts
- Make sure they have a copy of your Advance Directive
- Involve them in discussions about any changes you make in your advance directive.

**Take charge!**
STEP 4  Write it down – document your decisions, and share your form(s) with your agent, doctor, and loved ones.

 Completing your Advance Health Care Directive

Take charge!

Reminder:
If No Advanced Directive Is In Place ...

Your doctor is required to take measures to prolong your life!
The doctor may consult with family to determine your wishes if you cannot speak for yourself, however.....
• it is an emotional, difficult time for them
• family members may disagree about what they think you would want

An Advanced Directive is a gift to your family....and to yourself.

Take charge!

What Is An Advance Directive?

In California, an Advance Health Care Directive, is a form used to:
• Appoint your Health Care Agent and describe his/her authority to act on your behalf
• Guides medical professionals and your Health Care Agent to make decisions about medical treatments in accordance with your wishes

Take charge!

Putting It All Together: Documenting Your Wishes

Many options for your Advance Health Care Directive
Important Things To Remember About Advance Directives

1. They only come into play if you become unable to speak for yourself
2. There are many different forms...all are valid and legal if appropriately signed and witnessed
3. Forms vary in terms of which medical treatments and other care issues they address. You may add any detail you wish

Take charge!

One Other Form ... POLST

POLST – Physician Order for Life Sustaining Treatment

If you or a loved one has been diagnosed with a serious illness, you should also consider completing a POLST with your doctor

Take charge!

Once You’ve Completed Your Advance Directive....

- Discuss and give a copy to your Health Care Agent
- Discuss with your physician(s) and ask that the document be entered into hospital or medical plans on-line system/database
- Discuss and share with your family and other loved ones

Take charge!

Some Final Thoughts....

Let’s write it down.

What questions do you still have as you complete your Advance Care Directive?

Take charge!
Key Take-Aways

- Advance Care Planning is important for everyone!
- It’s a process, not just a document.
- Think...Talk...Choose...Write...Share....
  (and repeat as necessary)

*The goal is to create on-going engagement in critical conversations so that your personal values influence the treatment you receive at end-of-life.*

Take charge!

Congratulations.... you just took charge!

Thank You!

“It’s always too soon until it’s too late!”

- Ellen Goodman

Take charge!
Take Charge: Facilitator Notes

The slides are designed to include key information that should be shared with participants either by reading, paraphrasing, summarizing or illustrating with examples and stories. In addition, these kinds of notes are included:

- **Activity**: Facilitator directions for a discussion or activity associated with the slide AND notes on ways the activity can be varied if time or physical space are limited.
- **Background**: Information that may be of interest to the facilitator. Not critical, but may be shared with participants if time permits.
- **Emphasis**: A rephrasing or summary of a key point already detailed on the slide. Facilitators will want to be sure participants hear these points.

<table>
<thead>
<tr>
<th>Slide</th>
<th>Introduction and Background: What Advance Care Planning Is and Why it's Important</th>
</tr>
</thead>
</table>
| 1.    | This slide is displayed prior to start of the Workshop.  
**Activity**: Greet participants as they come in, have them sign in and get them settled.  
Welcome participants to the Advanced Care Planning Workshop. |
| 2.    | Explain you are a volunteer with  
**Emphasize** that you are not a medical or legal experts.  
Introduce yourself with a very brief story about the experience that brought you to this work. Have your facilitator partner do the same.  
**Background**: A brief, personal anecdote or story about why you got involved with this work will set a tone for the day, help build trust and hopefully make participants feel comfortable sharing their concerns and questions. |
| 3.    | Overview of and the philosophy behind the organization’s work.  
**Emphasize**:  
- Service in San Mateo and Santa Clara Counties  
- Offers typical/familiar direct hospice services to patients and families AND community education like this workshop. |
| 4.    | **Emphasize**: The philosophy behind community education work is that the more MHHC can do to make people comfortable talking about end-of-life issues, the more they can live their lives to the fullest while they are here! It’s ABOUT LIFE. |
| 5.    | **Note**: We do not take time to describe all of these services at this point.  
**Emphasize**:  
- Highlight range of services and mention that we will be explaining many of these later in the workshop.  
- Explain MH&HC particularly proud of the many activities in addition to direct patient care....of which this workshop is an example.  
- Reference **Community Connections** (booklet) and let them know there is a copy available for all participants. |
| 6.    | Welcome participants and ask them to briefly introduce themselves.  
**Note**: You may want to model the expected length/content of the introduction by introducing yourself again. Without a model, participants may go on too long.  
**Variation Option**: If there are more than 5-6 people in the room, there may not be time for individual introductions. Faster Alternative: |
Share that in your experience people come to a workshop like this for various reasons and with different levels of experience with Advance Care Planning.

Share: Some people come because they know how important Advanced Care Planning is, but have been procrastinating in getting it done. Raise your hand if this describes you.

Share: Some people come to this workshop because they have started the process of Advanced Care planning and have run into lots of questions about the process for which they need answers. Raise your hand if this describes you.

Share: Some people come to this workshop knowing very little about Advance Care Planning and why it’s important. They may be here because a spouse, a child or their doctor told them they should come. Raise your hand if this describes you.

Ask if there is anyone who came for any other reason and is willing to share.

Thank all for coming no matter what brings them here and tell them that you hope this workshop will meet the needs of people in all three categories.

7. Review goals of workshop.
   **Possible additional activity:** For participants who feel ready, you may want to offer to witness Advance Directives at the end of the session on Day 2.
   **Background:** Two witnesses should observe the author signing the document and then add their signatures and address to indicate they are witnesses. An AD does not need to be notarized if it has two signatures from qualified witnesses. Witness signatures are not required if it is notarized.

8. **Emphasize:** ACP is not an event but a process, and that an adult is never too young to begin this process. Procrastination can result in undesired consequences.

9. **Activity:** Read the examples and ask them if they agree. Ask them if they’ve heard other similar statements. This short interaction is a good lead-in to the next slide.

10. Use the animation in this slide: the stats come up individually....presenter can emphasize the contrast between what people say (first line) and what they do (second line)

11. **Emphasize** the stark contrast between hopes and end-of-life wishes of people and the stark statistics. Again, use animation to connect the statements in the upper list to those in the lower list, to drive/emphasize each point.
   **Background:** Stats in part 2 are cited by Jessica Zitter in Extreme Measures

12. **Emphasize** the oath physicians take to preserve life – and that they are bound to this oath, unless they have other instructions. That’s what they’ve been trained to do!

13. Some of this slide is an intentional repeat of slide 8 – this is meant for emphasis. Repeat what ACP is (first bullet). The last two bullets are different from slide 8. Bring in the concept that it’s not just a process but a cyclic process - think/talk/choose/write. One might revisit parts of this cycle as life’s circumstances change. The last bullet is an important one. A clear set of instructions shared with your loved ones and recorded in the AD lifts the stress and burden off their shoulders when they need to make decisions they hate, but know that’s what you wanted. A true gift of love. (FYI, this quote is attributed to Lucy Kalanithi)

14. **Activity:** Allow two minutes for participants to brainstorm answers to why most people avoid the conversation. In case no suggestions are offered, you may want to use animated slide to suggest possibilities.
   Acknowledge that the subject has been taboo. It’s difficult and unfamiliar...Remind them that the intent of this workshop is to give tools to make it easier.

15. Introduce the Toolkit. Toolkit is organized by the four steps in the Advance Care Planning process (Slide 18). Explain that this workshop is organized by those 4 steps....and we will do Steps 1 and 2 on Day 1 and Steps 3 and 4 on Day 2.
<table>
<thead>
<tr>
<th>Note: You can pass out the Toolkit at this point...but because they don’t actually use it during the workshop.... you may just want to tell them they will get one at the end of the day to remind them of key points when they are home.</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. <strong>Emphasize:</strong> Toolkit is the collaborative work of many different local organizations.</td>
</tr>
<tr>
<td>17. See notes in slide 15. This is a segue from the intro to the meat of the session as well as to use as a hammer throughout the session to remind students of the four steps, and the fact that it is a process</td>
</tr>
<tr>
<td><strong>Thinking about What Is Important about End-of-Life Care</strong></td>
</tr>
<tr>
<td>18. DIVISION SLIDE – Intro Step 1</td>
</tr>
<tr>
<td>19. Introduce and pass out Starter Kits. <strong>Background:</strong> Describe as one of the tools designed to help them “Think about What Matters Most”. The Starter Kit was written and is available through the Conversation Project, a national non-profit dedicated to encouraging Advance Care Planning. Their website has many good resources: <a href="mailto:conversationproject@ihi.org">conversationproject@ihi.org</a> <strong>Activity:</strong> Exercise is designed to familiarize with the tool and get them thinking about some of the issues that may influence their advance care decision making. Follow directions on slide. Assure participants that they will not be asked to share their answers publicly. <strong>Alternative:</strong> If Conversation Starter Kits are not available, use a handout* which includes some of the scales from pages 4-6. <em>(resources like this are available in the shared Google Drive folder)</em></td>
</tr>
<tr>
<td>20. <strong>Activity:</strong> In pairs or as a whole group, ask participants to consider questions on this slide. Ask for volunteers who may be willing to share.</td>
</tr>
</tbody>
</table>
| 21. After taking several answers to questions on Slide 21, point out that typically when people do this exercise they find some questions are easy for some and the same one hard for others **Emphasize:** Often times decision-making... is influenced by religious or spiritual beliefs, cultural norms, past experiences and family values
  - There are no “right” answers...and answers may differ within a family or couple. That’s why it is so important to explore for yourself what matters TO YOU!
  - You may find that you don’t have strong opinions about certain issues. That can be a valuable information too! |
| 22. Lead in to this slide by saying that there are other effective ways to get these conversations started. Describe background and source of GoWish, point to Coda Alliance as another organization with the same goals, point to their website. |
| 23. Describe this as one of the ways in which GoWish cards can be used. Time and physical set up permitting, you may hand out decks to groups and have them work with these cards for 5 minutes. Then spend another few minutes allowing the audience to share their reactions. No deep dives or discussions – we are just showing them the power of GoWish to stimulate thought process and conversations and how it elicits different reactions in individuals. If you are short of time, or if the physical arrangement in the room is inconvenient you could just pick a few cards at random and read them to the audience. Share some reactions. |
| 24. Address the bullets on this slide. Emphasize that “Go Wish” is not a decision making tool.....but a conversation starter. The value of the game comes from thinking about what the cards mean to you.....and why, so that you can eventually communicate that to others. |
| 25. Acknowledge that once we’ve explored our wishes, we may want, as part of our Advance Care Planning to address many different issues (described on slide). However, for the sake of this workshop, we are going to concentrate primarily on just two particular issues: (Segue to slide 27) |
| 26. **Emphasize** that these two issues will be the focus of our ACP workshop. |
27. **In thinking about medical care**, participants will want to consider two perspectives characterized by the two questions on the slide.

Explain that in the next two slides we will explore what goes into decision making about possible medical interventions and how to think about how they might influence quality of life.

28. Slide is animated to emphasize that typical EMT or emergency room treatments are designed to have benefit of prolonging life….but all come with burdens that you may have no way of stopping if you have not communicated your wishes. Use Facilitator Benefits and Burdens Cheat Sheet to illustrate a few.

29. **Video illustration from Extremis.**

30. Repeat question for emphasis.

31. **Emphasize:** The choice is NOT...Do something or Do nothing!!!

Segue: In the next section we will talk about the kinds of care or treatment that prioritize quality of life.

32. In slides 33-45 we provide the audience with the background knowledge, information and suggested approach to making decisions and choices related to end-of-life care. All decisions are centered on quality of life for patient and family. This leadoff slide to this section of the presentation highlights this central question.

33. This slide introduces “Palliative Care” which is a type of care focused on quality of life. It is form of care that can be requested at any time by any person with a serious or life threatening illness.

34. This slide details key features of Palliative Care and sets up the contrast with hospice care which is described in slides 35-36. Give examples of “medical specialty”….e.g. Doctors with special training....like cardiologists, gastroenterologists etc. Palliative care doctors are specially trained to care for the comfort and quality of life of seriously ill patients, while the primary medical team continues to provide curative treatment.

**Animate slide and read each point. Emphasize:**

1. Give examples of “medical specialty”….e.g. Doctors with special training....like cardiologists, gastroenterologists etc. Palliative care doctors are specially trained to care for the comfort and quality of life of seriously ill patients.
2. Palliative care addresses management of pain, along with other issues that affect quality of life for both patients and the family caregivers.
3. It is different from hospice because it does not mean the patient is dying.
4. It is a separate medical specialty offering care at the same time the patient may be receiving treatment from other specialists (e.g. you might see both an oncologist and a palliative care specialist at the same time.
5. You may seek palliative care services from any institution that offers them.

Level of care may depend on insurance.

35. This slide introduces hospice and illustrates it as a form of palliative care. It is similar in some ways but also very distinct. Hospice care also focuses on quality of life issues with patients and family caregivers, but it focuses on the last six months of life.

36. This slide details key features of Hospice care and includes ways in which it differs from Palliative Care.

**Animate slide and read each point. Emphasize:**

1. Eligibility for hospice requires medical professional opinion that patient is in last 6 months of life. Generally hospice patients no longer receive treatment aimed at a cure.
2. Hospice services are covered by Medicare and other forms of insurance.
3. Many organizations offer hospice services....you may request services from any in area where you live.

**Background:** Note that with hospice at home, we need to distinguish between hospice care and home nursing care or home assistance which are separate paid services.
MH&HC also offers hospice homes that do not charge for hospice services and care, but do bill for ‘hoteling’ - food and board – currently around $475 per day.

37. In previous slides we have been illustrating how Palliative Care and Hospice are different. The points on this slide emphasize how they are similar. **Emphasize:** These are both forms of care that focus on Quality of Life!

38. Slides 38-40 focus on what patients and families need to learn and consider in order to make informed decisions about what kinds of treatment they will pursue (or decline) The points on Slide 38 summarize the kinds of issues they may want to pursue with their doctor in order to make informed decisions. *(Handout: “What to Ask Your Doctor”... here)* The handout offers some specific questions to ask your medical team. Not all questions apply in all situations.

39. After gathering information from the medical team, patients will want to consider this information in relation to their personal beliefs and values. The questions on the slide illustrate ones that might guide a quality of life discussion. Read some or all of the questions or summarize. For example: “Is being alive, but mentally impaired, acceptable? Is not being able to care for oneself acceptable?”

40. Read this slide for emphasis. **Background:** Our society often describes efforts to pursue a cure with aggressive treatment as “a fight”...with the implication being that to decline aggressive treatment means “giving up”.

41–43 Slides 41-43 detail research findings on the benefits of Palliative Care and Hospice. If time permits you can share the detail on each slide. However, if time is limited you may want to summarize these three as follows: “Research has shown that Palliative Care and Hospice lead to positive patient and caregiver outcomes including:

- Higher satisfaction with quality of care
- Improvements in management of symptoms and pain
- Reduced caregiver burden
- Reduced use of futile treatments in intensive care
- And in some cases...longer life with improved quality of life.”

Offer to provide specific details and sources of research if participants are interested.

44. Read this slide for emphasis. It summarizes key questions and considerations from this section.

45. Explain that it is important that patients and families seek information and advocate for the services they want (or wish to decline), even if medical staff do not bring it up. (In next section we will talk a little about why doctors may be reluctant to bring up the subject of these services.) **Emphasize:** Serious illness and/or end of life brings with it anxiety about the illness itself, fears about treatments, financial issues and concerns about caregivers and loved ones. Both Palliative Care and Hospice are designed to help patients and loved ones deal with this anxiety. **Take Charge of seeking these services if you want them!** **Background:** Note that a few hospitals are beginning to integrate Palliative Care into the overall treatment plan for seriously ill patients rather than leave it to a possible specialty consult. This is a relatively new trend in the US (within the last 5-10 years) **but is not the norm, so you should emphasize that patients should seek a consult.**

46. End this section of the presentation with this quote from the internationally renowned Dr. Gawande (author of Being Mortal)

You may use this quote to recall tag line: “It's about life!”
| 47. | TRANSITION SLIDE: Step 2 Now that you’ve thought about what matters most to you, who needs to know? |
| 48. | To lead off this next section. Show the “It’s About the Conversation” Diane Sawyer video |
| 49. | Acknowledge that while talking to family is important. We will also want to think about the importance of sharing your wishes with your doctor and your Health Care Agent. |

50. Talking with family. Acknowledge that it is often a lot more awkward than it appeared in the video with Sawyer. Reference page 8 in Conversation Starter Kit. This page offers some ways to get a conversation started and what to talk about.

**Activity:** Before showing slides 49 and 50.... (or having participants look at Page 8). Ask participants to think about someone with whom they should have “The Conversation”. This could be someone with whom they want to share their personal wishes. OR It could be someone, like perhaps an elderly parent, whose health care wishes they are wondering about. Suggest that they review page 8 with that person in mind.... Then ask: “Is there an ice-breaker/opening line here you could imagine using with the person you are thinking about? (Show slide 49 while they think.) Can you think of a different way to get the conversation started with the person you have in mind? Call on volunteer to share their thinking. Occasionally participants will offer stories of how they have or might consider opening this conversation with a loved one. It’s a chance for participants to learn from one another.

51. This slide shows second half of list on Page 8 of Conversation Starter Kit. Reference it as a resource to guide the content of the Conversation. Remind participants they may also want to engage others in The Conversation by playing GO WISH or using the scales in the Starter Kit on pages 4-6

**Acknowledgement** getting the conversations started can be difficult. Read through conversation starters...note that they are in Conversation Starter Kit.

Ask if this may be the situation for anyone in the room. Offer them a chance to talk about how they might get the conversation going with the person they are concerned about.

52. Share that it is also critical that participants make their wishes known to their doctors. Acknowledge that this is not necessarily easy (Illustrate with stats on slide). Share that participants can’t necessarily wait for the doctor to initiate advance care planning conversations. They may need to bring it up.

53. Play approximately 5 minutes of this video.

In it, Dr. Sunita Puri talks about why doctors themselves may be reluctant or unfamiliar with Advance Care planning discussions.

**Background:**
Dr. Puri is a Palliative Care specialist at USC Medical Center and author of a new book entitled: That Good Night: Life and Medicine in the Eleventh Hour

**Activity:** If there’s time you may want to give participants opportunity to process what they heard in video by asking:

*Is there anything about what Dr. Puri shared that surprises you or confirms an experience you have had with a physician?*

54. **TRANSITION: Step 3 -- Another person who needs to know your wishes in your Health Care Agent.**

In this section we will describe:

- what a Health Care Agent is
- how to think about choosing this person and
- how to prepare them to help carry out your wishes if necessary.
55. Once you have done some thinking about your wishes for medical care...it’s important to consider who will share those wishes with your doctor, friends and family if you are unable to speak for yourself.

56. Many of us assume the logic of naming our spouse as our HCA. Offer examples of why that may not be the case. (Or ask participants to speculate.) Share examples of alternatives.

57. Just naming your HCA is not enough....You must empower that person with info about your thoughts and wishes so that they can speak confidently on your behalf. Offer the suggestions on the slide about how to keep HCA informed and ready to make decisions on your behalf.

### Completing an Advance Directive


59. Remind that, while Advance Care can involve many issues and topics, the two most critical are those on slide 58. **Background:** This is a legal document; this guidance to medical professionals gives them immunity if they follow your medical wishes. (American Bar Association Q and A)

60. **Background:** Participants often ask about what would happen if there is no AD in place and/or family members disagree on a course of action. Key things to remember:
   - Doctors will usually seek out input from family if there is no AD. However, they can only act on the input from a united family. If family members disagree and there is no AD, they may need to prolong life until a court or hospital ethics committee can rule.
   - An AD can give a doctor permission NOT to pursue aggressive interventions. However it does not compel the doctor to carry out your wishes. If the doctor disagrees with actions called for in your AD, they are obligated to recommend a different doctor.
   - An AD that is legally completed and shared with family and doctors well-before an emergency arises is the best way to ensure that your wishes will be carried out.

61. Acknowledge there are many different forms. (This slide shows pictures of several examples.)

62. Explain these key points about any of these versions:
   - They vary in wording.....level of detail.... and topics they ask about...
   - But all ask about Health Care Agent and wishes for medical care.
   - Once signed by witnesses or notary all are legal documents.
   **Background:**
   - MHHC provides participants with copy of California Advance Health Care Directive...but there are at least two other documents with same title that look very different. All are OK.
   - Five Wishes is published by Aging WithDignity.org and gets into detail about how you want to be treated at end-of-life...going beyond just medical care (e.g. what music at your bedside)
   - Many hospital and medical plan are developing their own.
   - We’re beginning to see online repositories of AD’s
   - Distinguish AD from Power of Attorney (for financial decision making only) and language about Health Care that may be included in a Trust. Trust Language can mirror Advanced Directives, can function as an AD, but are often tucked away in files or with lawyer. MAKE SURE THESE HAVE BEEN SHARED and that CONTENT/DIRECTIONS MATCH any AD on file with your doctor.
   - In the situation where there are multiple documents, the one most recently completed will supersede others.

63. Remind about the importance of sharing with key people.

64. Because participants may have heard of it and not know the difference between an AD and a POLST explain the purpose of the POLST:
   - Used primarily to guide the actions of EMTs and ambulance team should they be called to your home for emergency. They may not have access to your AD and their job is to keep patients alive until they can get them to a hospital.
- This is an order for treatment FROM A PHYSICIAN...
- If someone has serious illness they should talk to doctor about a POLST...fill it out together
- Post POLST on refrigerator or other conspicuous place in the house
- EMTs are trained to look for it there.

**ACTIVITY:** If time, provide time for filling out AD form, or answering questions from those who took form home after Session 1 and now have questions. Allow for Q and A with whole group so that participants can learn from questions others may have. When questions begin to sound unique to individuals, suggest bringing workshop to a close and remind you will stay behind to answer individual questions and/or witness completed documents.

**Closure**

**66.** Review Key Take Aways of this workshop. Use the animation on this slide to address each point. **Emphasize** that it’s a process that should be revisited especially following any significant life event.

**67.** This graphic represents the steps in the process and emphasizes the fact that it should be reviewed and changed as needed. **Background:** The American Bar Association recommends reviewing AD’s whenever one of these “Five D’s” occurs.
- Decade: Every ten years
- Death: Death of a loved one
- Divorce: Any major change in the family
- Diagnosis: When you are diagnosed with a serious medical problem and/or offered life prolonging treatments
- Decline: When you experience significant decline in health and/or diminished independence.

**68.** Share a sense of urgency: Ellen Goodman the Pulitzer Prize winning journalist and co-founder of The Conversation Project sums up the impact of putting off advance-care planning this way “It’s always too soon until it’s too late!”

**ACTIVITY:** Request individuals stay to complete evaluation forms....COLLECT
Offer once again to witness any completed AD forms. They should be signed in your presence.

**69.** Congratulate participants for the courage they have shown by attending a workshop on this topic... for engaging in difficult conversations about advance care planning..... And for TAKING CHARGE.

Back –Up Slide(s): Insert if desired

**Most important factors at end of life**

This bar graph shows results of survey conducted in answer to the question: “What is important to you at the end of your life.” If this level of detail is of interest, it can be inserted following Slide 11.
Appendix I: Volunteer Toolkit

Your Conversation Starter Guide

How to talk about what matters to you and have a say in your health care.

Institute for Healthcare Improvement
the conversation project

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We can’t plan for everything. But we can talk about what is most important — in our life, and in our health care — with those who matter most.

Talking with the important people in our life can bring us closer together. It also helps us create the foundation of a care plan that’s right for us — a plan that will be available when the need arises.

The Conversation Project wants to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected. We created this guide to help you start a conversation (and keep talking) so you can have a say in your health care — today and tomorrow.

It’s also important to choose what’s known as a health care proxy, or health care advocate — someone who would make health care decisions on your behalf if you became unable to voice those decisions yourself. Visit our Guide to Choosing a Health Care Proxy for guidance on picking a proxy.

If you are completing this document on a computer, first save it to your desktop with a name you can easily find again. Then open your saved document and type in your answers. (Otherwise, what you type will not be saved.) Completing it on your computer will create a digital document that you can easily share with others.

We’ll help you take it step by step.

You can take your time! There’s no need to say everything that matters in one conversation — you can start talking, then keep talking. It’s all about what works best for you.

STEP 1
Think About What Matters to You ......... 3

STEP 2
Plan Your Talk ............................. 4

STEP 3
Start Talking ............................... 8

STEP 4
Keep Talking ............................... 11

This document does not seek to provide legal advice.
STEP 1

Think About What Matters to You

To get ready to talk about what matters to you and your wishes for care through the end of life, it’s helpful to gather your thoughts as a first step. You don’t need to have the conversation just yet. Here are some helpful ways to think about what matters to you and prepare for your conversation.

1. What does a good day look like for you?

   SOME IDEAS: Is it time with family or friends? Enjoying favorite everyday activities? What do you need to enjoy a good life — through the end of life?

2. What or who supports you during difficult times?

   SOME IDEAS: Your faith, culture, family, friends, pets

3. Try finishing this sentence:
   What matters to me through the end of my life is...

   SOME IDEAS: Being able to recognize my children; being independent; being able to spend time with the ones I love

That’s your “what matters to me” statement.

Sharing it with people you trust could be a big help if they need to communicate with your health care team one day. They may need to share what’s important to you and what you need to be able to have a good day. They also may need to decide what type of treatment you’d want to receive. Completing this guide will help you refine what you want them to know about what matters to you.
STEP 2

Plan Your Talk

Having a say in your health care is more likely if you share how you feel about certain situations that could arise now, in the future, and toward the end of life.

For each statement below, mark the place on the line that is closest to what you think or believe about each statement now. There are no “right” or “wrong” choices — your answers are about what works for you.

1. As a patient, I’d like to know...
   - [ ] Only the basics about my condition and my treatment
   - [ ] All the details about my condition and my treatment

2. When there is a medical decision to be made, I would like...
   - [ ] My health care team to do what they think is best
   - [ ] To have a say in every health care decision

3. What are your concerns about medical treatments?
   - [ ] I worry that I won’t get enough care
   - [ ] I worry that I’ll get too much care
1. If I am diagnosed with a serious illness that could shorten my life, I would prefer to…

   Not know how quickly it is progressing or my doctor’s best estimation for how long I have to live

   Understand how quickly it is progressing and my doctor’s best estimation for how long I have to live

2. Any other notes you want to add?

3. If you were seriously ill or near the end of your life, how much medical treatment would you feel was right for you?

   I would want to try every available treatment to extend my life, even if it’s uncomfortable

   I would not want to try treatments that impact my quality of life in order to extend my life

4. Where do you prefer to be toward the end of life?

   I strongly prefer to spend my last days in a health care facility (hospital, assisted living, or nursing facility)

   I strongly prefer to spend my last days at home
Now, look at your previous answers. What do you notice about the kind of health care you said is right for you?

If you weren’t able to speak for yourself, would you want people to follow all your wishes or do what they think is best in the moment?

- I want the people I trust to do exactly what I’ve said, even if it makes them uncomfortable
- I want the people I trust to do what brings them peace, even if it’s different from what I’ve said

When it comes to sharing information about my health with others…

- I don’t want those close to me to know all the details about my health
- I am comfortable with those close to me knowing all the details about my health

When I die…

- I want to be alone
- I want to be with other people
What specific information would you want (or not want) shared with certain trusted people?

Look at your previous answers. What are the most important things for your friends, family, and health care team to understand about what matters most to you through the end of life?
STEP 3
Start Talking

How much do the people who matter to you know about what matters most to you? There may be some things they already know, and other things that you need to tell them. Sometimes we might think others know how we feel, but they don’t. Conversations help make what we think and how we feel as clear as possible.

1. Who needs to know what matters to you in your health care?
   Check all that apply:
   - Parent(s)
   - Spouse/partner(s)
   - Chosen family member(s)
   - Adult child/children
   - Faith leader (minister, priest, rabbi, imam, etc.)
   - Trusted friend(s)
   - Doctor(s)
   - Nurse practitioner/nurse(s)
   - Social worker
   - Other: ____________________________

2. Where would you feel comfortable talking?
   - At the kitchen table
   - At a favorite restaurant
   - In the car
   - On a walk
   - Video chat or phone call
   - At my place of worship
   - Other: ____________________________

3. The Conversation Project uses the saying, “It always seems too soon, until it’s too late.”
   When will you start this conversation?

---
8  The Conversation Project  theconversationproject.org  Institute for Health Care Improvement  IHI.org
You’ve gathered your thoughts, written down your ideas, and picked your trusted people. Now, how do you begin a conversation?

This list doesn’t cover everything, but here are some things you can say to start talking.

- “I need your help with something.”
- “Can you and I have a conversation about __________________?"
- “I was thinking about what happened to __________________, and it made me realize __________________.”
- “Even though I’m OK right now, I’m worried that __________________, and I want to be prepared. Can we talk about some things that matter to me?”
- “Will you help me think about my future?”
- “I heard about the Conversation Project and answered some of their questions about things that matter to me when it comes to my care through the end of life. I’d like to talk to you about it.”
- “When __________________ died, do you think their wishes and priorities were respected toward the end of their life?”

Here is a list of some other things you may want to cover when you talk.

- Do you have any worries about your health?
- What do you need to address to feel more prepared (examples: finances, property, legal documents, relationships, health care situations)?
- Do you have any fears, concerns, or mistrust about where or how you receive health care?
- Who do you want (or not want) to be involved in your health care?
- When you look ahead to the future, are there important events or dates you hope you’re there for?
- Are there kinds of treatment you would want or not want (examples: resuscitation attempts, ventilation, feeding tube)?
- If your health condition changed, when would it be OK with you to shift from trying to cure an illness to trying to enjoy the end of life as much as possible?
Tips for your talk

Imagine the conversation in your mind first. You can even write a letter that explains your values about the kind of care that works for you to figure out words that feel comfortable for you to use.

- You can also consider having a practice conversation, so you feel as prepared as possible to have a “real” conversation.
- You don't have to talk about everything or talk to everyone in the first conversation. In fact, we suggest you keep talking over time!
- Be patient. Some people are nervous or may need time to get ready to talk. Every time you start a conversation, it helps you come closer to making your wishes fully known. Keep trying.
- You don't have to lead the whole conversation; it's important to also listen to what the other person says so you can build trust.
- Nothing you say is permanent. You can always change your mind as things change in the future.
- You may find out during these conversations that you and your trusted people disagree. That's OK (no judgment). The important thing is that you're talking now and to keep talking — so you're prepared in case your health changes.
- You can share this guide, with or without your thoughts included, with your trusted people.
STEP 4

Keep Talking

Now that you’ve started the conversation, keep going! Talk to more people who may have a say in your health care. The more you talk, the more people you are close to will know what matters to you. And that makes it more likely that you’ll get the kind of health care you want — now and through the end of life. Here are some things you can think about to keep the conversation going.

1. When would be a good time to talk again?

   SOME IDEAS: It’s a good idea to have another conversation when life changes happen, such as the birth of a baby, when family and friends are together for a holiday or visit, before a trip, or when a health issue is getting harder to manage.

2. What might you want to repeat or explain again, so you’re sure your trusted people understand what’s important to you?

3. Who do you want to talk to next time? Are there people (such as family members who may disagree) who should hear things from you at the same time?

4. What do you want to make sure to ask or talk about next time?
What to do next

Now, it’s a good idea to record your conversation with an important legal document to be sure your choices are followed. This is called an advance directive. It has two parts.

1. Your Health Care Proxy
   This is the part of the advance directive where you name the person you have chosen to make health care decisions on your behalf, if needed, as well as an alternate if your first choice is unavailable. As explained in this guide, be sure to have a conversation — and keep talking — with these people to be sure they understand what matters to you. You can find more information and suggestions in our Guide to Choosing a Health Care Proxy.

2. Your Living Will
   This is the part of the advance directive where you describe your preferences and wishes for your health care if you cannot speak for yourself. These are many of the same things that you have thought about and discussed throughout this guide.

   Every state and most countries have their own advance directive forms. In the United States, the NHPCO (National Hospice and Palliative Care Organization) can help you find the right forms in your state (nhpco.org/advancedirective).

   It’s important to share your advance directive with more than your proxy alone. For example, if you pick an adult child to be your proxy and have other children, they should all be aware of what matters to you in your health care and know who you have chosen as your proxy. Talk to anyone who can help you have a say in your care through the end of life and provide copies of your advance directive to anyone who may need them. If you want tips on talking about what matters to you with your health care team, visit our Guide for Talking with a Health Care Team.

Learn more and share

VISIT US
theconversationproject.org

EMAIL US
conversationproject@ih.org

FOLLOW US ON SOCIAL MEDIA
@convoproject
@TheConversationProject
@convoproject
ACP Volunteer – Follow-up Script Example

Introduction / Building Connection / Introduction of Topic / Follow-up / Closing Remarks

Introduction

Volunteer (V): Good morning! My name is Jane Doe and I’m a volunteer with [insert organization name] for their Transitions Program.

   Note: verify you have the right patient/care giver

   Note: using the patient’s name is more personable than using the title ‘patient’

V: Am I speaking to [insert patient name]?

If not, V: What is your relationship with [insert patient name]?

Building Connection

V: How are you? What did you do today?

   Note: ‘How are you?’ is a standard conversation starter. It can be a good place to start. With experience, begin to think of alternative ways to start/begin a conversation. For example: What’s at the top of your mind today? What made you smile today? What is one thing you’re looking forward to?

V: Tell me a little bit about yourself.

   Note: This can be used to dig deeper and build further connection and trust with the patient. And can be used as a segue way to the next part.

Introduction of Topic:

V: (respond/affirm what they said about themselves and relate it back to you)
(for example) I also like to play guitar in my free time. Other things I do is tennis and volunteer. Which brings me to my current role. As a volunteer for [insert organization] I essentially just catch up with patients and see how they are doing.

   Note: ‘Follow-up’ is the key term, but it sounds technical and you want to be personable.
Follow-Up:

V: Have things/life been challenging lately? What are some challenges you are facing?

Note: It’s important to get a scope of what the patient is going through and their current quality of life.

V: Have you heard of an advance care plan? Do you have one and is it updated?

Note: Feel free to preface that there are some standard questions to be asked/topics to be covered. Or cleverly insert them into the conversation.

Advance care questions can be specific to the patient regarding their status/files on the EHR.

The volunteer can create a standard set of follow-up questions they can ask every time, some for example are:

- Are your needs being met?
- What are some challenges are you currently facing? If none, what are some wins/triumphs have you experienced recently?
- Do you have a current advance care plan such as a health care directive?
- We don’t seem to have a copy of your POLST. Do you happen to have a copy of it?

Educate as needed on what advance care plans are, their purpose, and importance.

Follow-up and provide email/fax/address information to where clients/care providers can send copies of advance care plans.

Closing Remarks:

V: Thank you for spending time with me today. It was a pleasure talking to you and getting to know you better.

V: A standard check-in is very few months. Would you like me or another volunteer to check-in with you sooner than that?

V: Have a good rest of your day. Take care.
Appendix J: Resources Handout

Resources for Advance Care Planning

Want to learn more about advance care planning and its importance and how it affects you? Look below for different links and research articles to gather more information and help you make informed decisions if and when the time is right.
Resourceful Websites

- https://theconversationproject.org/
- https://polst.org/polst-advance-care-planning/
- Advance Care Planning Fact Sheet
- Health Literacy (to understand medical terminology)
  https://www.ahrq.gov/health-literacy/index.html

Links/Examples of Advance Care Plans

- Five Wishes
  https://www.fivewishes.org/for-myself/
- State Specific Information
  https://www.caringinfo.org/planning/advance-directives/by-state/

Other Trainings

- Education Partnership with CSU Shiley Haynes Institute for Palliative Care
  https://coalitionccc.org/CCCC/Resources/CSU-Shiley-Haynes-Institute-for-Palliative-Care.aspx
## Appendix K: Project Timeline (Gantt Chart)

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Nov</th>
<th>Dec</th>
<th>Jan</th>
<th>Feb</th>
<th>Mar</th>
<th>Apr</th>
<th>May</th>
<th>June</th>
<th>July</th>
<th>Aug</th>
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</thead>
<tbody>
<tr>
<td>Microsystem assessment (gaps of care, financial analysis)</td>
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<tr>
<td>Select quality improvement focus and define AIM statement</td>
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<tr>
<td>Identify team members and key stakeholders</td>
<td></td>
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<tr>
<td>Draft project budget and implementation timeline</td>
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<tr>
<td>Project approval from facility directors</td>
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<tr>
<td>Creation of education program by CNL</td>
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<tr>
<td>Coordination of schedules for training sessions</td>
<td></td>
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<tr>
<td>Conduct volunteer staff training</td>
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<tr>
<td>Collect and analyze data (post-tests, safety audits)</td>
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<tr>
<td>Evaluate project outcomes</td>
<td></td>
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<tr>
<td>Update team and stakeholders</td>
<td></td>
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</tr>
</tbody>
</table>
Appendix L: Financial Analysis

Financial Analysis: Reducing Incidental Increased Length of Stay With Volunteer Education in ACP Follow-ups

<table>
<thead>
<tr>
<th>Cost Avoidance</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost of Extended LOS</td>
<td># of hospital admits</td>
</tr>
<tr>
<td>charges related to one patient for life saving measures due to inaccurate POSLT</td>
<td>includes: ER services, CPR, mechanical ventilation, hydration, artificial nutrition*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cost Implementation</th>
<th># of staff</th>
<th>by/rate</th>
<th>total hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational Program Creation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CNL Educator</td>
<td>1</td>
<td>$64</td>
<td>20</td>
</tr>
<tr>
<td>CNL Benefits (30%)</td>
<td>1</td>
<td>$19.20</td>
<td>20</td>
</tr>
<tr>
<td>Educational Program Delivery</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CNL Educator</td>
<td>1</td>
<td>$64</td>
<td>10</td>
</tr>
<tr>
<td>CNL Benefits (30%)</td>
<td>1</td>
<td>$19.20</td>
<td>10</td>
</tr>
</tbody>
</table>

**Net Savings (ROI)**

net savings = cost avoidance - cost implementation

$34,112.00

*prices from nearest hospital to the facility

(includes budget and cost avoidance)
Appendix M: Volunteer Competency/Evaluation Forms

ACP Volunteer Evaluation

Competency Assessment (Pre- and Post-)

Example. Draft 1

1. What is advance care planning?
   a. What matters most to you
   b. Prepared in advance for when you can’t make decisions
   c. Communicating wishes to your loved ones and healthcare team
   d. A process to take charge of the care you received that includes all of the above

2. What percentage of people actually talk about end of life wishes and care?
   a. 86%
   b. 27%
   c. 13%
   d. 52%

3. What is the reality of attitudes of death and dying?
   a. 70% die in institutions
   b. 50% of Americans die in pain
   c. 30% of families lose most of their life savings while caring for a dying loved one
   d. All of the above

4. True or false: In the absence of any other information about your wishes, physicians are trained to pursue all means necessary to prolong/save your life.
   a. True
   b. False

5. Order the steps of the Four-Step Process:
   _____ Choose your health care agent.
   _____ Think about what matters most to you.
   _____ Write it down — and share your plan.
   _____ Talk about your wishes with your family and friends.

6. What is the definition of hospice care?

7. What is the difference between palliative and hospice care?
8. List two benefits of palliative and/or hospice care.

9. Select all: Who should know about your healthcare end-of-life wishes?
   a. Your immediate family and loved ones
   b. Your neighbor
   c. Your doctors
   d. Your tennis league teammate
   e. Your Health Care Agent
   f. Your favorite barista who prepares your coffee perfectly every week

10. What is the percentage of people who have talked to their doctors about advance care planning?
    a. 7%
    b. 41%
    c. 67%
    d. 19%

11. Who is a health care agent/proxy?

12. List three characteristics of a good health care agent/proxy.

13. True or false: Your health care agent/proxy should not have a copy of your advance directive.
    a. True
    b. False

14. What does the POLST acronym stand for?

15. What is the purpose of a POLST form?
**Program Evaluation – Staff/Educator**

Instructions: Rate the Transitions Program volunteer education based on each standard below.

- **A** = Excellent/Agree
- **B** = Average/Acceptable
- **C** = Disagree/Needs Improvement
- **D** = I Don’t Know

Please offer suggestions for improvement.

<table>
<thead>
<tr>
<th>Standard</th>
<th>Rating</th>
<th>Suggestions for Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Volunteers are well prepared for this program.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It appears the scripts and toolkit that volunteers are provided/will use are adequate and effective.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Calls/interventions are made in a timely manner.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information received is relayed effectively.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interventions result in reduced discordant care and better plan of care.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interventions are helpful to the team.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interventions are helpful to patients and Families.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall, this program is effective and should continue.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Additional Comments:
Program Evaluation – Volunteer

Instructions: Rate the Transitions Program volunteer education based on each standard below.

A = Excellent/Agree
B = Average/Acceptable
C = Disagree/Needs Improvement
D = I Don’t Know

Please offer suggestions for improvement.

<table>
<thead>
<tr>
<th>Standard</th>
<th>Rating</th>
<th>Suggestions for Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel well prepared for this program and to carry out my responsibilities.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scripts, toolkits, and resources provided are adequate and useful.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have all the tools and resources I need.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have all the information I need</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The processes used to relay information are effective.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel supported in this role.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that my interventions/role are helpful to the team.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I believe this program is helpful to patients and families.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that overall, this program is effective and should continue.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Additional Comments:
Appendix N: Non-research Determination Form

CNL Project: Statement of Non-Research Determination Form

**Student Name:** Andrea Leomo

<table>
<thead>
<tr>
<th>Title of Project:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advanced Care Planning Educational Program for Hospice-Transitions Program Volunteers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Brief Description of Project:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A) Aim Statement:</strong></td>
</tr>
<tr>
<td>To educate volunteers in a hospice setting on advance care planning forms (ex. POLST, CAHCD) and resources resulting in an increase of knowledge by 15 percent.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>B) Description of Intervention:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>To create a program model to train and educate volunteers specifically for the hospice organization’s Transitions Program regarding advance care planning in a palliative/hospice setting.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>C) How will this intervention change practice?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Advanced care planning allows a hospice client in a clinical setting to consider and communicate the preferences in health care treatment that aligns with their wants and values. Patient care goals and values will be better identified, documented, and followed-up with volunteer help. Expanding the volunteer role within the organization’s Transitions Program can help reduce costs and increase patient safety and satisfaction of care.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>D) Outcome measurements:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre- and post-training tests will be given to the volunteers to measure efficacy of training. In the post-test, a score of 80% if considered a passing rate/competency rate.</td>
</tr>
</tbody>
</table>

To qualify as an Evidence-based Change in Practice Project, rather than a Research Project, the criteria outlined in federal guidelines will be used: [http://answers.hhs.gov/ohrp/categories/1569](http://answers.hhs.gov/ohrp/categories/1569)

☑ This project meets the guidelines for an Evidence-based Change in Practice Project as outlined in the Project Checklist (attached). Student may proceed with implementation.

☐ This project involves research with human subjects and must be submitted for IRB approval before project activity can commence.

5-17
EVIDENCE-BASED CHANGE OF PRACTICE PROJECT CHECKLIST *

Instructions: Answer YES or NO to each of the following statements:

<table>
<thead>
<tr>
<th>Project Title: Advanced Care Planning Educational Program for Hospice-Transitions Program Volunteers</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>The aim of the project is to improve the process or delivery of care with established/accepted standards, or to implement evidence-based change. There is no intention of using the data for research purposes.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The specific aim is to improve performance on a specific service or program and is a part of usual care. ALL participants will receive standard of care.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The project is NOT designed to follow a research design, e.g., hypothesis testing or group comparison, randomization, control groups, prospective comparison groups, cross-sectional, case control. The project does NOT follow a protocol that overrides clinical decision-making.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The project involves implementation of established and tested quality standards and/or systematic monitoring, assessment, or evaluation of the organization to ensure that existing quality standards are being met. The project does NOT develop paradigms or untested methods or new untested standards.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The project involves implementation of care practices and interventions that are consensus-based or evidence-based. The project does NOT seek to test an intervention that is beyond current science and experience.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The project is conducted by staff where the project will take place and involves staff who are working at an agency that has an agreement with USF SONHP.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The project has NO funding from federal agencies or research-focused organizations and is not receiving funding for implementation research.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The agency or clinical practice unit agrees that this is a project that will be implemented to improve the process or delivery of care, i.e., not a personal research project that is dependent upon the voluntary participation of colleagues, students and/or patients.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>If there is an intent to, or possibility of publishing your work, you and supervising faculty and the agency oversight committee are comfortable with the following statement in your methods section: &quot;This project was undertaken as an Evidence-based change of practice project at X hospital or agency and as such was not formally supervised by the Institutional Review Board.&quot;</td>
<td>X</td>
<td></td>
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</tbody>
</table>

**ANSWER KEY:** If the answer to ALL of these items is yes, the project can be considered an Evidence-based activity that does NOT meet the definition of research. 
**IRB review is not required. Keep a copy of this checklist in your files.** If the answer to ANY of these questions is NO, you must submit for IRB approval.

*Adapted with permission of Elizabeth L. Hohmann, MD, Director and Chair, Partners Human Research Committee, Partners Health System, Boston, MA.
STUDENT NAME (Please print): Andrea Leomo

Signature of Student: ____________________________ DATE 04/06/2023

SUPERVISING FACULTY MEMBER NAME (Please print): Francine Serafin-Dickson

Signature of Supervising Faculty Member: ____________________________ DATE 4/19/23
Appendix O: Results

<table>
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<tr>
<th>Volunteer</th>
<th>Pre-test Score</th>
<th>Pre-test %</th>
<th>Post-test Score</th>
<th>Post-test %</th>
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<tr>
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<td>14</td>
<td>93%</td>
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<td>14</td>
<td>93%</td>
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<tr>
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Volunteer Scores: 

- **Pre-test**: Blue bars 
- **Post-test**: Gray bars 

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