Respecting Choices®

Advance Care Planning Facilitator Course

Chapter 6
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Chapter 6

Making Advance Care Planning Work: Organizational Issues and Educational Strategies

In chapter 1, we described Respecting Choices as a comprehensive advance care planning program that advocates four key elements: training healthcare professionals and others to skillfully facilitate advance care planning discussions; developing community and organizational systems and practices to incorporate advance care planning into the routine of care; designing effective patient and community advance care planning engagement materials; and monitoring outcomes with continuous quality improvement methods. A major focus of this manual has been the specific skills and knowledge involved in training health professionals and others to facilitate advance care planning discussions. This final chapter will describe the three remaining elements necessary for a successful advance care planning program. Respecting Choices has a separate manual devoted solely to organizational issues. To learn more about this manual, go to www.respectingchoices.org.

Developing Community and Organizational Systems and Practices

There are four key components in designing community and organizational advance care planning program: leadership and commitment, standard policies and practices, defined advance care planning team roles and responsibilities, and effective strategies to educate the team. To demonstrate these key components, we provide examples from the La Crosse experience.

1. **Leadership and Commitment.** The La Crosse experience demonstrates how one community achieved success through a combination of leadership, commitment, and implementation of the principles of organizational design. One of the unique aspects of the advance care planning program in La Crosse is that it is a community program jointly developed by all the major healthcare systems in the area, as directed by their CEOs. These organizations agreed upon and implemented uniform practices, staff training, and education materials. This collaboration provides uniformity that helps individuals and
allows partnerships with other organizations, such as churches, educational institutions, and libraries. The La Crosse program planning committee adopted the following mission statement:

“Decision making about life-sustaining medical treatment will be improved if all adults are better informed about the realities and possibilities of modern medicine, assisted in making choices about future treatment should they become incapacitated, and assisted in communicating their values, feelings, and choices to those who care most about them, including health professionals who provide their care.”

To accomplish this mission, the following objectives were developed:

- All healthcare facilities within the community will have individuals who can inform and educate patients and their families about advance care planning. It is the expectation that physicians, especially in the outpatient setting, talk with their patients about advance care planning, routinely refer their primary patients to advance care planning facilitators, and follow up with discussions as necessary.

- The medical centers will develop a common educational program for advance care planning, the primary goal of which is increased understanding of medical decision making, of the role of patient goals, values, and beliefs, and of the communication among family members. A secondary goal of the program is to provide reliable information about alternative ways a patient might document goals, values, beliefs, and preferences.

- Only persons who have completed the advance care planning facilitator educational program will be authorized to provide advance care planning within the organizations. While primarily for medical center employees and staff, facilitator education is also available to community members such as clergy, social workers, home healthcare nurses, attorneys, and senior citizen advocates.

- The medical centers shall maintain policies that delineate standards and guidelines for consistent application of advance care planning practices.

2. Policies and Practices Related to Advance Care Planning. The La Crosse Task Force agreed upon several key provisions to be included in advance care planning policies and procedures throughout the community. A sample policy is included in appendix I of this chapter. To summarize, advance care planning policies and procedures should include the following provisions:

- Capable adult patients may freely enter written advance directives without specific limitation on the format.
This first provision allows the greatest freedom to patients and their physicians in recording preferences. While most patients choose to use a formal, written advance directive, some prefer to simply discuss their preferences or values with a trusted physician and then have the physician record these preferences as a dictated note. Such dictated notes typically deal with limitations on the use of CPR and intubation in patients with end-stage diseases. This openness to different types of documentation preferences allows physicians to add dictated comments to a patient’s legal document, patients to write letters or other informal ways of expressing preferences, surrogates to make written plans when their loved ones have become incapable, and flexibility in addressing cultural barriers in documentation.

If the ethical basis of advance care planning is to express how to best care for someone we love, and if the legal basis is to respect patient preferences and a capable adult’s right to refuse any treatment, it seems important not to interfere with the format of written expression of patient preferences. While it is appropriate to recommend the completion of a Power of Attorney for Healthcare–type document that meets statutory requirements, such a document may not be the best option for some individuals. Further, this format might need other supporting documentation over time.

- **Written directives shall be reviewed by qualified staff before they are entered or removed from patient charts.**

This provision emphasizes the importance of ensuring that documents are thoroughly reviewed before entering or removing them from the medical record. At Gundersen Lutheran, staff qualified to enter or remove documents includes physicians, physician assistants, nurse practitioners, trained advance care planning facilitators, and medical record personnel. When documents are entered or removed, the designated individuals review them for a variety of factors, including whether the request is from the patient, if the document is completed correctly, and if there are any concerns about the instructions.

It is not uncommon for 10% of the documents completed outside the organization to contain technical errors—for example, the patient forgot to sign the document, a witness is missing, or the witness is inappropriate. At times, patients may document a preference that is unlikely to be followed or is extremely unclear. In such cases, the patient or the patient’s attorney can be contacted for clarification.

- **A standard location for advance directives shall be designated within the medical record, and any document shall be clearly labeled with the patient’s name, the date entered, and the person who entered it.**

An organization should have a reliable, standard place in the medical record to keep written advance directives in order to ensure that immediate retrieval is possible when
treatment decisions must be made quickly. Immediate access is also critical to a physician who may never have met the patient before and who likely would be unaware of the person’s preferences.

When the Respecting Choices program began and medical records were physical charts, the medical centers in La Crosse agreed that all advance directives would be placed in green plastic sleeves to be located at the front of patient charts. Visible even when misfiled in the medical record, the sleeve is durable and portable. It was easily moved from the patient chart to the hospital unit flip chart during hospitalizations, thereby keeping the document at hand when it may be needed most. Even though charts are not always immediately available in the emergency department, the green sleeve was easily located once the chart arrived. Upon admission to the hospital, the green sleeve was transferred from the patient’s chart to the patient’s nursing unit chart and then returned to the medical record upon discharge from the hospital. In this way the patient advance directive was always easily accessible to any physician or nurse caring for the hospitalized patient.

As medical records evolve to an electronic format, new challenges and opportunities exist. Gundersen Lutheran has invested over two years in the development and design of an ACP application that is a component of a larger electronic medical record. In designing this ACP application, the goal was to capture all the critical implementation variables into a single electronic application system.

Finding this application in the electronic record is simple. There is a clear link on the first page, the patient summary page, that appears when you access the patient’s electronic chart. Once in the advance care planning application, it is possible to determine whether the patient has any type of written advance directive and, if so, to view this document as a PDF file. If the patient has a power of attorney for healthcare, the names of healthcare agents and their contact information are immediately in view, as is any preference about CPR. In addition, the application features a computer-directed system to interview a patient about advance care planning needs, to retrieve dictated notes involving advance care planning, to make referrals to advance care planning facilitators, and to allow facilitators and others to record notes about advance care planning education or interactions. This application is available to all Gundersen health professionals in all Gundersen care settings, making it a powerful way to communicate patient preferences and ACP discussions. Thus, if planning were started at Gundersen Lutheran Medical Center when a patient was hospitalized, a facilitator at a regional clinic could access this information through our integrated electronic medical record system when a patient returns for a referred visit.
• *A patient’s written directive will be honored—or the patient’s care transferred to a physician who will honor it—unless (1) there is clear evidence that the directive is a forgery, (2) the patient had requested that it be revoked, (3) the patient was incapable when the document was signed, or (4) the document asks the facility to do something illegal under state law.*

The La Crosse Task Force wanted a strong organizational commitment to honor the authentic preferences of a patient. While individual staff conscience was recognized and accepted, the organization took a stand on its willingness to follow the preferences of adult patients. Unless the organization has strong and clear evidence that the document was revoked, is a forgery, was not created by a decisional adult, or asks the organization to violate state law, the preferences will be followed. The organization has a responsibility to help find a physician to follow a valid written advance directive if a particular physician refuses.

• *Guidelines will be adopted to ensure that when patients transfer from one institution to another, copies of their advance directives are transferred, as well.*

To foster respect for honoring patient preferences and the community support of advance care planning, it is important to establish a mechanism to transfer documents when patients are moved to other organizations for healthcare. This ensures that patient preferences will be known. It is also a courtesy to other organizations, which also must ask patients if they have written advance directives.

In the La Crosse community, when patients are transferred from the hospital, discharge planners are responsible for identifying any written advance directives in patient records and for making copies of these documents to include in the packets of patient information provided to the admitting organizations.

• *All adult patients with whom advance care education or planning has been initiated will have advance care planning records put in their charts.*

Since advance care planning discussions take place over time and with different staff, it is important that a documentation system for these discussions (i.e. advance care planning record) be created for use by physicians, nurses, and advance care planning facilitators.

This advance care planning record documents both the advance care planning process and any written advance directives that have been developed. It documents the educational materials provided, issues discussed, and who was involved. Summaries of ACP discussions and patient reactions are documented, as well. This type of documentation is useful because it provides continuity between advance care planning sessions and a mechanism whereby the various staff facilitating this planning can communicate. The
information in the advance care planning record can also be useful in interpreting any written preferences provided by the patient.

- Physicians and other health professionals must review advance directives and convert preferences into medical orders when appropriate.

Ultimately, advance directives have little significance if the preferences of the patient are not incorporated into care plans and into medical orders that reflect specific patient preferences and guide patient care. This is especially important because the vast majority of people will die as a patient in some type of healthcare organization, in which medical orders guide care and treatment. In La Crosse, when a patient is admitted to the hospital, physicians are expected to review the written advance directive and write appropriate orders. Ignoring this responsibility likely would prompt an ethics consult to review the situation. When patients are discharged or simply remain in a community setting, physicians have the option of using the POLST form to convert patient preferences into medical orders.

3. Advance Care Planning Team Roles and Responsibilities. Responsibility for understanding the importance of advance care planning and knowing the appropriate resources for patients and their families ideally rests with multiple health professionals. While different team member roles carry with them different responsibilities for advance care planning—from initiating advance care planning discussions to simply providing educational information—the involvement of all professionals at some level will increase the opportunity for success. The Respecting Choices program accepts that persons other than physicians will engage in discussing end-of-life issues. This approach does not mean that physicians are being left out or have a minor role to play in advance care planning facilitation and discussion. On the contrary, it encourages health professionals to work as a team, taking advantage of each other’s strengths. While many organizations choose to designate staff to play instrumental roles for advance care planning, delineating specific responsibilities for all direct caregivers is critical to ensuring consistency and accountability throughout the healthcare system. Defining team member roles and responsibilities also allows for development of a clearer curriculum.

While this program takes the approach that there is strength in promoting education and basic competency in advance care planning among many healthcare roles, it provides more detailed information to advance care planning facilitators, physicians, and nurses.

Advance Care Planning Facilitator Role and Responsibility

Certified advance care planning facilitators come from many backgrounds: medicine, nursing, social work, pastoral care, law, community churches, and all types of volunteer organizations.
Facilitators use the education and skills provided in the Respecting Choices program in many ways, depending on their experience, education, background, interest, and role within the organization. It is critically important to identify the roles needed within an organization and community and to then determine who is best qualified or able to fill these roles.

At a minimum, advance care planning facilitators not only assist individuals in determining their preferences for future medical care, but they also educate other health professionals. Advance care planning facilitators also may assume any or all of the following roles and responsibilities:

- provide community education, both formally and informally
- coordinate advance care planning activities within an organization or community
- assist with the development and implementation of organizational systems that support advance care planning objectives
- provide emotional support to patients/families struggling with making end-of life decisions
- conduct performance improvement activities to continually evaluate quality outcomes related to advance care planning

It would be a mistake to believe that everyone who attends an advance care planning facilitator’s education program will use the preparation in the same way. To ensure that the resources necessary to address all aspects of advance care planning are in place, organizational leaders must define areas of responsibility and designate qualified people to fill them.

As an example of the necessity for a team approach for advance care planning facilitators, consider the efforts required to engage adults in advance care planning discussions before admission to the hospital. In the La Crosse area, when patients are scheduled for elective surgery or some other procedure, surgeons, associate staff, or nurses are asked to provide patients with advance care planning information during their pre-admission visits. If a patient requests assistance with these issues, staff must know who to contact for consultation. It is helpful to have a centralized advance care planning facilitator to call. An intake sheet communicates the need for consultation and relevant information. (See appendix II at the end of this chapter.)
Physician Role and Responsibility

Some might argue that, ideally, physicians would be completely responsible for advance care planning discussions—and there are many reasons to support this position; however, there are many obstacles to making it work in the real world. First, many adults see more than one physician, but physicians generally will engage in advance care planning discussions with only those patients with whom they have developed a close professional relationship. Second, many physicians do not want to do this type of facilitation or do not feel they can do a particularly good job of it. Finally, since physician time is at a premium in most settings, advance care planning discussions may not be a priority.

A team approach to advance care planning facilitation is probably a more realistic approach. For example, physicians might initiate discussion and provide information related to the patient’s medical condition. These discussions can motivate patients to undertake end-of-life treatment planning, as well as help them make final decisions based on health condition and treatment options. But between these beginning and ending conversations, patients often need help with basic information, values clarification, discussions with loved ones, and documentation of preferences. While these activities can certainly be carried out by physicians, they can also be performed by other adequately prepared facilitators. The team approach allows for a partnership between professionals who develop a good understanding of each other’s role and establish effective communication mechanisms.

In many organizations, it has been difficult to get physicians to support the team concept, in part because their focus often is solely on completing the legal document. Thus, physicians may view advance care planning as a premature intervention for their patient unless they understand that effective advance care planning is a process—that, ideally, the many decisions involved in completing the legal document are made only after patients have had time to reflect, to discuss with loved ones, and to consider end-of-life treatment options.

Respecting Choices attempts to address these physician concerns by focusing efforts on improving patient understanding, reflection, and discussion of end-of-life issues through a partnership between the health professionals providing care. Physicians generally have fewer objections to these goals and realize that when legal documents are completed as part of this process, patients and their loved ones have a reasonable understanding and agreement about what decisions will be made. Finally, the Making Choices patient educational materials, through their common name and image on booklets and posters, make it clear to patients that this advance care planning work is sponsored by the organization, is part of good care, and is not the individual bias of a physician. Patients
and their families can, therefore, benefit from multiple resources that are committed to improving care at the end of life.

Registered Nurse Role and Responsibility

The role of the registered nurse (RN) in advance care planning has often been overlooked or avoided. In implementing the Patient Self-Determination Act, many organizations assigned personnel in the business or registration department the task of asking the patient on admission if they had an advance directive. In complying with the letter of the law, opportunities for educating patients and initiating conversations were lost. Indeed, many organizations have since reassigned this responsibility to the admitting RN. Unfortunately, this reassignment often has not been accompanied by appropriate education regarding communication techniques or related interventions that may be required in gathering information from patients and their families. While it is understood that RNs sometimes do not have time for in-depth discussions and must refer patients to facilitators, they can still do a lot to engage patients in advance care planning. Opportunities exist to assess patient needs, initiate conversations, provide information, listen, make referrals, provide emotional support, assist with communicating patient preferences, and participate in developing a plan of care consistent with the patient wishes. A sample script and flow chart for an advance care planning admission assessment by an RN is included in appendix III.

Basic competency expectations related to advance care planning for nursing staff must be defined, and educational efforts must be designed to support skill acquisition.

4. Educating the Team. In order for an advance care planning program to be successful, a variety of healthcare professionals and others must invest in educational opportunities to enhance their knowledge and skills, although the level of knowledge and skills required for various roles will vary. Organizational leaders must invest time and resources in curriculum design and implementation, and hold professionals accountable for acquiring the necessary skills.

Educating healthcare professionals requires understanding of their educational background as well as the development of creative methods to assist them in learning new skills. Evaluations of the curricula within many professional schools in health-related fields reveal the absence of content related to end-of-life treatment and care. Further, many healthcare professionals complete formal education having never cared for a dying patient and the patient’s family. Exposure to the realities of the dying process and learning to address end-of-life issues often occur on the job, with little support or preparation. It is no wonder that some healthcare professionals avoid these situations—situations in which they feel uncomfortable or ill prepared, situations that harbor the
potential for conflict. Studies of professionals’ knowledge of current national recommendations and guidelines related to end-of-life issues and professionals’ responsibilities to effectively respond to these issues reveal not only a lack of awareness of ethical principles and legal rulings but also continued dissatisfaction and discomfort when placed in these situations.

One of the recommendations included in all national initiatives for improving end-of-life care is to increase the clinical competence of healthcare professionals in end-of-life issues. Professional organizations and regulatory agencies are responding to this challenge with educational opportunities. The Institute of Medicine has published necessary skills for professional preparation in end-of-life care for medical students. The American Association of Colleges of Nursing has distributed a list of recommended competencies and curricular guidelines for end-of-life nursing care in a document called “Peaceful Death.” In 1999, this association collaborated with the City of Hope Medical Center to develop these recommendations into a curriculum called “End-of-Life Nursing Education Consortium” (ELNEC), launching training programs in January 2001. The American Medical Association is provides national training conferences for physicians in a program entitled “Educating Physicians on End-of-life Care.” These educational opportunities can foster an environment of shared responsibility and improved advance care planning outcomes. Organizational leaders will need to develop strategies to address multiple questions in maintaining competency in advance care planning:

- What are the basic competencies of advance care planning for the various healthcare roles and responsibilities?
- What educational methods convey this information most effectively and in a cost-effective and time-efficient manner?
- Who will be responsible for evaluation of professional competency?
- What opportunities will be offered to professionals for practicing new skills and gaining valuable experiences?
- How will professionals be held accountable for their learning?

A variety of educational strategies may be effective in exposing a large group of professionals to the concepts of advance care planning, including both didactic and experiential learning strategies.

Generally, staff experience two types of education beneficial. The first, didactic, is an informational approach that clarifies the differences between the process of advance care planning and the completion of an advance directive. This type of education also focuses
on regulatory and policy issues. This information is often presented in a lecture, a discussion, or a combination of the two. Other didactic options—self-paced modules, computer-assisted learning, videotape reenactments—provide more flexibility for learners because they can be completed at the learner’s convenience.

The second type of education is *experiential*, which requires participants to learn to discuss end-of-life issues and to practice newly learned skills within the context of real patient and family situations. Designing experiential lessons requires creativity. And successfully facilitating such classes requires listening, clarifying, probing, and problem-solving skills, as well as the ability to stimulate critical thinking, to lead less structured discussions, and to create a supportive and nonjudgmental environment.

Disseminating the concepts of advance care planning to a large group of stakeholders (nurses, social workers, clergy, volunteers) is an educational challenge and a programmatic necessity. All staff working in healthcare organizations must become knowledgeable about the basic concepts of advance care planning, the policy and practices of advance care planning within their organization, their individual roles and responsibilities, how to identify an individual in need of advance care planning assistance, and how to make a referral to a qualified facilitator.

Respecting Choices has developed the following online programs to meet the challenge of educating large and diverse groups.

**Basic Concepts.** This half-hour training provides basic information about advance care planning for any employee working within a healthcare organization. It clarifies the difference between advance care planning and advance directives and reviews the components of basic healthcare planning for adults. Regulatory and policy issues are addressed, and learners are encouraged to become familiar with the advance care planning procedures and resources within their organization or community.

**RN Concepts (role of the nurse).** As a follow-up to the basic concepts of advance care planning training, this half-hour module specifically focuses on the role of the nurse. It identifies advance care planning competencies and assists nurses in understanding their responsibilities in such areas as identifying a patient’s need for medical information, providing basic information on advance care planning, advocating for the patient’s expressed wishes, and making referrals.

**Respecting Choices Advance Care Planning Facilitation Online Course: Part 1 (Foundational Facilitation Skills).** This program consists of a series of three critical thinking modules designed for any individual who is interested in learning the skills to facilitate basic advance care planning discussions. The content in this series includes skills at initiating conversations, engaging people in the ACP process, clarifying information,
exploring individual goals and values, selecting a health care agent and making referrals. Additionally, the content includes the skills at assisting individuals in creating written plans that represents their preferences and can be communicated to others.

Module 1. Advance Care Planning and Advance Directives: Understanding the Language, Concepts, and Tools

Module 2. Facilitating Basic Advance Care Planning Discussions

Module 3. Creating an Advance Directive: Communicating the Plan

Respecting Choices Advance Care Planning Facilitation Online Course: Part 2. This program consists of a series of three critical thinking modules designed for healthcare professionals who want to enhance their advance care planning facilitation skills for patients with progressive illnesses and those who we may not be surprised if they died in the next 12 months. The content in this series also helps learners to identify the skills necessary to address the multiple systems challenges required to implement an effective advance care planning program.

Module 4. Facilitating Advance Care Planning Discussions for adults with chronic, progressive illness

Module 5. Facilitating Advance Care Planning Discussions for adults who are expected to die in the next 12 months, or for those living in long-term care facilities

Module 6. Making Advance Care Planning Work: Organizational Issues and Educational Strategies

Patient and Community Education and Engagement

The importance of advance care planning as an opportunity for patients and the community at large to become knowledgeable about end-of-life issues, aware of their values, goals, and beliefs, and willing to make treatment choices must be emphasized. However, capturing the attention of this group regarding the importance of this issue and developing effective educational programs are challenges faced by advance care planning facilitators. Educating patients and the community and motivating them to participate in advance care planning involves creating engaging materials and developing community partnerships. The following suggestions for patient and community education are provided:
1. As discussed in chapter 3, it is important to develop educational materials that deliver consistent, common, and repetitive messages that can be utilized throughout the community.

To make these educational materials more effective, the La Crosse program attempts to make them widely available. Efforts have been made to work in partnership with a variety of organizations and other professionals, using as many forms of dissemination as possible.

**Displays**
Displays with handouts are placed in various settings. Of particular success has been an installation near the main elevators in an ambulatory clinic. Patients on their way to appointments or coming for laboratory tests will see this display, the main message of which is that people should talk with their loved ones about end-of-life issues. This display is stocked with Making Choices booklets and worksheets. A display has also been placed in the public libraries, along with Making Choices materials at the reference desk. This display also indicates that the Making Choices video can be checked out at the audiovisual desk of the library. These materials are provided to the libraries at no charge.

**Video**
It has been more difficult to make the video widely available than it has been for the brochures and worksheets. Many organizations lack an easy way to loan the video to patients. Many groups within the organizations allow patients to take the video home. An organization’s health resource center may loan the video as well. The video is shown twice a day on the in-house cable system in the hospital.

**Media**
We have attempted to keep end-of-life treatment planning and discussion in front of the public by encouraging stories in the local print and broadcast media. Our own organization has newspaper inserts and other newsletters. Local talk radio programs are often looking for a guest to talk about end-of-life issues. Such shows can become an important way to reach a whole new audience. An effort to promote and explain advance care planning is made at least twice a year. In each of these media efforts, it is important to indicate where people can obtain more information or assistance, so the ability to respond to requests must be in place before such publicity is undertaken.

2. Involve area leaders from organizations such as religious groups, businesses, and law firms. As these leaders become better informed about advance care planning, they can assist their respective groups in learning more about the relevant issues. One strategy used in some communities is to include community leaders on the institutional ethics committee. The goals of these ethics committees, therefore, include reaching out to the
community and holding community members responsible for organizing and supporting educational programming.

End-of-life treatment discussions occur in many settings outside of health organizations. In particular, they occur with some frequency at religious organizations and attorneys’ offices. Attempts to develop good working relations with both of these groups should be part of any program.

The advance care planning facilitator course is open to both clergy and attorneys. While the number of attorneys who have attended is small, success at attracting clergy and parish nurses has been good. Support from local bishops and grant money from some religious foundations have subsidized training of the clergy. When a clergy member or someone from a religious organization successfully completes the advance care planning facilitator program, the religious organization is given a set of patient educational materials, including the video, to use with their community.

We have also met with groups of clergy to explain the program and to provide an introduction to the Respecting Choices program. Whenever possible, we make presentations to local religious organizations.

Interaction with the legal community has been accomplished in two ways. We have sent letters explaining our work with advance care planning and addressing problems commonly found in advance directives created by local attorneys. Mailing lists have been obtained through either the bar association or a mail label service. We have also made advance care planning presentations to the county bar association. These presentations have focused on identifying technical problems commonly seen in advance directive documents and on explaining the Respecting Choices programs. We also emphasize that effective advance care planning involves more than completing a document; it is important that the process incorporate reflection and understanding. These contacts have been very helpful in creating a collaborative relationship between attorneys and health organizations regarding advance care planning.

3. Develop partnerships with community media personnel to host radio talk shows, advertise educational programs, and publicize patient stories, among other goals.

4. Survey members of the community about their knowledge of advance care planning. Ask for their suggestions for educational programs and ideas for focus groups, among others.

5. Participate in community events such as local fairs, festivals, and health-related programs.
6. Organize and present formal and informal community education on advance care planning. When giving a presentation to a community group, it is important to establish how long they are expecting you to speak. Some groups have only 15–20 minutes, while others allow 60–90 minutes. Depending on the length of time and the group’s goals, the presenter will be able to cover more or less material, with or without a lot of detail. Find out how many people are expected to attend and what equipment will be needed for presentation, as well. In all cases, provide attendees with brochures to take home and information about how they can get additional advance care planning assistance. Recognize that talking about death and dying will make some people uneasy. It may remind them of difficult decisions they have already made or of which they have been part. Tell the audience that while some of the information may cause some pain, the importance of the topic warrants frank and honest discussion.

7. One of the best ways to reach the community is through your healthcare organization’s employees. Include education for employees at their orientation and at annual health fairs. Encourage your employees to engage their families in advance care planning. Make sure they know about your organization’s advance care planning program and where to go for assistance.
Continuous Quality Improvement: Measuring the Effectiveness of an Advance Care Planning Program

The often repeated phrase “If you don’t measure it, you can’t improve it” certainly applies to advance care planning programs. An organization must be accountable not only for producing programs that are of value to the patients and families they serve, but also for proving those programs worthy of the organization’s investment of time and resources. As programs are implemented, organizational efforts should include establishing specific quality outcome goals, designing methods to measure attainment of those goals, and making continuous improvements based on these findings.

Selection of adequate quality outcomes and appropriate tools to measure the effectiveness of an advance care planning program are just beginning to emerge. What is acknowledged is that while collecting data on the number of advance directives completed is a beginning, it is not enough. Research has demonstrated that even when written advance directives have been completed, their existence is unknown, they are unavailable when needed, or they are ineffective in influencing treatment decisions. Advance care planning monitoring must measure outcomes indicative of an effective process, as defined by improved communication and patient understanding; the raw number of completed advance directive documents cannot measure such variables. Researchers have suggested the following as quality indicators of an effective advance care planning process:

- improved patient understanding of the importance of participating in advance care planning
- improved communication pathways between patient, physician, and other healthcare professionals
- evidence that patient preferences were followed and transferred to treatment decisions
- completion of advance directives well before a medical crisis
- increased patient and family satisfaction with the advance care planning process, the experience of dying, the amount of burden placed on loved ones, and so forth
- documentation of advance care planning discussions

Since the La Crosse Advance Directive Program was implemented, participating organizations have engaged in several quality improvement activities. A few examples are provided:

1. **Video Evaluation**
The Making Choices video was developed to motivate viewers to discuss end-of-life issues with their loved ones. After viewing the video, more than 669 individuals from 32 groups completed the survey, the results of which indicated that

a. the video helped them understand the importance of advance care planning (94.9%).

b. they would recommend the video to family or friends (96.3%).

c. they were very likely (60.5%) or would possibly (27.7%) talk with another family member about an advance directive.

2. Quality Improvement Projects

a. A yearly raw count of advance directive documents in patient healthcare records was made. A survey of charts has been conducted in the general file room, in specific medical specialty departments, and for patients discharged from the hospital between 1993 and 1996. This ongoing data collection has shown a steady increase in the number of advance directive documents recorded in patient healthcare records.

b. A focused quality improvement project was developed by the Advance Directive Quality Improvement Task Force at Gundersen Lutheran using the Plan-Do-Check-Act (PDCA) improvement model. With representatives from all disciplines, the Task Force spent a considerable amount of time describing the process of handling advance directive documents and advance care planning education. The resulting flow diagram revealed not only that the process was more complicated than supposed, but also that the actual process did not correlate with established procedures. This analysis identified several problems and gaps. Two of the problems and the actions taken to solve them will be described.

(1) Initial RN–patient interaction. A survey of nursing staff identified considerable variation of practice and behavior regarding questioning of patients about advance directives upon their admission to a nursing unit. Some RNs asked the question, “Do you have a living will?” while others asked “Do you have a Power of Attorney for Healthcare?” or “Do you have a written advance directive?” Clearly, this inconsistent terminology is confusing to patients and often indicated limited staff understanding. It became clear that even when patients indicated that they had documents of some type, nurses were not asking where the documents were located and, therefore, not ensuring that they were entered into the medical records. The survey also revealed that nursing staff did not know how to get help for patients who had questions about advance care planning or about completing advance directives.
We needed an improvement strategy that was more effective than just another educational inservice. In our approach, written scripts were created to provide an organizational standard for nursing practice. One script dealt with the admitting nurse asking patients about advance directive documents, and the other script dealt with the case manager asking patients with no written advance directive about their end-of-life preferences. These scripts are provided in appendix III at the end of this chapter.

A post-test demonstrated more consistent practice and behavior after this intervention. Over a year after the intervention, 86% of nurses could correctly explain what an advance directive was, compared with 70% before the intervention. Nurses were also much more likely to specifically inquire if patients had a power of attorney for healthcare after the intervention (72% vs. 47%). They were more likely to ask patients where their document was located (92% vs. 77%). Nurses were also more likely to ask patients who did not have an advance directive if they wanted more information (96% vs. 86%) and were more likely to provide patients with additional information (27% vs. 3%).

(2) A second improvement opportunity concerned the inconsistent transfer of patients’ advance directive documents from their health records to their unit records upon admission to the hospital, as was required by hospital policy. Education for unit secretaries was provided, and the hospital policy was revised to incorporate terminology consistent with that used on the units.

c. In 2000, an advance care planning work group gathered for a brainstorming session on the status of the current program, what was working, and what needed to be improved. It was decided to examine the level and quality of advance care planning discussions with patients with chronic, progressive illness (congestive heart failure, CHF and chronic obstructive pulmonary disease, COPD) in the outpatient setting, with the goal of encouraging early discussion of preferences for future medical care in this patient population.

Prior to making any changes, three assessments were conducted: (1) Through physician interviews, we explored physician views and concerns regarding advance directives and the frequency and quality of advance care planning discussions; (2) Through a chart audit, we determined the number of CHF and COPD patients who had completed advance directives; and (3) Through patient telephone interviews, we assessed the level of patient satisfaction with advance care planning discussions.

Results of the chart audit (N=111) revealed that 48% of patients with a diagnosis of CHF or COPD had executed an advance directive. Of these, 94% were in the medical
record; 24% requested no CPR under certain conditions, and 15% of the records had evidence of documentation of an advance care planning discussion.

Results of the physician interview demonstrated that while a high percentage (89%) of physicians initiated advance care planning discussions, only 26% initiated conversations with all patients, reserving these conversations for those more seriously ill (36%) or those who were older (16%). Barriers identified by the physicians who were interviewed was lack of time and an insufficient pool of people to whom to refer patients for advance care planning. Most physicians were comfortable initiating advance care planning discussions (84%) and supported other qualified professionals having these conversations for all (62%) patients or some (23%) patients.

The results of the patient telephone interviews revealed that few patients had discussed their preferences for future healthcare decisions with their physicians (31%), their chosen healthcare agent (36%), or their loved ones (33%).

These assessments proved to be very effective in raising awareness of the need to improve advance care planning strategies and in engaging professionals in making suggestions for change. As a result of this quality improvement project, we

- increased the number of trained advance care planning facilitators available to this patient population;
- clarified role responsibilities for advance care planning in the clinic;
- investigated strategies for improving documentation of the advance care planning discussion; and
- increased focus on improving communication between the patient, chosen healthcare agent, and physician.

To improve communication between the patient, chosen healthcare agent, and physician, an “Information Card for Healthcare Agents” was developed, which outlines the healthcare agent’s responsibilities and suggests strategies to promote increased understanding of patient preferences. In addition, Respecting Choices faculty incorporated strategies for strengthening the role of the healthcare agent into the facilitator manual and certification program.

The La Crosse Advance Directive Study

The outcomes of these initial efforts to develop a community and organizational approach to advance care planning were studied in a project entitled the “La Crosse Advance Directive Study” (LADS), which retrospectively reviewed all adult deaths in all local healthcare
organizations for an 11-month period in 1995 and 1996. The objectives of the study were to determine the prevalence and type of end-of-life planning and its correlation with treatment decisions. Data were collected from medical records, from death certificates, and from interviews with attending physicians and healthcare proxies. While other studies have documented low rates of advance directive completion, the LADS results stand in stark contrast. Of the 540 deaths included in the study, the prevalence of written advance directives was 85%, with most of these (95%) found in the medical record. Median time between the recording of the completed advance directive and death was 1.2 years, clear evidence of planning in advance of a medical crisis. And unlike other studies, which have found poor correlation between advance directive preferences and actual treatment decisions, we found that patient preferences to forgo life-sustaining treatment were honored by consistent medical orders reflecting these preferences.

While there are still lessons to be learned and improvements to be made, the results of the LADS provide strong evidence that certain strategies are likely to have a significant impact on the ability of healthcare systems to assist patients in choosing end-of-life preferences and the willingness of health professionals to respect them.
Chapter 6:
Exercises

1. Identify strategies for ensuring that an individual’s completed end-of-life treatment plan gets transferred to the medical record.

2. Describe four principles for implementing an organizational and community-wide advance care planning program.

3. Describe the role of the physician and nurse in advance care planning.

4. What strategies would you implement to involve the community you live in to engage in advance care planning discussions?
Appendix I

Gundersen Lutheran Policy on Advance Care Planning & Advance Directives

Advance Care Planning (ACP) and assistance in creating a written plan is accomplished by a team of professionals and non-professionals to include nurses, social workers, pastoral care, volunteers, and physicians.

The desires of an adult patient who is capable of making his or her own healthcare decisions supersede the effect of an advance directive at all times.

If an adult patient is incapable of making his or her healthcare decisions, then the patient’s advance directive is presumed to be valid.

An advance directive should be followed to the extent that it does not require a physician to perform any criminal act, does not violate that physician’s personal or professional ethical responsibilities, or does not violate accepted standards of professional practice. If a physician is unwilling to honor an advance directive because it violates his or her personal ethical beliefs, then transferring the care of the patient to another physician should be discussed with the patient or the patient’s surrogates(s).

Advance directives relevant to immediate patient care (e.g., “no resuscitation indicated”) will be written by the attending physician on the Hospital order sheets or out of hospital orders like the Physicians Orders for Life-Sustaining Treatment (POLST) form.

Validity
In all cases in which an advance directive is to be disregarded, persuasive and credible evidence must exist that:

- The patient lacked decision making capacity at the time the directive was made,
- The directive is a forgery; or
- The directive has subsequently been revoked by the patient

Review
Ordinarily, there should be no need to seek review of the enforceability of an advance directive any more that there ought to be routine review of a patient’s oral wishes. However, when doubts or conflicts arise, such as when there is conflict between the advance directive and the wishes of the patient’s family, or when there is a substantial doubt as to the
authenticity of the advance directive, a consultation should be sent to the Institutional Ethics Committee for its recommendations.

**Education**

Patients and families are educated on Advance Care Planning by use of the *Making Choices* educational program materials

Staff are educated on Advance Care Planning in the following ways (depending on role and responsibility):

1. General orientation
2. Computer-based training program on *Advance Care Planning*
3. Consultation by in-house ethics consultants and Advance Care Planning Coordinator
4. Attendance at *Education of Physicians on End of Life (EPEC) Care* as it is offered
5. Attendance at *Respecting Choices Advance Care Planning Course* (required of all Advance Care Planning Facilitators)

**Definitions**

**ADULT PATIENT:** any person at least 18 years old

**ADVANCE CARE PLANNING:** A process of assisting individuals in understanding, reflecting, and communicating future medical treatment preferences, including end-of-life care.

**ADVANCE CARE PLANNING FACILITATORS:** Designated individuals who have either attended the *Respecting Choices Advance Care Planning Course for Facilitators* or who are being trained by the Pastoral Care staff and have assigned roles and responsibilities within the Advance Care Planning Team.

**ADVANCE DIRECTIVE:** any written document representing the wishes and values of an adult, either while a patient or prior to becoming one, that:

   a) designates another person(s), i.e., surrogates(s), to make healthcare decisions on behalf of the patient if the patient is unable to make decisions for himself or herself;
   b) gives instructions to a healthcare professional as to the patient’s desires about healthcare decisions; or
   c) both designates a surrogate and gives instructions.

To meet this definition, for the purposes of this policy, an advance directive need not comply with any particular form for formalities, as long as it is in written form and it appears to be
authentic. (IT SHOULD BE NOTED THAT ADVANCE DIRECTIVES THAT DO NOT MEET THE STATUTORY REQUIREMENTS OF WISCONSIN’S CHAPTER 154 OR 155 MAY NOT PROVIDE THE LEGAL PROTECTION AS SPECIFIED IN THOSE STATUTES.)

PRIMARY PHYSICIAN: the attending physician who is responsible for the patient’s care

ADVANCE CARE PLANNING RECORD: A tool for the documentation of entry or removal of advance directives; educational materials provided; and discussions of advance care planning issues and concern by all healthcare providers. This tool serves as a communication mechanism to promote continuity of care among healthcare providers who participate in advance care planning. It is placed in the green sleeve.

Implementation

INITIATING ADVANCE CARE PLANNING DISCUSSIONS

The needs of individuals and their families for advance care planning will arise at different times and in different places. They will, therefore, benefit from healthcare professionals who initiate discussions, provide appropriate information, and develop follow-up plans. Advance care planning discussions will be initiated at any of the following:

1. as an outpatient or ambulatory component of a routine examination;
2. as an inpatient component of admission assessment;
3. as a scheduled appointment with an advance care planning facilitator;
4. as an individual expresses interest; and
5. as an individual’s health status changes.

ROLES AND RESPONSIBILITIES OF ADVANCE CARE PLANNING TEAM

The Role of the Registered Nurse

On Admission to the hospital by use of the ACP application in CWS:

1. Determine if patient has a written advance directive.
2. Determine if the advance directive is brought in with the patient, is entered in the ACP application in CWS, or is in the paper medical record.
3. If the advance directive is not available,
a. designate a person, e.g., a family member or friend, to bring in the advance directive as soon as possible.
b. obtain essential information that may be included in the advance directive, such as the name and telephone number of the healthcare agent, preferences for Do Not Resuscitate (DNR), Do Not Intubate (DNI), etc.

4. Review available advance directive with the patient and ask if it represents current preferences.

5. Notify physician of patient preferences that are new or have not been previously expressed (DNR) and require a physician’s order for honoring patient preference.

6. If no advance directive exists,
   a. offer to assist patient by giving information, e.g., Making Choices planning guide, booklet, information card, healthcare agent card, or power of attorney for healthcare document.
   b. make referral to Pastoral Care as appropriate.
   c. ask if the patient wishes to designate a surrogate decision maker and explain why this designation might be useful and needed.

Additionally, the RN will:

1. Provide information, clarification, and emotional support as needed.

2. Make referrals to Advance Care Planning Facilitators as appropriate.

3. Advocate for a plan of care consistent with patient preferences.

**The Role of Advance Care Planning Facilitators (includes physicians, nurses, social workers, pastoral care)**

1. Assist individuals in advance care planning: promote understanding, reflection, and communication of future medical decisions and end-of-life treatment preferences.

2. Make initial assessment of advance care planning needs and provide information.

3. Facilitate discussions about treatment preferences, according to their level of training and experience, with
   a. healthy adults;
   b. adults with chronic, progressive illnesses;
   c. adults with illnesses they may die from in the next 12 months; and
   d. adults with a new, serious acute illness.

4. Determine treatment preferences on admission.

5. Provide educational materials.
6. Document advance care planning discussions and interventions in the Advance Care Planning application in CWS.

The Role of the Physician

1. Initiate advance care planning discussions as appropriate.

2. Provide information and clarification of patient’s medical condition.

3. Provide educational materials to assist with advance care planning.

4. Make referrals to Advance Care Planning Facilitators as needed.

5. Review and clarify patient’s submitted advance directive.


7. Review advance directive documents upon admission to a hospital, nursing home, hospice, or home health agency; discuss preferences with patient or designated healthcare agent/surrogate, if possible, and write appropriate orders for the patient.

8. Dictate any changes to the patient’s plans for future care.

The Role of Pastoral Care

1. Respond to referrals from interdisciplinary team members to review and enter existing advance directives; provide information and assist in completion of Advance Care Planning documents and to document as needed in the Advance Care Planning application in CWS.

2. Provide emotional, spiritual and religious support to patients and families who are struggling with end-of-life decisions.

3. Assist patients and families in discerning their advance care planning preferences and communicating them to appropriate healthcare providers.

4. Make referrals to other interdisciplinary team members as needed.

5. In addition, pastoral care administrative staff will provide community education, maintain supplies of advance care planning materials, coordinate orientation of volunteers, and process advance directives from outpatients.

The Role of Volunteers

1. Assess an individual’s advance care planning needs.

2. Distribute advance care planning educational materials as appropriate and provide explanations.
3. Make referrals to professional resources (physicians, nurses, social workers, clergy, etc.) as appropriate.

4. Assist individuals in completing a valid power of attorney for healthcare (POAHC) document.

5. Enter a completed power of attorney for healthcare (POAHC) into the patient’s electronic medical record through the Advance Care Planning application in CWS.

6. Document activities on Advance Care Planning Record.
The Role of Social Workers

1. Respond to referrals from interdisciplinary team members to review and enter advance care planning documents, provide information and assist in completion of document, and document as needed in the Advance Care Planning application in CWS.

2. Assist patients and families in discerning their advance care planning preferences and communicating them to appropriate healthcare providers.

3. Make referrals to other interdisciplinary team members as needed.

4. Provide assistance with financial planning as appropriate.

ENTERING, REMOVING, AND TRANSFERRING ADVANCE DIRECTIVES

An advance directive may be entered or removed by authorized staff, to include physicians, advance care planning facilitators, designated medical records staff, and other healthcare providers as designated by the physician.

ENTERING AN ADVANCE DIRECTIVE

1. Review the advance care planning document for authenticity, accuracy, and clarity.

2. Enter the document into the Advance Care Planning application in CWS.

3. Stamp the document in the upper right hand corner “Entered on:” Write in the date and your initials by the stamp. Stamps are available on all units.

4. Place the completed document in the green plastic sleeve and place in the front of the paper medical record.

5. Send a written confirmation letter of entry of an advance directive IF the document is not personally delivered by the patient. Letters are available to Health Information Management staff in the Advance Care Planning application in CWS.

6. Notify physician of advance directives that include “red flags” (i.e., new preferences for withholding life-sustaining treatment such as No CPR (cardiopulmonary resuscitation); lack of knowledge regarding medical condition and/or personal information regarding a person’s life that may require investigation by the physician).
REMOVING AN ADVANCE DIRECTIVE

1. Notify the Help Desk when a patient makes an oral or written request to have an advance directive removed from the medical record. A ticket will be opened and sent to the appropriate group to be removed.

2. Authorized staff will document removal on the Advance Care Planning application in CWS and return the paper advance care planning document to the patient.

TRANSFERRING AN ADVANCE DIRECTIVE

1. The responsibility to transfer advance directives is assigned to the unit secretary, the social worker of the nursing care unit, a nurse in the clinic, or a medical records person, as appropriate.

2. Upon hospitalization, the unit secretary will transfer the green sleeve and its contents from the patient’s paper medical record to the hospital chart. (The attending physician or resident should review this document and discuss its contents with the patient or a designated surrogate, if possible, before writing orders based on the advance directive document.)

3. Upon discharge, the unit secretary will transfer the green sleeve back to the front of the patient’s paper medical record.

4. A social worker, a nurse in the clinic, or a medical records person, as appropriate, will provide a copy of an advance directive to
   a. the hospital where a patient is likely to go for emergency services.
   b. another healthcare facility if patient is being transferred from Gundersen Lutheran or its affiliates.
   c. another healthcare facility or physician caring for the patient, if requested by the patient or the patient’s physician.

DOCUMENTATION

Document all advance care planning discussions and activities in the Advance Care Planning application in CWS as appropriate.
Appendix II

Advance Care Planning Request: Intake Form

Date of request:

Name of patient:

Unit, room, department:

Current code status (as appropriate):

Patient’s state of residence:

Person requesting advance care planning information:

Best time to meet with the patient:

Comments:
Appendix III

Sample Script and Flow Chart for Advance Care Planning
Admission Assessment by Registered Nurses

Script/Protocol for Unit Nurses: Asking Patients about Advance Directives

Interview Script

“I would like to ask you some questions regarding your views or thoughts about future medical treatment. I know that these questions make some people uneasy, but I want to assure you that we ask all patients these questions so we might better understand and respect your values and beliefs.”

“Have you ever written down any of your thoughts or choices about future medical treatment, say in a Power of Attorney for Healthcare, a living will, or some other type of advance directive?” (You may need to explain what each of these names means. See the definitions at the end of this section.)

If the answer is yes: Is this document in your medical record?

If the answer is no: Have you ever considered or thought about these issues for yourself?

No. Would you like to have it put into your medical record?

Yes. We should you review the document to make sure it is up to date

Yes. Would you like to receive some educational materials besides this information card (point out card to patient) or would you like to talk with someone about advance care planning? (Check resource list for options.)

Is there anything you would like the staff to know about your thoughts or values regarding your medical care?
Note: If a patient is too ill or confused on admission, ask the above questions later or ask the family if they can provide the answers.

If a patient has a “No CPR” order and they are soon to be discharged, ask them if they would want to record this preference in their medical record, or ask the physician about the completion of the Physician Order for Life-Sustaining Treatment (POLST) form.

Definitions

Advance Directive: Any statement, oral or written, made by a capable adult, that indicates how he or she would want medical decisions to be made if the adult was to become unable to make them personally.

Power of Attorney for Healthcare: A legal document in which a capable adult (the principal) appoints another (the agent/proxy) to make his or her healthcare decisions if the principal becomes unable to make them. (Note: A regular power of attorney is for financial matters only.)

Living Will: A legal document in which a capable adult gives instructions to limit or stop certain medical treatments if the adult was incapable and had an irreversible condition. (Note: Some people confuse a will with a living will.)

List of Resources

Patient Education Materials

Making Choices™ Booklet
This 12-page booklet provides basic information about advance care planning and many stories about end-of-life decision making.

Making Choices™ Planning Guide
This is a 4-page worksheet that can help individuals and their families reflect on their values and beliefs.

Making Choices™ Video
This 15-minute video provides insight into the importance of discussing future medical treatments with loved ones. The video is played on the hospital education channel seven days a week at 1100 and 1600 hours at Gundersen Lutheran Medical Center in La Crosse, Wisconsin.
Advance Care Planning Facilitators

(A list of trained facilitators would be provided here.)
Sample Flow Chart for Advance Care Planning Admission Assessment by Registered Nurses
Chapter 6:
Further Reading

Academy of Hospice and Palliative Medicine. www.aahpm.org

American Hospice Foundation. www.americanhospice.org

Approaching death: Improving care at the end of life. www.nap.edu/readingroom/books/approaching


End of Life Nursing Education Consortium (ELNEC). www.aacn.nche.edu/elnec

End of Life Physician Education Resources (EPERC). www.eperc.mcw.edu


Growth House, Inc. [www.growthhouse.org](http://www.growthhouse.org)


Lynn, J. (2002). Lessons from the end of life in the program of all-inclusive care of the elderly. *Medical Care, 40*(12), 1133-1135.


*The National Center for Advanced Illness Coordinated Care.* [www.coordinatedcare.net](http://www.coordinatedcare.net)

*National Hospice and Palliative Care Organization.* [www.npha.org](http://www.npha.org)


*On our own terms: Moyers on dying.* [www.pbs.org/onourownterms](http://www.pbs.org/onourownterms)


*Promoting excellence in end-of-life care.* [www.promotingexcellence.org](http://www.promotingexcellence.org)


*TIME: Toolkit of Instruments to Measure End-of-life care.*


