



# **Advance Care Planning: Strategies and Tools to Assist Providers, Patients and Families to Plan for End of Life Care**

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## INTRODUCTION

Hello and welcome to the EPaD GEC Interprofessional Advance Care Planning Toolkit.

This toolkit contains various resources for providers, clinicians, patients, and caregivers. It is designed to assist you in accessing current information as well as recommended tools, resources and identified best practices in Advance Care Planning. It is a supplement to our Advance Care Planning presentation.

If you have not had an opportunity to access our educational resources, please visit our website <http://epadgec.jefferson.edu/education.cfm> to access them.

The toolkit is divided into three categories of resources and tools. 1) Resources are specifically designed for providers; 2) Resource to facilitate the ACP process that will be useful for professional providers, their patients and their patient's families; 3) Resources and tools specifically designed for use by individuals who want to begin the ACP process. You will find education and training tools, evidence-based interventions, access to state and alternative Advance Directive documents, information on professional, non-profit and advocacy organizations working to enhance and expand ACP in the United States.

## ***Background***

Advance Care Planning (ACP) regarding patients' preferences for end of life care is an integral component of inter-professional patient centered care. Over the past 25 years, a large body of research has investigated patient and provider attitudes about end of life care and addressed the importance and challenges of Advance Care Planning (ACP). During this time high profile legal cases (Quinlan, Cruzan, Schiavo) have brought public attention and discourse to these issues. The 2010 passage of the Patient Protection and Affordable Care Act (ACA) again stimulated much controversy and discussion on the medical-legal-ethical dilemmas of providing care at the end of life.

Legislation at the both federal level (Patient Self Determination Act, 1991) and at the state level has resulted in formal legal advance directive documents. Professional organizations and advocacy groups have emerged for the purpose of educating, encouraging and supporting individuals, families and health care providers about ACP and the importance of discussing patient preferences in advance of the last stages of life when critical decisions can be difficult. Despite extensive research, development of evidence based programs and the known benefits of ACP (Tamayo-Valázquez, et. al. 2010) most Americans have not completed advance directives nor had conversations with family members or health care providers about their preferences for end of life care. (California Foundation, 2012; Benson, et. al, 2012)

In recent years the ACP research and programs have put less emphasis on completing Advance Directives (AD) – Living Wills and Durable Power of Attorney for Healthcare, and placed more attention on the ACP communication process (Briggs, 2004; Bischoff, et. al. (2013): Ramsaroop, et. al 2007). Research has shown that just completing ADs does not guarantee the patient's preferences are followed or result in quality of end of life care (Brinkman-Stoppelenburg, et. al. 2014). Conversing with patients and families about their values and beliefs on end of life care, and providing them with information on the type of treatment decisions that are often required, has been shown to actually increase AD completion rates (Tamayo-Valázquez, et. al. 2010).

Advance Care Planning can best be defined as an on-going values-based conversation among patients, their loved ones and health care providers which framed around establishing goals of care. The ACP process provides patients with a voice about their care when they no longer can communicate, preserving individual preferences and autonomy, as well as supporting the appropriate use of health care resources (Morrison, SE, Perrod JK, Cassel JB, et al.). ACP has also been shown to help alleviate emotional distress at the end of life for families. (Sudore, et. al, Dettering).

### ***WHEN IS THE RIGHT TIME TO INITIATE THE ACP CONVERSATION?***

Questions continue about the optimal time to begin the ACP process, with whom patients should discuss their preferences, and in what situations. Research has shown that many older adults think optimal time for ACP discussions is when they are relatively well (Malcomson, et. al. 2009). It is never too early to begin thinking about what is important to you--what gives your

life meaning, to help think through your preferences for care at the end of life (Gesme & Wiseman, 2011). Most studies indicate that patients want to have these conversations with their primary care provider (PCP) (Ramsaroop, et, al 2007)). In some cases patients initiate this conversation with their PCP (see *Conversation Project* resource below), but it is most often left to the health care provider to initiate the process. The conversation may begin in the primary care setting with their physician, a nurse or social worker or in the hospital with a member of palliative care team or chaplain).

ACP is a dynamic process that often changes over time as individuals experience serious illness and/or develop chronic health conditions that worsen over time. As people age and adapt to physical and functional changes that may accompany worsening health (such as pain, reduced mobility or shortness of breath) they may feel differently about what they want at the end of life.

Unfortunately, families are often confronted with end of life decisions when there are immediate questions about continuing intensive and/or curative treatment. This often occurs at the hospital bedside, frequently in an ICU or in long term care facilities at a time when curative treatment is no longer an option. It has been shown to be very stressful when ACP has not occurred and/or there are no Advance Directives documents. Whenever the time comes (hopefully sooner than later), it is important to view ACP as a process that permits patients to think about and express their wishes if possible, and for loved ones and healthcare providers to understand, accept and support their wishes.

***“Start Early, Focus on Goals, and Have Ongoing Discussions”*** (Gesme & Wiseman, 2011)

ACP includes multiple steps and ongoing discussion. The step-wise process is briefly described below.

- **Contemplate** your values and wishes for end of life care. There are tools available to assist people with this process (see *Conversation Project—Starter Kit and Engaging with Grace* in the resource section).
- **Share** with your family members what is identified as being most important and treatment preferences at the end of life.
- **Begin the conversation** with your health care provider about your values and preferences for end of life care as part of their overall goals of care. The conversation may be initiated by patient or health care provider.
  - The conversation is best framed as an on-going process which may change as an individual’s health and functional status.
  - It is important that health care providers educate patients and families about health conditions, treatment options and trajectory of illness to facilitate

decisions on what care and treatments might be wanted or might not be acceptable.

- Providers can provide patients and family with resource information to help them better understand the choices that may need to be made about care.
- **Designate a Health Care Agent/Representative** – typically a family member or close friend who knows and understands their preferences and has agreed to act as their agent should the patient not be capable of making their own decisions at the end of life. **Document** ACP conversations and patient preferences in their medical record.
- **Legal documents** (e.g. Living will/ Healthcare Power of Attorney). Documentation may include medical chart orders such as Do Not Resuscitate (DNR), Do not Intubate (DNI), Do not Hospitalize (DNH).
- **Revisit** end of life care preferences with loved ones and primary care providers as health and functional status change over time.

The following list of resources provides health care providers with tools and strategies designed to facilitate ACP process as described above.

## Provider Resources

### *Provider Education and Training Tools*

1. Institute for Healthcare Improvement (IHI): *Open School Course for Conversations about End of Life Care* <http://tinyurl.com/EOL-Conversations>  
In conjunction with the Boston University School of Medicine and The Conversation Project, the IHI Open School offers this online course to introduce students and health professionals to basic skills for having conversations with patients and their families about end-of-life care wishes. This course will also help you develop skills to have conversations with patients and their families about their preferences for care at the end of life. As part of developing these skills, the course invites you to “have the conversation” yourself, with a family member or other loved one.
2. *Advance Care Planning: An Introduction for Public Health and Aging Services Professionals* <http://tinyurl.com/CDC-ACP-training>

This web-based course developed by the CDC is targeted to public health and aging services professionals to consider their role in assisting older Americans plan and document what should be done in the event they become seriously ill or lose decision-making capacity. The course modules cover:

3. Respecting Choices<sup>®</sup> Advance Care Planning

<http://www.gundersenhealth.org/respecting-choices>

*Respecting Choices* is a comprehensive evidence-based advance care planning program developed in the early 1990s at the Gundersen Health System in La Crosse Wisconsin. During the past 15 years *Respecting Choices* has worked with organizations and communities all over the world to replicate and tailor model of ACP. This model provides a staged approach to ACP which takes into consideration the current state of an individual's health and over time. The model is based on concepts of 1) understanding the importance of ACP, the consequences of not planning and what is involved in the planning process; 2) the opportunity to reflect on personal values, goals, and beliefs which serve as the foundation to decision-making, and 3) discussion with others about decision-making—family, their physician, religious advisors and most importantly—their designated health care agent.

4. **ACP Decisions**

[www.acpdecisions.org](http://www.acpdecisions.org)

A series of videos developed by a multidisciplinary team of clinicians at Harvard University including ethicists and palliative care doctors that helps patients understand the risks and benefits of various end-of-life treatments. Designed for patients facing advanced dementia, cancer, and heart disease among many other conditions, the videos capture the experiences of actual patients to illustrate the trajectory of diseases or conditions and spark conversation among physicians, patients, and their caregivers about advanced care planning. The videos are not designed for individual patient or family viewing. They are meant to be viewed with the provider present and to stimulate follow-up discussion on planning for end of life care.

5. ***The One Slide Project***

[www.engagewithgrace.org](http://www.engagewithgrace.org)

*Engage With Grace: The One Slide Project* is designed to help to initiate end of life conversations. A single slide containing five questions is designed to get people to talk about their end of life preferences with their loved ones and professionals. The “one slide” can be used at professional meetings, conferences, or in less formal events. The slide can be downloaded from the website at <http://www.engagewithgrace.com/Download.aspx>. There are two sample introductory slides one for speaking with colleagues and the other for speaking with loved one.

6. **Steps to Prepare Patients for In-the-Moment End-of-Life Decision Making**

Examples of conversation starters found in Sudore and Fried, 2010. Re-defining the “Planning” in Advance Care Planning: Preparing for End-of-Life Decision Making. *Annals of Internal Medicine*, 153(4), 256-261. (with permission of the authors)

7. **Physicians Orders for Life Sustaining Treatment (POLST):** The POLST Paradigm is based on a conversation between the patient and their health care professional. The POLST conversation is about: (a) patient' specific disease, treatment options (including benefits and alternatives), and what will happen as the patient's disease continues; and (b) goals of care and values. After the conversation, the health care professional completes a POLST form, marking the treatments the patient does or does not want at the end of their life.
  - a. **POLST Pennsylvania**  
<http://tinyurl.com/Aging-Institute-of-UPMC>
  - b. **DMOLST** –Delaware Medical Orders for Scope of Treatment (DMOST)  
<http://delawaremolst.org/>  
As of December 2013 the State of Delaware does not have a sanctioned form in use. The old MOLST form, introduced a couple of years ago, was discontinued by order of the Director of the Delaware Division of Public Health citing legitimate concerns around a lack of supporting legislation.

### ***Resources to assist providers facilitating family meetings***

The following resources may be helpful for professional providers as well as their patients and families.

1. *Communication in the ICU: Holding a Family Meeting*  
<http://www.uptodate.com/contents/communication-in-the-icu-holding-a-family-meeting>
2. Medical College of Wisconsin. End of Life/Palliative Care Education Resource Center (EPERC)
  - a. Preparing for the Family Meeting  
[http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff\\_222.htm](http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_222.htm)
  - b. The Family Meeting: Starting the Conversation  
[http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff\\_223.htm](http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_223.htm)
  - c. Responding to Emotions in Family Meeting, Fast Facts and Concepts  
<http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff.224.htm>
  - d. The Family Meeting: Causes of Conflict, Fast Facts and Concepts  
<http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff.225.htm>

## ***Cultural Considerations in End of Life Care***

1. Stanford Geriatric Education Center

<http://sgec.stanford.edu/>

Stanford Geriatric Education Center (SGEC) is a nationally recognized leader in the field of ethnogeriatrics, or health care for elders from diverse populations. The website provides inter-professional educational resources on managing the health and well-being of diverse elders, including specific cultural influences on end of life decision making. The SGEC's Curriculum in Ethnogeriatrics provides overall training about providing care to older adults from diverse cultural backgrounds. There are also ethnic specific modules that provide more comprehensive coverage for individual ethnic populations of elders in the United States. <http://www.stanford.edu/group/ethnoger/>

2. *Addressing Cultural Diversity in Hospice Care*

<http://tinyurl.com/Addressing-Cultural-Diversity>

Hospice Information Center, Hospice Foundation of America

Audio presentation with handouts and slides which looks at how our differences, and our similarities, affect end-of-life decisions, and how hospice care can support culturally diverse patients and families. (50 min)

Hospic

3. Lesbian Gay Bisexual and Transgender (LGBT) issues and resources

Health care providers working with LGBT individuals should discuss ACP with their LGBT patients and encourage them to complete valid advance directives. In the absence of advance health care directives most states have provisions for a family member to make health care decisions when a person is unable to do so for themselves. All or most states give priority for health care decision making to the spouse or adult children or other biological family of the patient. Although a growing number of states recognize same sex marriage, domestic partners or civil unions, the laws do not apply to long term, unregistered relationships by many LGBT adults. Also, for couples who do have a legal relationship in one state, traveling to a different state may invalidate the same decision-making authority if they are in a state that does not recognize same-sex relationships.

- a. Services and Advocacy for Gay, Lesbian and Transgender Elders (SAGE)

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

- b. Hospice Foundation of America

Audio and slide presentation which addresses issues and concerns of LGBT

<http://tinyurl.com/LGBT-and-EoL-issues>

- c. National Resource Center of LGBT Aging  
[www.lgbtagingcenter.org](http://www.lgbtagingcenter.org)

## ***Religious/Spiritual Considerations***

Selected Religious Beliefs and Traditions Regarding Death and Dying

Taken from End of Life Nursing Education Consortium (ELNEC) Core Curriculum

[http://www.hopkinsmedicine.org/pastoralcare/faith\\_info\\_directory/relig\\_eol.docx](http://www.hopkinsmedicine.org/pastoralcare/faith_info_directory/relig_eol.docx)

Scott E. Shannon, MD and Paul Tatum, MD (2002) Spirituality and End of Life Care.

*Missouri Medicine* 99 No. 10

[http://ethics.missouri.edu/docs/Shannon\\_Tatum\\_Nov\\_2002.pdf](http://ethics.missouri.edu/docs/Shannon_Tatum_Nov_2002.pdf) accessed 6-23-14

## **Patient/Family Resources**

### ***The Conversation Project***

<http://theconversationproject.org/>

*The Conversation Project* is a grass-roots campaign started by health professionals, media, clergy, patients and families dedicated to helping people talk about their wishes for end-of-life care. In 2011 *The Conversation Project* began to collaborate with the Institute for Health Improvement (IHI) [www.ihl.org](http://www.ihl.org), a non-profit organization dedicated to improving health and health care worldwide. The Conversation Project's goal is to "make it easier to initiate conversations about dying and empower people to talk now and as often as needed so their wishes are known when the time comes."

The website provides tools to empower patients and families to begin the advance care planning process. A "Starter Kit" to help prepare individuals to think about their wishes for end of life care, with whom, when and where they want to talk with about their preferences, and approaches for beginning these conversations. A second workbook, "How to Talk to your Doctor" helps prepares patients to talk with their health care team (e.g. physician, nurse, care manager, etc.) about their goals of care.

Materials are available in English, Spanish, French and Mandarin.

### ***Caring Conversations***

The Center for Practical Bioethics

<http://www.practicalbioethics.org/resources/caring-conversations>

Resources to assist individuals and families for ACP and EoL conversations, including resources tailored resources for young adults and military veterans.

Materials are available in English and Spanish

## ***Caring Connections (NHPHO)***

### **Aging with Dignity**

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

An advocacy organization providing resources to support individuals and families with advance care planning including the development of the “Five Wishes” Living Will, which is accepted in 42 states and translated in over 25 languages, including bi-lingual versions.

### ***Advance Directive Documents***

Advance Care Directives are legal documents used to document an individual’s end –of –life treatment preferences (Living Will) and who they designate to make treatment decisions should they be incapacitated and not able to make their own decision (HCPA).

1. Living Will: a legal document which spells out the types of medical treatments and life-sustaining measures you want and don't want, such as mechanical breathing (respiration and ventilation), tube feeding or resuscitation. In some states, living wills may be called health care declarations or health care directives. Each state has their own legislation on the content and form of ADs, although other types of living will documents can be recognized in many states.

**Five Wishes** is a living will developed by Aging with Dignity a national non-profit organization with a mission to “affirm and safeguard the human dignity of individuals as they age and to promote better care for those near the end of life.” It is written in everyday language and helps start and structure important conversations about care in times of serious illness. Five Wishes is recognized in 42 states. There are eight states in which Five Wishes does not currently meet the legal requirements as they require use of their statutory state form to express personal wishes (Alabama, Indiana, Kansas, New Hampshire, Ohio, Oregon, Texas and Utah). However, Five Wishes can be used in each of these states by follow the instructions to complete the statutory form(s) for the state and attach it to a completed Five Wishes. Five Wishes is available in 26 languages.

2. Health Care Power of Attorney: Medical or health care power of attorney (POA). The medical POA is a legal document that designates an individual — referred to as the health care agent, representative or proxy — who can make medical decisions for an individual in the event that they are unable to do so. This is different from a power of attorney which authorizes someone to make financial transactions for an individual.

### **The U.S. Living Will Registry**

**The U.S. Living Will Registry** is a secure, on-line database where patients, families and health care providers and facilities can store advance directive documents. The Registry electronically stores advance directives and organ donor information, and makes them available to health care

providers across the country 24 hours a day by telephone and secure Internet through an automated system.

<http://www.uslivingwillregistry.com/faq.shtm>

**Advance Directives from all 50 states** can be downloaded from the *Caring Connections* website

<http://tinyurl.com/DownloadStatesAdvanceDirective>

### ***Family Caregiver Alliance (FCA)***

<https://caregiver.org>

FCA is a community-based non-profit organization dedicated to serving the needs of families and friends providing long term care for a loved one at home. FCA provide education and regarding caregivers' daily challenges to better the lives of caregivers nationally, provide caregivers with the assistance they need and deserve, and champion their cause through education, services, research and advocacy.

### ***Caring Connections***

[www.caringinfo.org](http://www.caringinfo.org)

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer and community engagement initiative to improve care at the end of life.

- CC Provides free resources and information to help people make decisions about end-of-life care and services before a crisis.
- Brings together community, state and national partners working to improve end-of-life care through a national campaign called It's About How You LIVE.

### ***African –American Spiritual and Ethical Guide to End-of-Life Care***

Gloria Thomas Anderson (2006) Compassion Books, Burnsville, NC

This small user-friendly book is a culturally sensitive guide walks people of color through the spiritual, practical and legal considerations in end-of-life care, addressing their unique history, culture and generational family values.

*Holding a Family Meeting*

<https://caregiver.org/holding-family-meeting>

## **Professional Organizations and Advocacy Groups**

Hospice Foundation of America (HFA)

[www.hospicefoundation.org](http://www.hospicefoundation.org)

HFA is a non-profit organization which conducts professional development programs, public education and information, research, publications and health policy issues.

**The National Hospice and Palliative Care Organization (NHPCO)** <http://www.nhpc.org/>

The largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end of life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.

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## **Interprofessional Guidelines/Standards**

American Academy of Nursing (April 15 2013) *Policy Brief: Advance Care Planning as an Urgent Public Health Concern.*

<http://www.aannet.org/policy-brief--advance-care-planning-as-an-urgent-public-health-concern>

accessed 5/30/14

*Role in Advance Care Planning* (October 2013)

Hospice and Palliative Care Nurses Association, Position Statements

<http://www.hpna.org/DisplayPage.aspx?Title1=Position%20Statements>

accessed 5-30-14

NASW Standards for Social Work Practice in Palliative and End of Life Care

<http://tinyurl.com/SocialWorkStandardsEOL>

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