Advance Care Planning in Lifelong, Age-Friendly Communities: Increasing Awareness and Engagement Toolkit – 2026 Edition

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This edition builds on the original 2023 toolkit, with updated language, expanded activities, and current research to better support Lifelong, Age-Friendly communities in bringing Advance Care Planning into everyday practice.

With deep appreciation,

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Introduction

Community members in Lifelong, Age- Friendly communities work to make Maine's towns and cities more responsive to their members living longer as well as more inclusive of people living with chronic illness or disability. Together, they aim to "create places where everyone can lead active, healthy, and engaged lives throughout their lifetime." These communities bring together local organizations and businesses, foundations, academic institutions, faith-based and social groups, elected officials, and engaged residents of all ages. Their efforts focus on one or more of the eight domains of livability— including Community Supports and Health Services.

One area of interest in the community supports and health services domain is the need to discuss and address advance care planning and end-of-life issues. This toolkit explains what advance care planning (ACP) involves and helps members of lifelong, age-friendly communities introduce these issues to their communities through a variety of activities and resources.

What is ACP & Why Does it Matter?

Thanks to public health gains over the last century, people are living longer than ever before. But longer lives often bring longer periods of serious illness or disability. In fact, while life expectancy has increased, healthy life expectancy has not kept pace — meaning people now live more years in poorer health. At the same time, the COVID-19 pandemic reminded us how quickly illness and death can occur. This reinforces the value of planning ahead —not only for our own care, but for our families, caregivers, and communities.

Although much of the research deems a person to be nearing end-of-life when death is anticipated to take place within the next 12 months, given the trajectory of dementia related illnesses as well as other debilitating life-limiting illnesses, using a broad definition of ACP may be more appropriate—processes that support individuals of all ages and of any health condition in understanding and sharing their personal values, life goals, and preferences regarding future medical and non-medical care.

Research has found that advance care planning, particularly advance directives and/or living wills, has a positive impact on the quality of end-of-life care.

While most people planning for end-of-life indicate a preference to die at home in the community where they have developed attachment to the physical and social environment, very few people are able to die at home or in the community of their choice because health care policy and local services do not always

facilitate a desired death. Lifelong, age-friendly communities can play a role in advocating for policy change and the development of new programs or the expansion of existing services. By initiating planning in the community before a crisis happens, family members, loved ones, and providers have sufficient time to explore beliefs, values, and concerns not just about medical decisions, but also the social, legal, and financial dimensions of life events that may leave an individual unable to speak or act on their own behalf.

A commission convened by the United Kingdom-based research journal The Lancet has called on both the medical community and the public to reconsider societal attitudes about end of life. In describing the social determinants of death, the commission wrote, “Individual or community experiences of [dying] are determined by a constellation of factors such as political unrest or conflict, access to and trust in health-care services, relationships, discrimination or oppression, poverty, education, and many others”. Addressing advance care and end-of-life planning must involve more than just the health service sector of society; it means family and community working alongside healthcare professionals as equals. Using a public health approach results in improved health outcomes, mitigates avoidable suffering, and strengthens community capacity for care and support by mobilizing and maximizing “family, community, and workplace supports in an effort to reorganize a culture of denial toward a culture of acknowledgement of this universal experience [of death and dying]”.

Research has demonstrated success through utilizing a community-based approach. It also has shown that multiple parties including the health care provider and potential health care proxy along with the individual making ACP decisions can and should be involved in discussions and decision-making. Additionally, a 2023 systematic review

found that when ACP is built into practice, healthcare professionals report reduced moral distress and increased job satisfaction. This reinforces the value of integrated, collaborative approaches — benefiting individuals, families, and providers alike.

A 2024 scoping review found that many older adults are open to ACP, but have limited understanding of the process — and that general health literacy strongly influences their readiness to engage. This presents an opportunity for Age-Friendly initiatives to partner with health centers to provide accessible education and strengthen community capacity.

Communities' Engagement in ACP

In 2022, Oh and White conducted a review of action plans and progress reports submitted to the AARP Network of Age-Friendly States and Communities (NAFSC) to assess how local groups were approaching Advance Care and End-of-Life Planning (ACELP) as part of their efforts to improve community supports and health services. They found that most communities noted only one or two ACP-related activities in their action plans. Common examples included:

- Promoting conversations about end-of-life planning
- Encouraging the completion of advance directives
- Facilitating financial or legal planning (e.g., powers of attorney)
- Promoting awareness of hospice and palliative care

Less common activities included education around guardianship or last wills and testaments. Notably, no communities had included funeral planning in their written action plans. However, progress reports revealed that some communities were doing far more than originally planned. Of the six communities that reported ACELP activities in their progress updates:

- Only one had planned for it in their original action plan
- All six had taken steps to engage their community, such as:
    - Hosting workshops or health fair tables
    - Providing translated ACP materials
    - Educating care providers

    - Advocating for hospice or palliative services

This gap between planning and practice may indicate genuine community need and responsiveness. The research also supports national and international findings that conversation-based approaches to ACP are highly effective.

Why Community Engagement Matters

Talking about decline, chronic illness, incapacity, and death is not easy — but these conversations help people live more fully and prepare more confidently. Communities that embed ACP into practice and policy are better equipped to support residents across the lifespan.

ACP efforts work best when individuals, families, organizations, and professionals come together. It is not solely a healthcare initiative. Successful communities recognize ACP as a shared civic and cultural responsibility.

National Research

As noted by Oh and White Age-Friendly communities across the country have taken creative and practical steps to normalize end-of-life conversations, improve public understanding of planning tools, and build ACP into everyday life. Some of the most common and promising activities include:

- Launch a “Conversation Project” initiative to encourage residents to talk with family, friends, and healthcare providers about their care preferences. You can learn more on the Conversation Project website.
- Create a “Conversations of Your Life” (COYL) Task Force, modeled after the New Jersey Health Care Quality Institute’s program to spark local engagement. You can learn more on New Jersey’s Health Care Quality Institute’s website.
- Distribute File of Life forms, which attach to refrigerators and include emergency contacts, advance directives, and POLST forms. You can learn more on the File of Life’s website or POLST’s website.

- Make advance care documents like Five Wishes available in multiple formats and languages through libraries, senior centers, or health systems. You can learn more on Five Wishes' website.
- Offer community education events in collaboration with healthcare, legal, and faith-based partners. Common topics include:
    - Advance directives
    - POLST
    - Funeral and legacy planning
    - Long-term care
    - Financial and legal preparedness
- Provide ongoing community education through:
    - Web and social media content
    - Speaker series and workshops
    - Resource tables at health fairs
    - Caregiver and provider trainings
    - Self-care and grief support education
- Highlight compassionate, diverse images of dying through storytelling projects, media, or film screenings.
- Encourage earlier use of planning tools and services by embedding ACP into other initiatives (e.g., wellness programs, dementia education, legal aid)

Maine Age-Friendly Activities

- Host an aging & loss workshop.
- Continue the "Choices That Matter End-of-Life Community Conversations Campaign" community outreach and education
    - collaboration with healthcare organizations to incorporate end-of-life decisions into healthcare plans, electronic healthcare records (EHRs), etc.
    - focused effort in April for National Healthcare Decisions Day
- Engage the community in a plan to increase conversations regarding end-of-life decision making.

- Identify current community resources available to assist with end-of-life planning.
- Form a collaborative advance directives sub-team to develop a 1-year plan to begin Advance Directive Conversations.

Graduate Students' Research

In 2022 White and her research classmates at the University of Maine School of Social Work conducted a study, "Advance Care and End-Of-Life Planning in Lifelong, Age-Friendly Communities in Maine", as part of their program. The purpose of their research was to determine the degree these communities engaged in ACELP activities, which ACELP activities they pursued, barriers to engaging in such activities, as well as resources or assistance needed for communities to move forward in their efforts.

Based on a survey conducted:

- Fifty percent reported that they had engaged in "at least one and as many as seven of the ACELP activities described, with advance directive/living will activities being reported most frequently".
- Of the survey respondents who answered, 74% reported that they were either somewhat or very interested in engaging ACELP activities, with most respondents (80%) expressing interest in both advance directives/living wills and long-term care planning.

The research group also conducted interviews with six of the lifelong, age-friendly initiatives.

- While expressing varying reasons for interest, all interviewees recognized the need or importance of engaging in ACELP activities.
- Barriers to engaging in ACELP activities included the pandemic and misconceptions or stigmas around death and dying.
- Two major needs identified for ACELP engagement were human resources and funding.
- Primary focus of engagement was educating the public, and more specifically around having conversations and advanced directives.

- Interest in funeral and financial planning, long-term care, and last will and testament activities were also indicated for community education.

The hope is that this becomes a regular part of community programming…and reaches—all parts of our resident base…It's an issue that affects not just seniors…but we'd like to expand it to our whole community and anyone who would like to participate"

- Interviewee

Sample ACP Activities

The following are real-world activity ideas for introducing or expanding Advance Care Planning (ACP) in your community. They are grouped by general cost and resource level. Even small, low-cost events can spark meaningful reflection and conversations.

Activities with little to no cost

Hold a book club

- Choose a time and location for the book club. It may be held in someone's home, a public space, or an online forum. Consider discussing future times and location during the first gathering.
- Decide how often you want to meet. A month is the standard, but if you plan on reading longer books you may want to meet every 6 weeks.
- Invite members: The ideal size is between 8-16 members. A great way to gather a diverse group is to invite 3-5 people and ask each to invite 3 or 4 friends.
- Prior to the book club, prepare discussion questions and/or book related activities.
- Pick 2 or 3 book options to discuss with the group for the following meeting.

Hold a Death Café

You can learn more on Death Café's website.

- A Death Cafe is a group directed discussion around the topics of death, dying, and bereavement with no agenda, objectives or themes.
- The website provides step-by-step guidance and key elements for holding a Death Cafe; registration is required to host an event.

- The event can be held at a community recreation center, local library, or other building. Many places will offer this space free of charge. In these cases, consider giving the attendees an opportunity to make a small donation to the organization providing the space. Another option is to host your event at a local cemetery or other outdoor space. Historically, cemeteries have been used as spaces for gathering and reflection within communities.
- Cake (or something similar) is typically served along with coffee, tea, and/or water. Consider asking attendees or co-facilitators to bring these items to help reduce costs.

Host a Video & Discussion Series: Death: A Personal Understanding.

- This instructional series on death and dying and consists of 10 half-hour videos, which help viewers gain a greater understanding of death and dying through case studies and moving personal stories of people facing their own death or the death of a loved one.
- Plan a weekly or monthly series using one video per session, followed by a discussion. The length of the event with the discussion is approximately 1 hour.
- Consider having bottled water available for attendees.
- Video/audio equipment for DVD playback is needed.
- The event can be held at a community recreation center, local library, or other building. Many places will offer this space free of charge. In these cases, consider giving the attendees an opportunity to make a small donation to the organization providing the space.
- While the series is a bit dated (1999), it remains quite relevant. Access is now limited but may be available through local lending resources or by request through Mourning Ventures of Maine.
    - What is Death?
    - The Dying Person
    - Facing Mortality
    - Deathbed
    - Fear of Death and Dying

    - Sudden Death
    - A Child's View of Death
    - Grief & Bereavement
    - Death Rituals
    - The Good Death

Create a local ACP "Display Kit"

- Build a portable display board or tabletop presentation of ACP resources, such as printed advance directives, educational handouts, and local/state resources.
- Display the kit at libraries, activity centers, community meals, and faith events.
- Consider rotating kits between organizations.
- Encourage visitors to take materials and spark conversations.

Use conversation card decks at events

- Use card-based tools such as Go Wish, The Death Deck, or Hello Game to prompt values-based discussion at various events such as health fairs, town events, and book clubs.
- Some card sets are printable or available free online.
- Play the game as described on the deck instructions or invite attendees to pick 3 cards they relate to and share in pairs or small groups.

Host a "Before I Die" community board

- Create a chalkboard, whiteboard, or poster space in a visible public location with the prompt: "Before I die, I want to…"
- Encourage people of all ages to contribute responses using markers, sticky notes, or chalk.
- Refresh regularly and consider photographing responses for social media (with permission).
- This visual activity encourages reflection and public dialogue.

Activities with a small amount of funding

Host a table at a health fair or other public event.

- Register a table (often for a small fee).
- Set up a display of ACP materials including books, examples of advance directives, discussion starters (Go Wish cards or similar tools), and some printed materials from reliable websites. (See list of Resources.)
- Books and other materials can often be borrowed from local organizations such as a library, hospice, or medical facility.
- Engage attendees in discussions about the importance of ACP and provide them with a list of resources.
- Use this time to promote another community event, such as an ACP seminar, workshop, or presentation offered by your lifelong, age-friendly committee or in collaboration with another organization or business.
- Printer and paper are needed to provide handouts.

Host a Five Wishes advance directives presentation.

You can learn more on Five Wishes' website.

- The Five Wishes Advocate Toolkit provides guidance for outreach and hosting a community presentation.
- A revisable PowerPoint presentation is provided for use free of charge. You may add slides to include more information, if desired.
- Consider purchasing a starter kit, family kit, or financial planner kit. The family package includes 10 copies of Five Wishes, two copies of the Conversation Guide for Individuals and Families, a Five Wishes at Home guide, and the Five Wishes Digital Video (English) or DVD (Spanish).
- Attendees can also complete a digital Five Wishes through the website or purchase a single Five Wishes paper form for a small fee.
- Present to a specific organization or to the community at large at a community recreation center, local library, or other building.
- Consider serving snacks and water and/or coffee.

Organize a Death Over Dinner gathering

You can learn more on Death Over Dinner's website.

- Death Over Dinner allows a group of community members to gather to discuss specific topics related to death, dying, and bereavement. The website provides materials for viewing, reading, and listening prior to the event.
- The event can be held at a local restaurant, where each person is responsible for their own meal. A potluck dinner is another option and can be held in a local space.

Start a community "ACP Lending Library"

- Build a box or binder with curated books, forms, articles, and handouts. Include examples of advance directives, planning checklists, and simple conversation tools.
- Make it available for local borrowing (e.g., a town office, library, or faith center).
- Consider offering themed kits (e.g., dementia-specific, LGBTQ+ planning, caregiver-focused).

Activities with a community partner

Movie and discussion event

- Team up with a local movie theater or other community partner(s) such as hospice for a free showing of a movie such as Being Mortal.
- Hold a discussion before or after the movie.
- Consider having a table display in the lobby for various resources including examples of advance directives, suggested books, discussion starters (Go Wish cards or similar tools), and a handout of resources for attendees to take with them.
- A printer and paper are needed to produce handouts.

Host a "Prepare For Your Care" movie event

You can learn more on Prepare for Your Care's website.

- The Prepare For Your Care website has resources to guide you through a movie event and discussion. The film (approximately 30 minutes) explains the important steps involved in advance care planning.
- Hold the event at a local movie theater if you can collaborate with a community partner to cover the cost of the theater. You may also consider a smaller event using a large television screen, perhaps saving some costs

Community ACP seminars.

- Collaborate with a community partner to host a community seminar or presentation highlighting a local expert or experts on advance care planning (ACP) topics.
- These events can last from 1-3 hours and can involve one topic or several topics.
- A location that allows attendees to sit at a table to write notes is recommended.
- Consider providing water, coffee, tea, and snacks.
- Advertise the event through website and Facebook pages (your lifelong, age-friendly sites and your collaborator's), chamber of commerce listings, flyers, and local newspapers.
- Include time for Q&A and handouts participants can take home.
- Funding required for booklets and/or other handouts.

Dementia and advance care planning presentation.

- Similar to the community seminars described above, create a presentation focusing specifically on dementia and advance care planning.
- Some helpful resources for this event:
    - Advance care planning and dementia - Advance Care Planning Australia
    - For Caregivers of People with Alzheimer's or Other Forms of Dementia - The Conversation Project
    - Legal and Financial Planning for People with Dementia - National Institute on Aging
    - Planning for the Future After a Dementia Diagnosis - Alzheimers.gov
    - Free: Dementia Friendly Funeral Guide - RitualsToday.co.uk

Partner with a local ACP facilitator or educator

- Work with a community-based professional (such as Mourning Ventures of Maine) to host planning workshops or group sessions.
- Individual topics can include values exploration, advance directives, or health care proxies.
- Consider hosting small group programs to help community members get help with the entire planning process.
- These partnerships can reduce pressure on volunteers and ensure sessions are thoughtfully facilitated.
- Promote jointly via community channels.

Local policy or systems forum

- Work with local officials or healthcare systems to explore ways to incorporate ACP into clinics, electronic health records, and social service outreach.

Intergenerational storytelling event

- Host a facilitated conversation between older adults and youth, where values, lessons, and “what matters most” are shared across generations.
- This strengthens community ties while planting early seeds for ACP.

Why ACP Activities Matter

Planning conversations don’t need to be clinical or intimidating. By making them social, creative, and accessible, communities can reduce stigma and normalize thinking about the future. Whether it’s a chalkboard, a shared meal, or a resource table, every activity is a step toward trust, reflection, and empowerment — across generations.

ACP Terminology

A helpful glossary for community members, caregivers, and local leaders

Planning and decision-making

Advance Care Planning (ACP)

- Conversations and documents that help people reflect on and share their preferences for future care — especially if they ever become unable to speak for themselves. ACP can include medical, emotional, legal, and financial wishes.

Advance Directive

- A legal document outlining what kind of care you would want — or not want — if you couldn't speak for yourself. Usually includes:
    - A Living Will (your instructions for care)
    - A Health Care Proxy or Health Care Power of Attorney (the person who can speak for you)

Living Will

- A part of the advance directive that shares your wishes about specific treatments, such as life support, in the event of serious illness or injury.

Health Care Proxy / Agent / Surrogate

- A person you choose to make medical decisions for you if you cannot. Sometimes called a health care representative or surrogate decision-maker.

Substitute Decision-Maker

- Someone who steps in to make decisions if no advance directive is in place and no proxy is named. Laws vary by state.

Ethical Will (or Legacy Letter)

- A non-legal document that shares your values, beliefs, life lessons, or hopes with loved ones. A personal way to pass on meaning, not money.

Legal and financial terms

Power of Attorney (PoA)

- A document authorizing someone to act on your behalf.
    - A Health Care PoA makes medical decisions
    - A Financial PoA handles money, property, or benefits

Last Will and Testament

- A legal document that outlines how your assets should be distributed after your death.

Trust

- A legal arrangement that allows one person or institution (the trustee) to manage property for someone else (the beneficiary), based on instructions from the grantor.

Beneficiary

- A person or group named to receive money, property, or other benefits under a will, trust, or insurance policy.

Probate

- The court process to validate a will and distribute a person’s estate after death.

Guardianship

- A legal relationship in which a court appoints someone to make decisions for another person who is unable to do so. Can apply to minors or adults with cognitive limitations.

Title

- Legal ownership of an asset, like a home or vehicle. How it's titled affects what happens to it after you die.

Medical terms and treatment decisions

Life-Sustaining Treatment

- Medical care that supports vital body functions and can keep a person alive — even when recovery is unlikely. Examples include:
    - CPR (cardiopulmonary resuscitation)
    - Ventilators
    - Feeding tubes
    - Dialysis
    - Artificial hydration

DNR (Do Not Resuscitate)

- A written order that tells healthcare providers not to perform CPR if your heart or breathing stops.

POLST (Physician Orders for Life Sustaining Treatment)

- A medical order completed by a physician with a patient who has an advanced serious illness or frailty. It outlines what types of life-sustaining treatments they do or do not want. This medical order and travels across care settings. POLST is not a replacement for an advance directive — both may be important, depending on the situation.

Hospice

- A type of care for individuals nearing the end of life, focused on comfort, dignity, and support rather than cure. Can be delivered at home, in a facility, or a dedicated hospice residence.

Palliative Care

- Specialized care for people living with serious illness that focuses on quality of life, symptom relief, and emotional/spiritual support — at any stage of illness, not just end-of-life.

Comfort Care

- A broad term for care that prioritizes comfort over cure. Includes pain management, emotional support, and dignity-focused approaches.

Ventilator

- A machine that helps a person breathe when they are unable to breathe on their own due to illness, surgery, or injury.

DNI (Do Not Intubate)

- A medical order that tells providers not to insert a breathing tube or place a person on a ventilator. Often paired with or added to a DNR.

Persistent Vegetative State

- A condition in which a person is awake but unaware, with no signs of purposeful brain activity. Often irreversible.

Resources

These books and websites provide useful tools, reflections, and step-by-step guidance for individuals, families, and communities engaging in Advance Care Planning (ACP).

Books About ACP, Planning, and End of Life

Baines, B. (2002). Ethical Wills: Putting Your Values on Paper

Introduces the tradition of ethical wills and offers practical tips for writing your own to share life lessons, hopes, and values with loved ones.

Butler, K. (2019). The Art of Dying Well

Practical, community-friendly advice on navigating aging, illness, and dying — with emphasis on patient empowerment and planning.

Byock, I. (1997). Dying Well

Explores how individuals and families can experience personal growth and meaning at the end of life through compassionate care and honest conversation.

Dunn, H. (2016). Hard Choices for Loving People (6th ed.)

A trusted guide for navigating complex medical decisions near the end of life — including CPR, feeding tubes, antibiotics, and hospice options.

Gawande, A. (2014). Being Mortal: Medicine and What Matters in the End

Written by a surgeon, this book explores how healthcare can better support meaning, autonomy, and dignity as people approach death.

Hurme, S. (2015). Checklist for Family Caregivers

A practical guide from the American Bar Association, covering financial, legal, healthcare, and emotional aspects of caregiving and end-of-life planning.

Kalanithi, P. (2016). When Breath Becomes Air

A memoir by a neurosurgeon facing terminal cancer that speaks to purpose, legacy, and how we live in the face of mortality.

Lemberg, D. (2014). Taking Care at End of Life

Helps readers write a personalized, values-based advance directive through reflection and practical examples.

Miller, B.J. & Berger, S. (2019). A Beginner’s Guide to the End

A clear, compassionate, and comprehensive guide for living well through serious illness and preparing for the end of life.

Website and Planning Tools

Caring Connections – National Hospice and Palliative Care Organization (NHPCO)

Comprehensive information on advance care planning, hospice, and grief.

Caring Connections Website

Coda Alliance – Go Wish Cards

A values-based conversation tool to clarify personal priorities.

Code Alliance Website

Death Café

Resources to host informal, agenda-free discussions about death, dying, and life. Death Care Website

Death Over Dinner

Guides for hosting a group meal with meaningful conversations about end-of-life planning. Death Over Dinner Website

End in Mind Project

Offers events and storytelling tools that promote reflection on mortality and meaning. End in Mind Project Website

Five Wishes – Aging with Dignity

A user-friendly advance directive that covers medical, emotional, and spiritual care. Five Wishes Website

Funeral Consumers Alliance

Education and consumer rights information for funeral planning. You can learn more on Funeral Consumers Alliance Website.

Last Things (Maine-focused)

Funeral planning resources and guides for residents of Maine. You can learn more on Last Things' website.

Mourning Ventures of Maine LLC

A Maine-based resource offering community education, guided advance care planning (ACP), and values-based planning support. You can learn more on Mourning Ventures' website.

MyDirectives

Free, secure online platform for creating and storing advance directives. You can learn more on MyDirectives' website.

National Healthcare Decisions Day – The Conversation Project

Ideas and toolkits for community observance of NHDD (April 16). You can learn more on the Conversation Project's website.

National Institute on Aging – Advance Care Planning & End-of-Life Guides

Downloadable PDFs for caregivers and individuals. You can access documents on the NIA's website.

POLST.org

Official site explaining POLST forms, their intended use, and provider guidance. You can access forms on POLST's website.

Prepare for Your Care

ACP education tools, a planning video, and conversation starters. Great for events. You can learn more on Prepare for Your Care's website.

The Conversation Project

Planning templates, conversation guides, and community engagement ideas. You can learn more on the Conversation Project's website.

Reimagine

Creative approaches to exploring loss, planning, and legacy through art and community events. You can learn more on Let's Reimagine's website.

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