

# Advance Care Planning: Discuss Your Healthcare Wishes

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## The Foundation of Advance Care Planning

Advance Care Planning (ACP) represents a crucial process in modern healthcare, fundamentally shifting the focus of end-of-life care from reactive intervention to proactive, patient-centered decision-making. It is not merely a single form or document, but rather a series of structured, ongoing conversations between an individual, their loved ones, and healthcare providers regarding future medical treatment preferences should the individual lose the capacity to make or communicate those decisions themselves. This process is deeply rooted in the ethical principle of **autonomy**, ensuring that a person's values, beliefs, and goals for care remain central, even when they are critically ill or incapacitated. Effective ACP discussions move beyond simple choices about resuscitation status, delving into the nuances of quality of life, acceptable burdens of treatment, and the specific circumstances under which certain interventions would be desired or refused, thereby providing a clear roadmap for future medical management that honors the patient's deeply held convictions about living and dying, mitigating the risk of unwanted or futile treatments.

The imperative for engaging in ACP stems from the recognition that unforeseen medical crises, such as sudden trauma, stroke, or advanced stages of chronic disease, can rapidly strip individuals of their cognitive ability to participate in crucial medical deliberations. Without prior guidance, surrogate decision-makers are often left guessing or projecting their own desires onto the patient, leading to significant emotional distress, moral conflict, and treatments that may conflict sharply with the patient's actual wishes, often resulting in prolonged suffering or unnecessary resource utilization. Therefore, the discussion phase of ACP serves as the critical mechanism for translating abstract values into concrete, actionable medical instructions. This comprehensive planning process encompasses discussions about palliative care options, pain management strategies, the use of life-sustaining treatments like mechanical ventilation or artificial nutrition and hydration, and the designation of a trusted surrogate, ensuring that all aspects of potential future care are thoroughly addressed and documented while the patient retains full cognitive capacity and sound judgment.

Furthermore, ACP is increasingly viewed as a standard component of holistic health maintenance, rather than an activity reserved only for those facing imminent mortality. Initiating these conversations earlier in the life cycle, particularly upon diagnosis of a chronic illness or during routine primary care visits, allows for reflection and refinement of preferences over time, adapting to changing health statuses and personal circumstances, thereby ensuring the plan remains relevant and aligned with the individual's evolving perspective. The success of ACP is measured not merely by the completion of a legal form, but by the depth of understanding achieved by the designated healthcare agent regarding the patient's ethos concerning life extension versus comfort and dignity. This continuous dialogue fosters clarity, reduces uncertainty for families and clinical teams, and ultimately supports the provision of care that is both medically appropriate and ethically aligned with the patient's enduring definition of well-being.

## The Scope and Purpose of the Advance Care Planning Dialogue

The scope of the ACP dialogue is expansive, encompassing far more than the traditional "Do Not Resuscitate" (DNR) order; it seeks to articulate a comprehensive philosophy of care across various health trajectories and potential clinical scenarios. The primary purpose is to identify and document the individual's **goals of care**, which serve as the overarching framework for all subsequent medical decisions. This involves exploring complex trade-offs, such as the willingness to endure significant pain or loss of independence for a small chance of recovery, versus prioritizing comfort and symptom management even if it means shortening lifespan. Discussions must address specific, challenging scenarios, including irreversible coma, advanced dementia, end-stage organ failure, and severe neurological damage, prompting the individual to consider what quality of life thresholds they deem unacceptable and under what circumstances they would prefer comfort measures only, ensuring that the documented plan is robust enough to handle the ambiguities inherent in critical clinical practice.

A crucial element within the scope of the discussion is the exploration of personal values. Healthcare providers trained in ACP facilitation must skillfully guide the patient to articulate the fundamental principles that define their life and their sense of self-worth, such as the ability to communicate, the capacity for meaningful relationships, independence in daily activities, or adherence to spiritual practices. By grounding the medical preferences in these core values, the resulting plan becomes far more durable and interpretable by the surrogate decision-maker when faced with novel clinical situations not explicitly covered in the legal documents. For instance, understanding that a patient values lucid interaction above all else can help the agent decide against aggressive ventilation that might preserve life but induce persistent sedation or chronic delirium, highlighting the essential interconnectedness of core human values and specific treatment choices in the context of critical illness.

The secondary, yet equally vital, purpose of the ACP dialogue is relational and supportive: it aims to substantially reduce the emotional and moral burden of decision-making placed upon family members and designated healthcare agents during times of acute crisis. When patients clearly articulate their wishes beforehand, the agent transitions from the difficult, guilt-inducing role of guessing what the patient would want to the more supportive and less stressful role of executing the patient's stated instructions. This clarity can prevent profound family conflict that often arises when siblings or relatives disagree on the appropriate course of action, particularly when the patient's wishes were ambiguous or non-existent. The discussion acts as a prophylactic measure against moral distress for both the family and the clinical team, ensuring that care delivered aligns with the patient's deepest wishes, thereby promoting a more peaceful, dignified, and ethically sound end-of-life experience for all parties involved in the care continuum.

## Key Participants and Optimal Timing

The success of the ACP discussion hinges on the inclusion and preparation of key participants and the strategic timing of the initiation. Central to the process is the individual (the patient) who must possess **decisional capacity**--that is, the ability to understand the information presented, appreciate the consequences of their choices, and communicate their preferences clearly and consistently. The healthcare provider, often a physician, nurse practitioner, or specially trained social worker, serves as the facilitator, responsible for introducing the topic, providing accurate, unbiased medical information regarding prognosis and treatment options, and ensuring the discussion is conducted in a sensitive, non-coercive manner. However, the most critical participant besides the patient is the designated **Healthcare Proxy** or **Surrogate Decision-Maker**. This individual must be present for, or fully briefed on, the discussion to gain a deep contextual understanding of the patient's goals and values, moving beyond the mere literal interpretation of the legal document to grasp the true spirit of the patient's preferences and intentions.

Optimal timing for initiating ACP is significantly earlier than traditionally assumed, moving away from the crisis model of planning. Experts recommend integrating ACP into routine preventive care for all adults, especially those over the age of 50, and immediately following the diagnosis of any progressive chronic illness, such as advanced cardiac disease, chronic obstructive pulmonary disease, or early-stage neurological disorders. Early engagement allows for multiple, less-pressured conversations over time, reducing the emotional intensity and enabling the patient to process complex choices without the duress of an impending crisis. When the conversation is deferred until the patient is acutely ill, cognitive impairment, severe pain, or high levels of anxiety can severely compromise the quality and validity of the decisions made, often leading to hurried and incomplete planning that fails to truly represent the patient's enduring wishes and values.

Furthermore, the setting of the discussion plays a vital role in its effectiveness. Ideal ACP discussions occur in a quiet, private, and comfortable environment, allowing ample, uninterrupted time--often requiring more than one session--to address all concerns and questions comprehensively. The facilitator must employ open-ended questions and active listening techniques, ensuring that the dialogue is truly patient-led, focusing on the patient's narrative and values, rather than being a rapid, provider-driven checklist. Key substantive topics that must be covered include the appointment of the proxy, detailed discussion of specific life-sustaining treatments (e.g., CPR, mechanical ventilation, dialysis), and defining the precise boundary between curative intent and palliative focus. Documentation must follow immediately, utilizing state-specific or nationally recognized forms, such as the Physician Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOLST) forms, where applicable, to ensure the preferences are translated into legally binding, portable medical orders.

## Core Components and Documentation

The substantive core of the ACP discussion revolves around specific, mandatory components that must be thoroughly explored and documented to create a legally and clinically robust plan capable of guiding care in diverse settings. The foundational component is the nomination of the **Healthcare Agent** or proxy, which requires a careful consideration of who possesses the necessary qualities: deep trustworthiness, emotional stability under pressure, physical proximity or accessibility, and most importantly, the willingness and ability to set aside personal beliefs to advocate strictly for the patient's stated preferences and goals. The documentation must clearly state the scope of powers granted to this agent and precisely when those powers become effective, typically upon certification by one or more physicians that the patient has lost the capacity to make or communicate medical decisions.

The second critical component involves defining preferences regarding the use and refusal of specific life-sustaining treatments. This requires presenting the patient with realistic clinical scenarios and explaining the burdens, benefits, and potential outcomes of interventions such as Cardio Pulmonary Resuscitation (CPR), which often has very low success rates and high morbidity in frail or chronically ill populations, as well as the use of mechanical ventilators, artificial nutrition and hydration (feeding tubes), and the administration of potent antibiotics for life-threatening infections. The discussion must define the specific conditions under which the patient would accept or refuse these measures, moving beyond simple blanket statements. For example, a patient might accept a ventilator for a potentially reversible condition like acute pneumonia, but explicitly refuse it if they are in a persistent vegetative state or facing end-stage dementia, necessitating nuanced, conditional documentation that captures this distinction accurately.

Documentation is the ultimate tangible output of the ACP discussion, transforming conversational preferences into legally recognized and clinically actionable instruments. These typically include an **Advance Directive** (often a Living Will), which documents the patient's wishes regarding treatments in terminal or irreversible conditions, and the **Durable Power of Attorney for Healthcare**, which formally names and empowers the agent. Increasingly, high-quality discussions result in portable medical orders like POLST/MOLST, which are brightly colored, physician-signed forms that translate the patient's wishes into immediate, actionable medical orders that legally travel with the patient across different care settings (home, hospital, nursing facility, ambulance). Ensuring these documents are stored securely, accessible electronically via health records, and regularly reviewed is absolutely essential for the operational integrity and functionality of the ACP process, preventing critical information loss during time-sensitive emergencies.

## Psychological and Emotional Considerations

Engaging in ACP discussions inevitably triggers significant psychological and emotional responses

in both the patient and their loved ones, necessitating exceptional sensitivity, empathy, and specialized communication skill from the facilitator. For the patient, confronting one's own mortality, discussing potential irreversible incapacitation, and evaluating the limits of medical technology can evoke intense fear, anxiety, profound sadness, and sometimes defense mechanisms like denial or minimization. The discussion must therefore be paced appropriately, allowing the patient ample time to process potential losses--such as the loss of independence or cognitive function--and to work through the implications of complex medical choices. Facilitators must actively validate these feelings and create a safe, non-judgmental space for emotional expression, recognizing that emotional readiness often precedes cognitive clarity in these difficult conversations. Failure to address underlying emotional distress can lead to avoidance, superficial compliance, or the eventual revocation of previously stated preferences, severely undermining the entire planning effort and leaving critical decisions unresolved.

For family members and designated surrogates, the emotional burden is often centered on feelings of guilt, overwhelming responsibility, and the paralyzing fear of making the "wrong" choice under immense pressure. Participation in the structured ACP discussion helps mitigate this by transforming the agent's role from independent, burdened decision-maker to faithful interpreter and advocate of the patient's known will. However, the facilitator must also proactively address potential resistance, disagreement, or emotional conflict among family members who may hold differing views on the patient's best interest based on their own values or religious beliefs. It is crucial to manage expectations, emphasizing that the final plan reflects the patient's autonomous, documented wishes, not necessarily a family consensus, while simultaneously providing emotional support and counseling to those who find the choices difficult to accept. The goal is to achieve alignment and understanding of the patient's intent, even if total emotional agreement on the underlying philosophy of care is ultimately unattainable among all relatives.

Furthermore, deeply held cultural, religious, and spiritual beliefs profoundly influence how individuals conceptualize illness, death, dying, and the appropriate extent of medical intervention. An effective ACP discussion requires **cultural humility**, necessitating the provider to inquire about and respect beliefs that might influence decisions regarding pain management, the use of life support, or the timing and setting of death. For some cultural groups, discussing death proactively is strongly taboo, requiring the provider to approach the subject indirectly, perhaps focusing on "future health planning" or "legacy choices" rather than explicitly "end-of-life choices." Recognizing that preferences are intrinsically shaped by deeply held worldviews ensures that the resulting care plan is not only medically sound but also spiritually and culturally congruent, promoting dignity and adherence to the patient's holistic identity and personal narrative.

## Facilitating Effective Communication

Effective communication is the bedrock upon which successful ACP rests, requiring specialized

training and refined techniques that extend far beyond standard medical interviewing skills. The facilitator must utilize clear, concise, and jargon-free language, translating complex medical terminology (e.g., "intubation," "vasopressors," "dialysis," "sepsis") into understandable explanations of what the intervention entails, what the patient will experience, and what the realistic prognosis might be for the patient's specific condition and age. Using visual aids, simple, relatable analogies, and structured questionnaires can help ensure that the patient accurately grasps the implications and potential burdens of their choices, moving away from abstract concepts to concrete consequences. Crucially, the communication style must be consistently empathetic, non-judgmental, and patient-centered, fostering a deep sense of trust and encouraging the open disclosure of deeply personal fears and values.

A highly recommended technique for ensuring decisional quality is the use of "testing questions" or "what-if scenarios" to gauge the depth of the patient's understanding and the consistency of their stated choices across different potential outcomes. For example, instead of simply asking, "Do you want CPR?" the provider might ask, "If your heart stopped and we successfully tried CPR, there's a significant chance you might survive, but you might also end up needing a breathing machine permanently and require long-term nursing care. Under those specific conditions, what would be most important to you regarding your independence?" This method compels the patient to consider the potential downstream burdens and quality-of-life implications of intervention, leading to more informed, reflective, and durable decisions. Active listening, including summarizing the patient's preferences back to them (the "teach-back" method), is absolutely essential to confirm accuracy and ensure that the documented plan truly reflects the patient's intent, minimizing the risk of devastating misinterpretation during a crisis.

Moreover, effective ACP communication is inherently iterative, meaning it must never be treated as a one-time event but rather as a continuous process that requires revisiting and updating the plan whenever there is a significant change in the patient's health status (e.g., a new diagnosis, functional decline), life circumstances (e.g., divorce, death of a spouse, relocation), or medical understanding of their prognosis. Providers should encourage patients to view their advance directives as living documents and schedule periodic review sessions, perhaps annually or following a hospitalization, to ensure ongoing relevance. Furthermore, communicating the documented plan effectively to the entire multidisciplinary care team—including specialists, hospital staff, emergency responders, and long-term care facilities—is vital. This often involves integrating the documents into the Electronic Health Record (EHR) and utilizing standardized state-wide registries to maximize accessibility when the patient is unable to speak for themselves, ensuring that the patient's voice is heard across the fragmented landscape of the healthcare system.

## Ethical and Legal Frameworks

Advance Care Planning operates within a robust framework of legal mandates and ethical

principles designed to rigorously protect patient rights and ensure the moral validity and clinical enforceability of the planning process. Ethically, ACP is grounded in four core principles of biomedical ethics: **autonomy** (the right to self-determination), **beneficence** (acting in the patient's best interest), **non-maleficence** (the duty to avoid causing harm), and **justice** (fair distribution of healthcare resources). The discussion must uphold autonomy by ensuring the patient is making fully voluntary, informed decisions free from any form of coercion, undue influence, or emotional manipulation. Legally, the validity and enforcement of advance directives and proxy appointments are strictly governed by state laws, which dictate specific requirements for witnessing, notarization, and the precise clinical circumstances under which the proxy's authority is activated, making it imperative that providers use forms and procedures compliant with the jurisdiction where the patient resides and where care is delivered.

A key legal distinction that fundamentally drives the ACP discussion is the difference between an instructional directive (the Living Will) and a proxy directive (the Durable Power of Attorney for Healthcare). The instructional directive specifies treatments to be accepted or refused under defined terminal conditions, but often lacks the necessary flexibility to address unforeseen clinical circumstances. The proxy directive, conversely, delegates comprehensive authority to a trusted agent who can make real-time decisions based on the patient's known values and goals when the specific clinical situation was not anticipated in the written document. The discussion must meticulously clarify the interaction between these two instruments, ensuring the patient understands that the agent's primary role is to interpret and follow the patient's prior wishes, not to substitute their own judgment, unless the patient explicitly grants them the authority to decide based on what is deemed "best interest" in truly ambiguous or novel situations where the patient's intent is unclear.

Ethical dilemmas frequently arise when the patient's previously documented wishes appear to conflict directly with the current clinical reality, the treating physician's professional judgment, or the family's desires for continued aggressive treatment. In such contested cases, the meticulous ACP discussion documentation serves as the primary ethical and legal guidepost. Healthcare providers have an ethical and often legal obligation to honor a validly executed advance directive, even if they personally disagree with the choice (e.g., refusal of a potentially life-saving treatment). If conflict persists and cannot be resolved through mediation, institutional ethics committees are frequently consulted to formally mediate disagreements, interpret the patient's intent in light of their values, and ensure compliance with both the patient's right to autonomy and established legal standards. The clarity achieved during the initial, high-quality ACP discussion is the most powerful tool available to resolve these complex medico-legal conflicts, underscoring the absolute necessity of detailed, comprehensive planning.

## Barriers to Implementation and Solutions

Despite widespread professional recognition of its importance, the effective implementation of comprehensive ACP discussions faces several persistent and significant barriers at the patient, provider, and systemic levels. On the patient side, the most common hurdle is **avoidance or denial**--the deep-seated human reluctance to confront one's own mortality or the optimistic belief that the conversation is unnecessary until a crisis occurs. Patients may also lack sufficient health literacy, making it difficult to fully grasp the technical implications and likely outcomes of complex medical interventions. Solutions involve the proactive, normalized introduction of the topic by primary care providers, framing the discussion as a necessary, routine part of future health and well-being planning, and utilizing accessible educational materials that demystify medical procedures and clearly explain realistic outcomes.

Provider-level barriers are also substantial, often stemming from severe constraints on clinical time, insufficient formal training in advanced communication skills specific to end-of-life issues, and profound discomfort with initiating and managing emotionally charged conversations about death and dying. Many clinicians report feeling inadequately prepared to handle the psychological distress and complex family dynamics that arise during these discussions, leading them to either rush the process, rely heavily on checklists, or avoid the topic entirely until it is too late. Addressing this requires robust, standardized training programs focusing intensively on communication techniques, value elicitation, cultural sensitivity, and recognizing emotional cues. Furthermore, healthcare systems must allocate dedicated clinical time and financial resources for ACP, recognizing it as a reimbursable, high-value clinical activity, thereby incentivizing clinicians to invest the necessary time and emotional energy to conduct these discussions properly.

Systemic barriers include the critical lack of interoperability and accessibility of documented directives across different healthcare settings. A directive completed meticulously in a primary care office may not be immediately available or recognized in an unfamiliar emergency department or during a transfer, rendering the planning efforts useless at the moment of greatest crisis. The fragmentation of care necessitates technological solutions, such as centralized electronic registries (e.g., state-level POLST registries) and mandatory integration of advance directives into Electronic Health Record (EHR) systems that are accessible 24/7 by all authorized providers. Overcoming these barriers requires collaborative efforts among policymakers, legal experts, technology developers, and healthcare institutions to create a seamless, integrated system where the patient's documented wishes reliably follow them throughout their entire healthcare journey, ensuring that the critical effort expended in the ACP discussion translates into consistent, patient-centered care delivery.