

# **How to Start Advance Care Planning Conversations with Hispanic Older Adults:**

**A Guide for Healthcare Professionals**



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## About MHP Salud

MHP Salud is a national nonprofit organization that implements and runs Community Health Worker (CHW) programs. These programs provide peer health education, increase access to health resources, and bring community members closer. MHP Salud also has extensive experience offering health organizations training and technical assistance on CHW programming tailored to their specific needs.



## Introduction

According to the US Census Bureau Population Estimates, the number of Hispanic individuals aged 65 and over is expected to grow significantly over the coming decades. In 2017, Hispanic Americans made up just 8% of people aged 65 and older in the US; however, that number is expected to grow to 21% by 2060.<sup>1</sup> Approximately 70% of Americans do not have any Advance Care Plan in place,<sup>2</sup> and Hispanics are less likely than other groups to engage in Advance Care Planning (ACP). In fact, one study found that those who identify as Hispanic are less likely to have a healthcare proxy, or person who can make medical decisions for them, identified than non-Hispanic whites.<sup>3</sup> Older Hispanic individuals with serious medical conditions lack information about ACP,<sup>4</sup> and there is a lack of culturally and linguistically appropriate information available for this population.<sup>5</sup>

This guide is intended to help healthcare professionals better understand how to engage in conversations with older Hispanic adults about ACP. It will help healthcare professionals identify the different types of ACP documentation, who can start the conversation, cultural considerations with assisting Hispanic older adults with ACP, tips and strategies for starting the conversation, and other resources.

## What is Advance Care Planning?

Advance Care Planning (ACP) is a process that involves an individual learning about the different decisions they may need to make about their health and/or end-of-life care in the case that they are unable to make those decisions on their own; considering those decisions ahead of time; and sharing their decisions and preferences with others who need to know.<sup>6</sup> In general, ACP allows people to live with dignity until the moment of their death through having their wishes documented and communicated to their loved ones and healthcare providers.

## Why is ACP Important?

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There is a common misconception that ACP is only for older individuals or people who are ill. In fact, it is best to start this process when a person is relatively healthy! It is true that as people age, ACP becomes even more important; however, there is no need to wait to begin the ACP process. Below are situations in which one could benefit from ACP:

- **Unexpected Events:** Regardless of someone's health status, debilitating and life-threatening events, such as a car accident, can occur at any age.
- **Chronic Conditions:** In 2014, 60% of all adults in the US had at least one chronic condition, and 42% had more than one chronic condition.<sup>7</sup> Hispanic/Latinos in the US experience disproportionate rates of certain chronic conditions. For example, according to the 2020 National Diabetes Statistics Report, the prevalence of diagnosed diabetes was 12.5% among Hispanic origin adults and 7.5% for non-Hispanic whites.<sup>8</sup>
- **Cognitive and Memory Disorders:** Alzheimer's Disease disproportionately affects older Hispanic/Latino adults; the prevalence of Alzheimer's Disease among Latinos is 50% greater than non-Latino whites.<sup>9</sup>
- **Other Terminal Illnesses:** Neurological diseases, advanced cancers, and heart and lung disease are some examples of terminal illnesses where prior ACP can make a meaningful difference in end-of-life care.

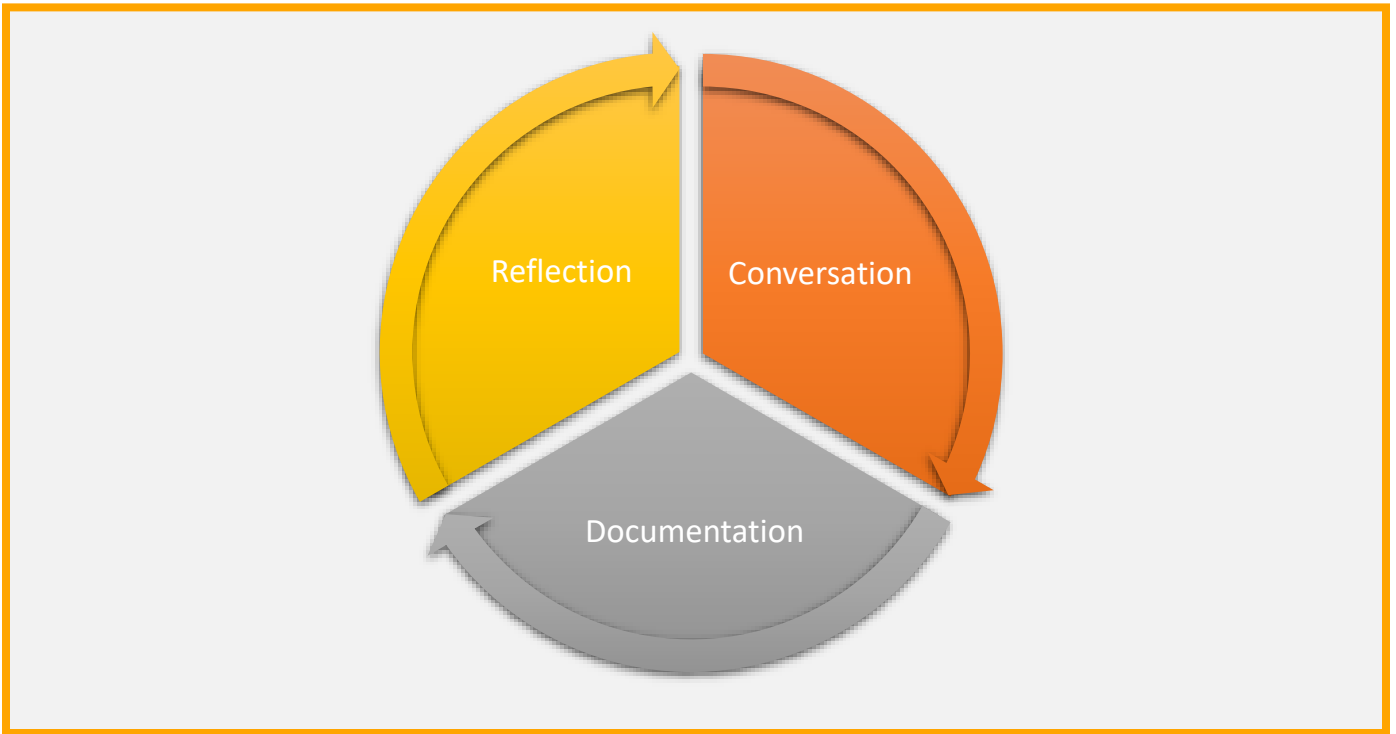
ACP is a process that can benefit the individual and their loved ones. Having discussions about their wishes and values for end-of-life care with health professionals and loved ones is vital for the following reasons:

- **Reduce Burden on Loved Ones:** A patient having discussions with their family members and loved ones about their end-of-life wishes and goals can minimize the burden of making such decisions when the time comes, as they will not need to make decisions based on what they *think* the patient wanted and can feel more confident. This also helps prevent conflict among loved ones who disagree on the appropriate course of action.
- **Improve Quality of Care:** ACP allows for a patient to express what kind of care they would like to receive at the end of their life and where they would like to receive it. According to the nationally representative Health and Retirement Study, older adults who engaged in ACP were more likely to receive hospice Care, were more likely to use it for greater than three days and were less likely to die in a hospital.<sup>10</sup> This is significant because most older adults prefer to receive end-of-life care at home.
- **Have Autonomy & Ensure Wishes are Met:** Unfortunately, physicians often are unaware of their patients' preferences for medical treatment.<sup>11</sup> ACP allows individuals to clearly state their values, goals, and wishes for medical treatment through documentation, which will ensure those wishes are followed by the medical team.
- **Inform Individuals of Their Options:** There are misunderstandings among many older adults about what Palliative Care and Hospice Care are and when they are used. Engaging in ACP conversations with professionals who understand and can provide accurate explanations and examples of what Palliative Care is and what Hospice provides, can help patients make informed decisions about their end-of-life care. When these options are better understood and not feared by patients, it allows for the full range of healthcare options to be considered.

## The ACP Process and Types Documentation

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The process of ACP includes reflection and consideration of one's wishes, discussion of the topic and one's wishes with loved ones, and documentation of their wishes. Keep in mind that ACP is a process, so it is important to encourage patients to regularly review decisions and documentation, especially if there is a change in health status. There are three phases to this process: Reflection, Conversation, and Documentation.<sup>12</sup>



### **I. Reflection**

The first phase of the ACP process is reflection. This entails patients reflecting on their values and wishes for their healthcare until the end of their lives. Many have not given this much thought unless they have been personally involved in the end-of-life care for someone else. We will review tips and strategies below on how to assist older Hispanic adults in this phase of the ACP process.

### **II. Conversation**

The next phase of ACP is having conversations with loved ones and/or health professionals about one's values and wishes for their healthcare— this phase is the primary focus of this guide. Many Hispanic older adults express their wishes to have family care for them at home until the time of their death. However, it is less common for Hispanic older adults to discuss the specific kind of healthcare they wish to receive. Conversations about specific end-of-life situations are important for ACP.

### **III. Documentation**

Once someone has considered their values and wishes for end-of-life care and made decisions about who their Healthcare Proxy should be, this information can be documented through the following: Healthcare agent or “proxy,” Advance Directives or the Living Will, and a Medical Orders for Life-Sustaining Treatment (MOLST).



Below you can find more specific information about each:



## Healthcare Proxy

**What?** An individual who is designated and legally empowered to make decisions related to a person's health care.

**Other Names:** This person can be referred to as simply a “proxy” or “agent”. Other names might include: Surrogate, Advocate, Healthcare Representative, or Designate for Durable Power of Attorney for Health Care, or Durable Power of Attorney.

This person should<sup>13</sup>:

- Know the person's preferences
- Have the emotional capacity to be a strong advocate for their preferences
- Live close by and be available
- Be willing and able to serve in this role

Once the proxy is selected and agrees to the role, this information should be shared with other loved ones and medical team of the individual. It is crucial for patients to engage in regular ACP conversations with this person not to make decisions now, but to help guide them to make healthcare decisions in the future on behalf of the patient.

**Note:** People often think that the “next of kin” or closest family member will automatically be selected for this role if one is not one chosen. This may be true in some states; however, there still may be disagreement among family and loved ones as to what his person should be, and the individual may wish to have someone else, such as a close friend or their unmarried significant other, be their proxy. This person may also be eligible to make financial decisions on behalf of the patient, depending on which terminology is used and the laws of the individual state. It may be helpful to contact your local Area Agency on Aging to find out about the laws in your state.

**Cultural Considerations:** Although it is the norm for Hispanic and Latino older adults to be taken care of by family members, it is important not to generalize or assume that they will select their children to be their proxy. Extended family members may take on this role. For example, nieces and nephews may take care of their older aunt or uncle. It may also be necessary for older Hispanic adults to decide who their proxy will be together as a family and to include other family members in the decision-making process for what kinds of treatment they wish to receive. See the section *Cultural Considerations for ACP with Hispanic Older Adults* for more information about the importance of family in decision making among Hispanics.

**Additional Resource:**

- ✓ **Medicare Interactive: Locating legal assistance to help plan future care:**  
<https://www.medicareinteractive.org/get-answers/planning-for-medicare-and-securing-quality-care/preparing-for-future-health-care-needs/locating-legal-assistance-to-help-plan-future-care>



## Advance Directive Documents

**What?** An advance directive is a written document, recognized under state law, that explains the provision of health care an individual wishes to receive if they are incapacitated.

**Other Names:** Advance Directive, Living Will or Medical Directive

These documents typically include specific information about the following<sup>14</sup>:

- If someone wants Cardiopulmonary Resuscitation (CPR)
- If one wants to use equipment to help keep them alive (such as a ventilator or breathing machine)
- A Do Not Resuscitate order or “DNR” (instructions to not use CPR if someone stops breathing or their heart stops)
- If one wants food and/or fluid through a tube if they cannot eat or drink
- If one wants treatment for symptoms such as pain and nausea, even if they cannot make other decisions (this can be called “comfort care” or “Palliative Care”)
- If one would like to donate their organs or other body tissues after death.



This is not an exhaustive list. These decisions can be hard to make and may change over time; thus, it is important to encourage patients to revisit such documentation regularly. It is impossible to have every scenario on Advance Directives; therefore, having conversations about their values and goals for end-of-life care with loved ones is extremely important to guide the healthcare proxy in unexpected situations.

**Note:** Laws on this type of documentation will vary by state including when and how often one should renew their advance directive.

**Cultural Considerations:** Hispanic older adults often need to have these conversations with their family and make decisions together about their healthcare. It is important to understand how religious beliefs and spirituality influence one's values and wishes. Finally, it is vital to have a culturally and linguistically competent healthcare provider to help older adults understand their options. See *Cultural Considerations When ACP with Older Hispanic Adults* for more information.

#### Additional Resources:

- ✓ **PREPARE for your care:** <https://prepareforyourcare.org/advance-directive>
- ✓ **AARP ACP documents by state:** <https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/>



## MOLST

**What?** Medical Orders for Life Sustaining Treatment, or a form that has specific medical orders in the case of an emergency.

**Other Names:** POLST (Physician Orders for Life-Sustaining Treatment)

A MOLST often includes the one's wishes for life sustaining treatment<sup>15</sup>:

- The use of CPR
- If one wants to use equipment to help keep them alive (such as a ventilator or breathing machine)
- Treatment guidelines

- One's wishes for being hospitalized and/or transferred to a hospital or medical facility in the future
- If one wants food and/or fluid through a tube if they cannot eat or drink
- The use of antibiotics

A MOLST helps an individual express their wishes for health treatment but is not an advance directive. A MOLST can be used in emergency situations to express that one does not wish to receive certain life sustaining treatments.

**Note:** MOLST documents are only available in some states and must be signed by a qualified member of the individual's healthcare team. Emergency personnel such as EMTs and Paramedics are required by law to provide every possible treatment to keep someone alive and cannot use advance directives (examples in the above box), but they can use a MOLST. <sup>16</sup>

**Cultural Considerations:** It is important for Hispanic older adults to have these conversations with their family and make decisions together about their healthcare.

#### **Additional Resources:**

- ✓ Helpful Phrases for POLST Conversations (English and Spanish):  
[https://coalitionccc.org/wp-content/uploads/2016/01/POLST\\_Helpful\\_Phrases\\_Eng\\_and\\_Spanish.pdf](https://coalitionccc.org/wp-content/uploads/2016/01/POLST_Helpful_Phrases_Eng_and_Spanish.pdf)
- ✓ What is MOLST/POST/POLST? <http://conversationsofalifetime.org/wp-content/uploads/2018/06/What-is-MOLST-POST-POLST.pdf>

Almost all states require that these documents be made official by having two qualified witnesses sign and notarize them. Once this is completed, patients should share documents with loved ones, close friends, and their healthcare team. Remind patients that when these documents are needed, it is best to have them readily available (not locked up with one's other important documents).

Patients may also want to consider plans for settling their finances and planning their funeral. Discussing the basics of their funeral wishes and/or any religious or spiritual considerations with their loved ones or healthcare agent, is important. For example, Hispanic individuals may be more likely to be of the Catholic faith, and therefore, they may not believe in cremation and wish to have a church service as part of their funeral. Discussing funeral costs and plans for payment may be helpful in ensuring their proxy and/or family can plan appropriately.

## Who Could Start the Conversation?

Conversations about ACP can be difficult and can cause discomfort because it forces patients to think and talk about death, which can be scary and bring up strong emotions. However, the more the topic is discussed, the more likely older adults are to engage in ACP. Below lists the different professions and groups of people who can initiate ACP conversations with older Hispanic adults and the benefits of each:

### Community Health Workers

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The American Public Health Association defines Community Health Workers as:

“A Community Health Worker (CHW) is a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the CHW to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery.

A CHW also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy.”

In other words, **a CHW is a trusted member of the community who empowers their peers through education and connections to health and social resources.**

CHWs are members of the community they serve, and, therefore, are particularly well-qualified to assist older Hispanic adults in the beginning conversations of ACP. CHWs are aware of the cultural expectations among this group when it comes to end-of-life care. With the proper training, they can facilitate discussions with older Hispanic adults and improve the likelihood of them engaging in the ACP process and improve health outcomes.<sup>17</sup> In fact, studies show that CHWs who assist older Hispanic adults in ACP:

- Improved health outcomes including significant reductions in seeking urgent health care and hospitalizations<sup>1</sup>
- Increased comfort in discussing end-of-life goals<sup>2</sup>
- Were perceived as extremely helpful in the ACP process<sup>3</sup>
- Provided education and materials in one's preferred language and in a culturally appropriate manner
- Engaged patient's family in ACP when appropriate<sup>4</sup>

CHWs have many roles and can provide a wide range of services to older Hispanic adults. The following are examples of CHW roles in the ACP process:

- Assist with cultural mediation through navigating the US Healthcare System, various forms/documents, and legal steps to ACP, as well as explaining the different medical options they have within the US Healthcare system
- Provide culturally and linguistically appropriate education about ACP and end-of-life care options, conduct home visits if necessary
- Coordinate care through providing referrals to health and social services if necessary
- Provide coaching and social support to patients through the ACP process
- Advocate for Hispanic older adults to ensure they feel comfortable expressing their wishes and ensure others involved in the ACP are doing so in the patient's interest
- Build Hispanic older adults' capacity by empowering them to express their wishes for their healthcare and ability to document this through ACP
- Conduct outreach to the older Hispanic adult population
- Facilitate conversations with patients and their families

The above-mentioned roles allow CHWs to provide comprehensive assistance to older Hispanic adults in a culturally appropriate manner.

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<sup>1</sup> Litzelman et al., *Impact of Community Health Workers on Elderly Patients' Advance Care Planning and Health Care Utilization: Moving the Dial*. (Med Care, 2017), 319-326 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5352503/>

<sup>2</sup> Maldonado et al., *Wellness in Sickness and Health (The W.I.S.H. Project): Advance Care Planning Preferences and Experiences Among Elderly Latino Patients*. (Clinical Gerontologist, 2017), 259-266 <https://www.tandfonline.com/doi/abs/10.1080/07317115.2017.1389793>

<sup>3</sup> Nedjat-Haiem et al., *Implementing an Advance Care Planning Intervention in Community Settings with Older Latinos: A Feasibility Study* (Journal of Palliative Medicine, 2017), 984-993 <https://www.liebertpub.com/doi/abs/10.1089/jpm.2016.0504>

<sup>4</sup> Maldonado et al., *Wellness in Sickness and Health*, 259-266 <https://www.tandfonline.com/doi/abs/10.1080/07317115.2017.1389793>

## Healthcare/Service Providers

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Primary care providers and other healthcare providers including social workers, cardiologists, endocrinologists, gerontologists, oncologists, and other specialty providers can play a role in assisting older Hispanic adults with ACP. This subject is often avoided by primary care physicians because they feel conversations are difficult to navigate when they are initiated later or after a diagnosis.<sup>5</sup> Conversely, when started early providers say the conversations can feel procedural and not involve in-depth conversations.<sup>5</sup> Discussing this topic regularly at visits in a culturally sensitive and linguistically appropriate manner can assist older adults in thinking about ACP. If this were done among all health professionals, it would normalize this process and possibly increase understanding and the benefits of ACP among older Hispanic adults. In the section *Starting the Conversation about ACP* you will find some tips for healthcare professionals, including CHWs, for starting such conversations.

## Informal Caregivers and Family Members

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Informal caregivers, also called family caregivers, are any family member, partner, friend or neighbor who has a strong personal relationship with and provides care to an older adult or person with a chronic or disabling condition.<sup>6</sup> Hispanic caregivers often take on many responsibilities and experience high burdens when caring for their older adult loved ones. In fact, according to the Family Caregiver Alliance in 2015, Hispanics had the highest prevalence of caregiving among the different racial/ethnic groups.<sup>7</sup> Hispanic caregivers also experience higher burdens than their White or Asian American peers; forty-five percent (45%) of Hispanic caregivers experience high burden caregiving and spend about 30 hours a week providing care.<sup>7</sup>

Informal caregivers and family members could help begin conversations with older Hispanic adults about ACP. This group may find it difficult to bring up the topic because of their personal relationship with the older adult. Having the assistance of another person or professional, such as a trained CHW, can empower caregivers by providing them information and tools/materials that may assist them in engaging their loved ones in ACP conversations. They may be able to facilitate this process together with the caregiver if appropriate. Research has shown that for

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<sup>5</sup>The Conversation Starters: Research Insights from Clinicians and Patients on Conversations about End-of-Life Care and Wishes (John Hartford, 2016) <https://www.johnhartford.org/images/uploads/reports/ConversationStartersFocusGroupsReportFINAL.pdf>

<sup>6</sup> Family Caregiver Alliance, *Definitions* (Accessed Dec 12, 2020) <https://www.caregiver.org/definitions-0>

<sup>7</sup> National Alliance for Caregiving and AARP, *Caregiving in the US* (2015) <https://www.caregiver.org/caregiver-statistics-demographics>

Hispanic communities, including family in these conversations is important for older adults<sup>8,9,10, 11</sup> and family should therefore be a large part of discussing one’s end-of-life decisions.

## Helpful Informal Caregiver Resources

English	Spanish
<ul style="list-style-type: none"> <li>✓ <b>Prepare to Care: A Planning Guide for Families (AARP)</b>  <a href="https://www.aarp.org/content/dam/aarp/caregiving/2018/02/prepare-to-care-guide-english-aarp.pdf?intcmp=AE-CAR-P2CGD-ENG">https://www.aarp.org/content/dam/aarp/caregiving/2018/02/prepare-to-care-guide-english-aarp.pdf?intcmp=AE-CAR-P2CGD-ENG</a> </li> </ul>	<ul style="list-style-type: none"> <li>✓ <b>Cuidando a Los Nuestros: Una Guía de Planificación para La Familia (AARP)</b>  <a href="https://www.aarp.org/content/dam/aarp/caregiving/2018/02/prepare-to-care-guide-spanish-aarp.pdf?intcmp=AE-CAR-P2CGD-ENG">https://www.aarp.org/content/dam/aarp/caregiving/2018/02/prepare-to-care-guide-spanish-aarp.pdf?intcmp=AE-CAR-P2CGD-ENG</a> </li> </ul>
<ul style="list-style-type: none"> <li>✓ <b>Caring Conversations: Making Your Healthcare Wishes Known</b>  <a href="https://practicalbioethics.org/resources/caring-conversations.html">https://practicalbioethics.org/resources/caring-conversations.html</a> </li> </ul>	<ul style="list-style-type: none"> <li>✓ <b>Caring Conversations: Haga Saber Sus Deseos Sobre su Cuidado Medico</b>  <a href="https://practicalbioethics.org/resources/caring-conversations.html">https://practicalbioethics.org/resources/caring-conversations.html</a> </li> </ul>
<ul style="list-style-type: none"> <li>✓ <b>Alzheimer’s Association End-Of-Life Decisions: Honoring the wishes of a person with Alzheimer’s disease:</b>  <a href="https://www.alz.org/national/documents/brochure_endoflifedecisions.pdf">https://www.alz.org/national/documents/brochure_endoflifedecisions.pdf</a> </li> </ul>	

<sup>8</sup> Cervantes et al., *Qualitative Interviews Exploring Palliative Care Perspectives of Latinos on Dialysis* (CISAN, 2017), 788-798. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5477217/>

<sup>9</sup> Nedjat-Haiem et al., *Exploring Motivational Interviewing to Engage Latinos in Advance Care Planning: A Community-Based Social Work Intervention* (Am J Hosp Palliat Care, 2018), 1091-1098 [https://www.researchgate.net/publication/323940551\\_Exploring\\_Motivational\\_Interviewing\\_to\\_Engage\\_Latinos\\_in\\_Advance\\_Care\\_Planning\\_A\\_Community-Based\\_Social\\_Work\\_Intervention](https://www.researchgate.net/publication/323940551_Exploring_Motivational_Interviewing_to_Engage_Latinos_in_Advance_Care_Planning_A_Community-Based_Social_Work_Intervention)

<sup>10</sup> Cruz-Oliver et al., *What Evidence is Available on End-of-life (EOL) Care and Latino Elders? A Literature Review* (Am J Hosp Palliat Care. 2014), 87-97. <https://pubmed.ncbi.nlm.nih.gov/23503564/>

<sup>11</sup> Crist et al., *Knowledge Gaps About End-of-Life Decision Making Among Mexican American Older Adults and Their Family Caregivers: An Integrative Review* (J Transcult Nurs. 2019), 380-393. <https://pubmed.ncbi.nlm.nih.gov/30465474/>

## Cultural Considerations for ACP with Older Hispanic Adults

Hispanic/Latinos are a very diverse group, and there are likely to be significant differences in beliefs that affect ACP among them. For this reason, it is important to be open-minded and ask open-ended questions when working with patients to be sure that we are learning about each patient's unique situation and not generalizing, which can have unintended negative effects. With that in mind, this section provides information from research on cultural barriers and facilitators to take into consideration when working with Hispanic/Latino older adults.

### Barriers to ACP for Hispanic Older Adults

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Hispanic populations experience various barriers to accessing and utilizing healthcare. When we consider the various steps that must be taken to engage in ACP and understand the barriers a patient may encounter, healthcare professionals can have more meaningful conversations with older Hispanic adults about their wishes and engage them in ACP. This section will discuss these barriers.

- **Medical Mistrust:** Among the Hispanic community there is a common mistrust in the US healthcare system and western medicine.<sup>18</sup> This stems from a combination of many factors which may include: cultural traditions and beliefs such as using natural or home remedies; impersonal interactions with healthcare providers; a history of unethical treatment of Hispanic patients<sup>19</sup>; and a lack of Hispanic representation among providers.<sup>20</sup> The US healthcare system is often overwhelmingly complex, and negative experiences or unsuccessful attempts to navigate it can lead to distrust, especially among immigrants.
- **Lack of Culturally Competent Care:** Healthcare providers often lack cultural and linguistic competency for working with older Hispanic adults. In a nationally representative survey, 49% of Hispanics aged 40 and over had difficulty communicating with healthcare providers because of a cultural or language barrier.<sup>21</sup> This same study found that Hispanics lack confidence that home health aides, assisted living communities, and nursing homes can accommodate their cultural needs.<sup>22</sup> One study found that Hispanic adults prefer to have end-of-life conversations at home with their family and the provider and for the provider to speak their language, understand their culture, and show empathy.<sup>23</sup> Another study found that it is important for healthcare



professionals to project hope for their patient when engaging in conversations about end-of-life decisions with Mexican-Americans.<sup>24</sup> Hispanic communities place value on warm and genuine interactions with providers. Suppose a provider takes the time to genuinely get to know their patient and ask about their family. In this case it can open the door for a more trusting relationship and better communication.

- **Lack of Linguistically Appropriate Materials:** Not only is there a lack of health professionals who speak Spanish, but there is a lack of materials and resources about ACP in Spanish (including documentation templates). Materials should also be culturally appropriate, not simply translated. For example, one study brings up a common issue illustrating the difficulty of simply providing services in Spanish: According to the Oxford Spanish Dictionary 2009, hospice translates to *hospicio*, meaning “orphanage or place for poor or homeless people.”<sup>25</sup> If a provider is encouraging an older adult to consider hospice care without this understanding, it can unintentionally discourage that individual or create a negative patient-provider relationship.
- **Health Literacy and Education:** in 2018, 57% of Hispanic Americans over 65 years old had finished high school.<sup>26</sup> Lower levels of education and health literacy among this group can make ACP difficult; many medical terms and documents can be confusing for older Hispanic adults. It is important to educate appropriately, provide materials that are easy to understand, and offer extra support when working with this population.
- **Income:** Hispanic older adults have the highest level of poverty in the US at 20%.<sup>27</sup> More than half (50.7%) would live below the federal poverty line if it were not for Social Security. Hispanics are the least prepared for retirement nationwide, and as this population ages, we will see this disparity continue to grow.<sup>27</sup>
- **Insurance Status and Eligibility:** Hispanic older adults are more likely to be uninsured than non-Hispanic whites; in 2014 older Hispanic adults were uninsured at rates of 4.2% versus 0.8% of non-Hispanic older adults.<sup>28</sup> These numbers differ among US-born and foreign-born Hispanics. According to the Pew Research Center, of Hispanics born in the US aged 65 or older only 2% did not have health insurance, versus 8% of Hispanics born outside of the US in 2014.<sup>29</sup> Additionally, understanding what health insurance options are available to individuals and navigating the systems necessary to enroll can be confusing and extremely challenging for older Hispanic adults.
- **Fear of Disclosing Immigration Status:** Immigrant older Hispanic adults who do not have a legal immigration status, or who have family members or caregivers in that situation, may not wish to interact with health and social services or apply for health insurance (or are ineligible for federal insurance programs) for fear of being deported or causing the deportation of a loved-one. There is also a fear of being determined a “public charge” which may prevent someone from obtaining a legal immigration status in the future.<sup>30</sup> It is important to develop a trusting relationship and show empathy and understanding around one’s reluctance to disclose personal information or engage with systems.

- **Reliance on Family for Caregiving:** As mentioned in the above section of this guide, it is often the expectation that Hispanic older adults be taken care of by family members and prefer to have an at-home death. Because they rely heavily on their family for all their needs, they are less likely to need to rely on other end-of-life services.<sup>31</sup> It is often not understood that there are options for Family Caregivers to receive payment for their services in many states. Caregivers can reach out to their local Area Agency on Aging for resources and guidance on this issue.<sup>32</sup>

## Other Cultural Considerations

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- **Religious and Spiritual Beliefs:** It is common to rely on religion and spirituality to cope with suffering and death among Hispanics.<sup>33</sup> Death can be seen as a natural part of life and something that should not be interfered with through medical interventions; therefore, prioritizing comfort may be a common preference while engaging in ACP.<sup>34</sup> When working with older Hispanic adults, it is important to understand their beliefs and how it may influence their end-of-life wishes and ACP decisions.
- **Familismo:** *Familismo* is a cultural value among Hispanic/Latinos that prioritizes family over individual interests. The importance of, and reliance on, family caregiving can be attributed to this cultural value. When engaging in ACP conversations with older Hispanic adults, it can be helpful to frame topics in a way that show the benefits to the family (including extended family). Often older Hispanic adults do not want to burden their family members; referencing how ACP will reduce this burden may assist in motivating older Hispanic adults to engage in these conversations. As discussed above, it is also important to include family members in these conversations and decisions. It can be recommended that healthcare professionals focus primarily on having conversations about ACP with older Hispanic adults, rather than try to obtain signatures, to allow for thoughtful conversations with family before making decisions.<sup>35</sup>
- **Acculturation:** Research is lacking on the topic of acculturation and ACP among older Hispanic adults. However, among immigrant populations, acculturation to American culture may influence their willingness to engage in ACP and the decisions they make when planning for end-of-life care. Among first-generation Hispanic immigrants it may be more difficult to engage in conversations around ACP, especially among those who immigrated later in life. This may be due to cultural differences related to end-of-life expectations and available care in the US and the patient's country of origin. Hispanics who immigrated as children or those who are second generation and beyond may be more open to discussions about ACP.

## Starting the Conversation about ACP

In this section, you will find some information about different techniques used by health professionals to have conversations with older Hispanic adults about ACP.

### Motivational Interviewing Techniques

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Motivational Interviewing (MI) is a guided style of communication designed to encourage patients to strengthen their own motivation for and commitment to behavior change. Utilizing some basic techniques of MI can assist professionals in engaging in ACP conversations with older Hispanic adults. In fact, research suggests that MI is a tool that can be used with older Hispanic adults who are hesitant to begin ACP.<sup>36</sup> Below are some helpful strategies of MI, using the acronym OARS:

**Open-Ended Questions:** Asking open-ended questions also encourages individuals to engage in conversation and to share more information, whereas yes/no questions may close the door to communication. Open-ended questions might start with “how... what...tell me about...” For example, instead of asking someone “do you have an advance directive?” you might consider asking “what do you know about advance directives?”

**Affirmations:** Affirmations are compliments or statements that praise positive behavior. While talking with older adults, it is important to listen carefully and acknowledge positive aspects of their lives and behaviors. This promotes self-efficacy and encourages individuals to engage in ACP. An example might be simply saying something like, “you are a good parent/partner” or “you do what is best for your loved ones.”

**Reflective Listening:** Reflective Listening is repeating what you believe someone has said to check and make sure you understand them accurately. This can be difficult but, with practice, can be a useful tool. If a patient says, “I don’t need an advance directive because my son will take care of me and he knows me, he would never let me die alone in a hospital.” You can reply with, “Your son will be your caretaker and knows your wishes, so you feel you don’t need to plan for your care.”

**Summarizing:** Finally, summarizing what has been discussed can help reinforce any important topics that were discussed. You can also ask the individual if you are

understanding correctly and give them the opportunity to correct you. For example, you might say “So you’re saying... is that right?”

## Tips and Strategies for Initiating Conversations

Advance Care Planning is important for many reasons and finding the reason that resonates most with the patient can help facilitate conversation. Below are some tips and sample prompts to consider when initiating end of life conversations with older Hispanic adults:

Tip	Description	Conversation Prompts
<b>Evaluate Readiness</b>	It can be helpful to gauge where the person is in the ACP process, keeping in mind their circumstances. Have they started thinking about end-of-life decisions? If not, why not?	Sample question:  <i>What thoughts have you had about the care you want if you become unable to take care of yourself or make decisions for yourself?</i>
<b>Roll with Resistance</b>	Some older adults may be more argumentative than others when initiating conversations about ACP. It is important to not engage in any arguments and stay neutral. It can be helpful to use the MI techniques above to engage in meaningful conversations.	For example, if a patient angrily states, “I don’t need any documents and you can’t make me sign anything!”  <i>It sounds like you have made up your mind about what you want. What have you shared with your loved ones regarding your wishes?</i>
<b>Identify Values and Goals</b>	Helping the person identify their values can help guide them in their decision making. With values in mind, the individual can identify their healthcare goals. What gives their life meaning? What hopes do they have for the remaining time of their life? This helps frame the	You may provide a list of values and ask the patient to identify a few that are important to them, then list them in order of importance.  Sample questions:

	discussion in a positive light by having them view “how they want to live out their days” vs “how they want to die.”	<p><i>What brings quality or value to your life?</i></p> <p><i>What ideas and hopes do you have for your life?</i></p>
<b>Promote Benefits of ACP</b>	Many older Hispanic adults do not know about or have not considered the benefits of ACP. Highlighting such benefits may help guide the conversation.	<p>For example, if the patient values family, you may consider asking questions about family then highlight the benefits of ACP for their loved ones:</p> <p>Sample questions:</p> <p><i>What can you do to help reduce conflict among family members who disagree about how to make healthcare decisions for you if you are unable to?</i></p>
<b>Take Ownership of Care</b>	Framing the discussion as an opportunity to take ownership of what happens to them when they are unable to make decisions for themselves.	<p>Sample question:</p> <p><i>How confident are you that someone else can make the same decision you would make for your care?</i></p>
<b>Recognize Spiritual and Religious Influence</b>	Religion and spirituality play a large role for many Hispanic older adults in the care options they choose to have (or not to have).	<p>Sample questions:</p> <p><i>What spiritual beliefs do you have that may influence the healthcare you wish to receive if you become incapacitated?</i></p> <p><i>Do your religious beliefs prevent you from receiving _____ life-sustaining-treatment? (list treatment)</i></p>

<p><b>Use Examples</b></p>	<p>It may help to provide examples from the news, personal experience, and/or success stories/testimonials when discussing ACP. This may be especially helpful with discussing Palliative Care options and hospice care.</p>	<p>If someone is hesitant to consider hospice care after learning about what it is and how it can be helpful, providing an example can help:</p> <p><i>When my uncle was diagnosed with stage IV prostate cancer, he received hospice care. He stayed home and was taken care of by his family until his death. He was also visited by a nurse regularly to make sure he was not suffering or in severe pain. What care would you hope for in that situation?</i></p>
<p><b>Talking about Specifics</b></p>	<p>Talking through specific scenarios and decisions with patients can encourage them to share this information with loved ones. These conversations can be difficult, so it is important to be empathetic and express hope for the individual when working through specifics.</p>	<p>Sample questions:</p> <p><i>What would you want if you were permanently unconscious?</i></p> <p><i>What if you had a terminal illness and treatment failed you?</i></p> <p><i>What if you had a severe stroke and had not responded to treatment?</i></p>

## Addressing Common Questions and Concerns

When having ACP conversations, there will undoubtedly be questions that come up from patients. Below are some common questions and possible responses:

**1. Q: What if I change my mind?**

**A:** You can cancel or change/update your advance directive or healthcare proxy at any time. To do this you will want to destroy all old copies and share new ones with your loved ones and providers. In fact, changing your documents is an important part of the ACP process. You might consider updating or changing your documents if: you get a new medical diagnosis that will

change your life significantly, you experience a change in marital status, or about every ten years as your thoughts and wishes might change.<sup>37</sup>

**2. Q: What if my family disagrees?**

**A:** Disagreements can happen and are common between family members when talking about the eventual death of a person they love. Having conversations about your values and goals for the end of your life with your family can help everyone understand your wishes. Open conversations help everyone understand where disagreements and emotional responses are coming from. Factors like grief, denial, anger, guilt, and acceptance can all play a role in how loved ones talk about difficult medical decisions. It may help to have someone, like a social worker, help facilitate these conversations with your family.<sup>38</sup>

**3. Q: What if I do not have anyone to list as my proxy?**

**A:** A proxy does not have to be a family member. You may also consider a friend or someone you know from other parts of your life such as your church or community center. If you cannot identify anyone you would like to be your proxy, it is still helpful to write down your wishes for healthcare in case of the event that you are unable to make decisions for yourself. This can give you peace of mind that your healthcare providers know what your wishes are.

**4. Q: What is Palliative Care?**

**A:** Palliative Care is a kind of specialized medical care that provides relief from pain and other symptoms of serious illness. The goal is to make the patient more comfortable and improve the quality of life for them and their loved ones. Palliative Care can be given to someone with any diagnosis at any point in their life and can be offered to them together with other treatments.<sup>39</sup>

**5. Q: What is Hospice Care?**

**A:** Hospice Care is a kind of specialized medical care that focuses on the quality of life of a patient who has an advanced, terminal illness. Hospice Care involves managing a person's symptoms, rather than the disease. Hospice Care allows for someone to live out their days with quality and dignity wherever they choose to be with their loved ones. Hospice also provides support for caregivers and family members and includes them in decisions. Palliative care is often a part of Hospice Care but can also be provided separately from Hospice.<sup>40</sup> Hospice Care is covered by Medicare. For more information about insurance coverage talk with your doctor and visit: <https://www.medicare.gov/coverage/hospice-care>.



## Additional Resources

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### Patient Resources

English	Spanish
<p>✓ <b>The Conversation Project: Being Prepared in the Time of COVID-19</b> <a href="https://theconversationproject.org/wp-content/uploads/2020/04/tcpcovid19guide.pdf">https://theconversationproject.org/wp-content/uploads/2020/04/tcpcovid19guide.pdf</a></p>	<p>✓ <b>The Conversation Project: Estar preparado durante el brote de COVID-19</b> <a href="https://theconversationproject.org/wp-content/uploads/2020/04/tcpcovid19guide-Spanish.pdf">https://theconversationproject.org/wp-content/uploads/2020/04/tcpcovid19guide-Spanish.pdf</a></p>
<p>✓ <b>The Institute for Healthcare Improvement: Your Conversation Starter Kit</b> <a href="https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConvoStarterKit-English.pdf">https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConvoStarterKit-English.pdf</a></p>	<p>✓ <b>The Institute for Healthcare Improvement: Su Kit Para Iniciar La Conversación</b> <a href="https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConvoStarterKit-Spanish.pdf">https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConvoStarterKit-Spanish.pdf</a></p>
<p>✓ <b>Finding Your Way</b> <a href="https://coalitionccc.org/wp-content/uploads/2014/02/Finding-Your-Way-English.pdf">https://coalitionccc.org/wp-content/uploads/2014/02/Finding-Your-Way-English.pdf</a></p>	<p>✓ <b>Como Encontrar Su Camino</b> <a href="https://coalitionccc.org/wp-content/uploads/2014/01/Finding-Your-Way-Spanish.pdf">https://coalitionccc.org/wp-content/uploads/2014/01/Finding-Your-Way-Spanish.pdf</a></p>
<p>✓ <b>Caring Conversations: Making Your Healthcare Wishes Known</b> <a href="https://practicalbioethics.org/resources/caring-conversations.html">https://practicalbioethics.org/resources/caring-conversations.html</a></p>	<p>✓ <b>Caring Conversations: Haga Saber Sus Deseos Sobre Cuidado Medico</b> <a href="https://practicalbioethics.org/files/caring-conversations/caring-conversations-2019-spanish-complete.pdf">https://practicalbioethics.org/files/caring-conversations/caring-conversations-2019-spanish-complete.pdf</a></p>

## Provider Resources

- ✓ CDC training on ACP: [https://www.cdc.gov/aging/advancecareplanning/care-planning-course.html?CDC\\_AA\\_refVal=https%3A%2F%2Fwww.cdc.gov%2Faging%2Fadvancecareplanning%2Fcare-planning-course.htm](https://www.cdc.gov/aging/advancecareplanning/care-planning-course.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Faging%2Fadvancecareplanning%2Fcare-planning-course.htm)
- ✓ Motivational Interviewing: <https://motivationalinterviewing.org/understanding-motivational-interviewing>
- ✓ A Resource for CHWs on ACP Best Practices: <https://chwsolutions.com/wp-content/uploads/2018/08/aaaCHW-Best-Practices-ACP-Jul-21-2018.pdf>

### Helpful Websites:

- ✓ Center to Advance Palliative Care (CAPC): <https://www.capc.org/>
- ✓ National Hospice and Palliative Care Organization (NHPCO): <https://www.nhpco.org/>
- ✓ National Institute on Aging – Advance Care Planning: <https://www.nia.nih.gov/health/caregiving/advance-care-planning>
- ✓ Coalition for Compassionate Care of California Resources: <https://coalitionccc.org/%20%20%20>

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