

Advance Care Planning Study

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ABSTRACT

This report sets out to research and analyze the potential for a community-based initiative to increase the number of Taos County residents who complete an advance directive.

Literature has shown that persons with advance directives are more likely to have fewer intensive medical interventions at end-of-life and enter hospice earlier resulting in a higher quality of life at end-of-life, family members report less stress and anxiety and there are decreases in cost of end-of-life care.

Literature also has found that a facilitated process called Advance Care Planning is the most effective means for increasing the number of persons with advance directives. There are a number of good guides and organizations that train persons to facilitate conversations with individuals and groups. The most notable is Respecting Choices®. It provides training to both change the health care systems' approach to ACP and facilitation training for laypersons to guide conversations with their neighbors and friends. Their program is based in a three-tiered system related to age and health status. This program is evidence-based and is being used as the direct service and systems changes component of the Honoring Choices® framework for larger state run initiatives.

Taos County is in a good position to successfully implement an initiative. While the community's readiness level is low, many of the essential components for infrastructure are present: health council, active community members involved in end-of-life issues, recognition amongst health care professionals and others that there is a need for this type of work, and active collaboration with the primary health care system.

Introduction

At the end of your life if you can no longer speak for yourself, what sort of care and treatment will you want?

For most Americans what they want and what happens to them at the end of life are completely different. When asked, a majority says they want to end their lives at home with family, but the truth is most Americans will die in hospitals or nursing homes and will often receive life-extending treatment that has been shown to increase trauma and decrease quality of life. Many will likely be attached to machines, receiving intensive medical intervention and dying amongst strangers (medical providers) rather than with family members.

And yet, this is preventable. The cure is simple but can feel impossible. The cure is a willingness to talk about a very hard subject – end of life. For most, end-of-life is abstract, yet it is inevitable and unpredictable. And while, most people have thought about this, they have not had the deep discussion that leads to clarity about what a person values and wishes for at the end-of-life. And, if a person has taken the time to think deeply, they rarely write it all down. Most Americans do not have Advance Directives.

In his book The Conversation Dr. Angelo Volandes suggests that all of us should discuss what we want at the end of our lives with our families, close friends and our doctors and we might begin by asking ourselves these questions:

- What kinds of things are important to you in your life?
- If you were not able to do the activities you enjoy, are there any medical treatments that would be too much?
- What fears do you have about getting sick or medical care?
- Do you have any spiritual, religious, philosophical or cultural beliefs that guide you when you make medical decisions?
- If you had to choose between living longer or having a higher quality of life, which would you pick?
- How important is it for you to be at home when you die?

These are not easy questions to answer and the asking is even harder.

But what researchers are finding is that those people who consider these questions, write down their wishes and choose an appropriate person to make decisions for them are less likely to receive intensive intervention at the end of life and also have a higher quality of life at the end of their lives. Their families show a marked decrease in stress and anxiety and even travel through the grief process more quickly. So what can be done to encourage people to have this crucial conversation and make their wishes known? How do we increase the number of people who complete an advance directive?

A Review of the Literature

Consistently, research shows that a majority of people when asked how they want to spend the end of their lives they respond that they want to be at home with their families. While nearly 80% of all Americans believe they want to spend their last days at home, less than a quarter die at home (Morhaim & Pollack, 2013). The majority die in hospitals or nursing homes.

Why is this so?

Across the country and abroad, communities, health care systems, health councils and palliative care advocates are asking this very same question. And it is an important question because research shows that patients who had aggressive medical intervention at the end of life had lower quality of life than those who received palliative or hospice care. A recent study in the New England Journal of Medicine found that for a group of lung cancer patients those who received the earlier introduction of palliative care experienced a longer and higher quality of life than those who received aggressive treatment (Temel, 2010).

1976 - California Natural Death Act of 1976:

1990 - US Congress enacts the Federal Patient Self Determination Act

1999 – IOM Report finds that few people have advance directives and often they are not being adhered to.

2009 – Affordable Care Act includes provisions to reimburse physicians for discussing end of life and advance care planning with patients. This is labeled as “Death Panels” by politicians and it is removed from the bill.

2015 – Centers for Medicare & Medicaid announce changes to fee schedule providing codes for physicians’ reimbursement for discussing advance care planning.

So, what can be done?

Some historical context

Nearly 40 years ago, as part of the consumer rights movement of the 1970s, the California Natural Death Act of 1976 was passed. The law was intended to give people the right to choose the medical care they wanted by writing binding “advance directives” for medical treatment. Consumers’ could take control over their care even when they could not speak for themselves. In 1990 the US Congress enacted the Federal Patient Self Determination Act. This act requires all health care facilities receiving Medicare reimbursement “... ask patients whether they have advance directives, to provide information about advance directives, and to incorporate advance directives into the medical record” (Issues & Medicine, 2015).

In 2009, the Affordable Care Act was being considered in Congress. The Act included provisions for Medicare to pay physicians to have conversations about end-of-life and encourage advance care planning. Politicians rallying against the Act took this small part of the Act and claimed this was akin to “Death Panels.” They said that this provision would allow medical establishments to deny end of life care to people. This hadn’t then and still has never been substantiated in research. In fact, the opposite is true.

Recently in the news, the Centers for Medicare and Medicaid Services released the new physician fee schedule that provides codes for physicians to be reimbursed for time spent discussing advance care planning with their patients (Belluck, 2015). This will be given time for feedback and could be implemented as of January 1, 2016.

(Detering, 2010)

So, why are we doing this?

Advance Care Planning, Advance Directives and Health Care Agents

Interestingly, to this day, there is not strong data on the actual number of people who have advance directives. There is no uniform tracking system for advance directives. While information is collected through hospitals, people must provide directives to hospitals. A person may have a directive but it isn't stored in a hospital's medical records or may be stored in their medical record at their physician's office but is inaccessible to a hospital. A study in Maryland found that while more than 60% of people surveyed wanted their end of life wishes honored only about a third of them had completed the forms (Morhaim & Pollack, 2013).

The Institute of Medicine's report *Dying In America: Improving Quality and Honoring Preference Near the End of Life* discusses results from a 2012 survey that found that 42% of those surveyed had participated in a discussion about end-of-life but only 23% had actually written down their wishes. This group demographically was generally over 65, white, highly educated, had higher income levels and was diagnosed with one or more chronic health condition. The respondents predominantly wanted to speak with their doctor about these issues but more than 90% said their doctors had never asked them about their wishes (Issues & Medicine, 2015). Remarkably, studies show that "end -of-life discussions are associated with less aggressive medical care near death and earlier hospice referrals." Meanwhile, "less aggressive care and earlier hospice referrals were associated with better patient quality of life near death." (Wright, et al., 2008) We must identify our priority.

Although the Federal Ruling of 1990 requires medical facilities to ask people about advance directives, inform them about them and store them in their medical records, a 2008 review from Health and Human Services found that hospitals and intensive care settings are the least likely places for advance care planning to take place. From the physical, mental and cognitive state of a patient in crisis to the medical culture to do all that is possible to extend life, most agree that advance care planning should begin before a crisis is at hand (Issues & Medicine, 2015). As reported by the Institute of Medicine (IOM) 40% of medical inpatients are not able to make their own treatment decisions. Nursing home residents are much more likely to have advance directives in place as 44-69% cannot make their own decisions (Issues & Medicine, 2015).

The Maryland study also found that while most people had thought about end-of-life issues, nearly 25% of those without directives didn't know about them (Morhaim & Pollack, 2013). Many believed they were too young and healthy to need one, were concerned about the

cost of completing one and thought it might be very time consuming (Morhaim & Pollack, 2013). The study also found difference based on race and ethnicity with more whites than blacks having directives. They hypothesized that this was rooted in differing cultural mores related to family decision-making, distrust of the health care system or poor communication between physicians and patients. (Morhaim & Pollack, 2013)

Fifteen years ago a 1997 report by the IOM concluded that the low rate of people completing advance directives and the rate at which they were being followed was caused by:

- Patients' and families' lack of awareness of or interest in completing forms;
 - Clinicians' unwillingness to adhere to patients' wishes;
 - Difficulties in having meaningful family conversations about patients' wishes and in making choices in the face of prognostic uncertainty;
 - Lack of institutional support and processes for completing advance directives; and
 - Cultural and legal factors, including resistance within the medical community
- (Marilyn J. Field and Christine K. Cassel & Life, 1997)

Simply giving people the paperwork for completing an advance directive was not working. Major changes needed to be made in how to discuss end of life, how to guide people in considering and writing down their wishes, how to encourage people to discuss their wishes with their family, friends and physicians and how within the system to store and track peoples' directives (Marilyn J. Field and Christine K. Cassel & Life, 1997).

Since the 1997 report a new concept has gained a foothold in the conversation about end-of life wishes. In this report they recognized the potential for a process that would guide people over a the course of a life time in making their wishes known and allowed for changes to be made as lives and health change. Advance Directives and Durable Power of Attorney would naturally result from this process. (Marilyn J. Field and Christine K. Cassel & Life, 1997) This process is Advance Care Planning (ACP.)

Seen as more effective than just completing an advance directive and durable power of attorney, the process encourages deep discussion about quality of life factors, honesty about disease progression and the levels of intervention that are available to the patient. Most importantly, this process can and should begin early, before a medical crisis or diagnosis. An ACP process includes four steps (Pearlman, 2014)

1. Thinking through one's relevant values and preferences
2. Talking about one's values and preferences with one's spokesperson, close family members and health care providers,
3. Documenting them with an advance directive, and
4. Reviewing them periodically and updating them as needed.

The goals of the process are to (Pearlman, 2014):

- Maximize the likelihood that medical care serves the patients' goals
- Minimize the likelihood of over- or under-treatment

- Reduce the likelihood of conflicts between a patient's spokesperson, family members and health care providers.
- Minimize the burden of decision making on the spokesperson and/or family members.

According to the IOM, there are still many challenges to an ACP process (Issues & Medicine, 2015):

- The natural reluctance of patients, families, and clinicians to explore death and dying;
- A fragmented health care system that can make the discussion of end-of-life preferences “someone else’s problem”;
- Poor-quality communication in the conversations that are held, often in hurried or crisis situations; and
- Inadequate structural supports for advance care planning, including clinician training, payment, and record keeping.

Advance Care Planning – What is it?

Advanced Care Planning begins with a simple question: how do I want to spend the last few months of my life? This is important. ACP is about living not about dying.

But understanding end-of-life and the many ways in which modern medicine has been able to prolong life is key to making decisions about the future. Advanced Care Planning is the process by which a person considers their options for end of life care, in particular, planning for the time when they may be unable to communicate their wants and needs.

Advanced Care Planning is a process that can be revisited and should be revisited regularly. Most ACP occurs when people become elderly, sick or both but ACP should begin as soon a person becomes an adult. Most of the impetus for discussing ACP has come from media stories about young people who have suffered catastrophic injuries and modern medicine has kept their bodies alive but they are not really living. These right to die cases have pointed out that not only the elderly or the infirmed need to consider what type of care one would want if one cannot speak for him or herself.

Many believe that discussing end of life may lead to hopelessness and a shortening of the will to live. Studies, though, have found the opposite to be true; planning decreases a person's and their families' stress and increases the quality of end of life (Wright, et al., 2008).

Advance directives are an outcome of the ACP process. An advance care directive is made up of two forms: a living will and a durable power of attorney for health care. Essentially, the durable power of attorney is the document where an individual appoints a person, called a health care agent (or representative or proxy) to make decisions for their health care in the event that they are unable to do this for themselves. The health care agent is usually a

spouse or family member or close friend. The living will documents a person's instructions to his/her health care agent and family of their wishes at end-of-life.

Advance Care Planning information and forms are available from physician's offices, hospitals, on-line, through attorneys, and in books. ACP is more effective than Living Wills alone. First, ACP is not a one-time activity, but rather encourages on-going discussion with family, friends and medical providers over the course of one's life. ACP emphasizes considering quality of life, what one values and brings meaning to life and how to best make this happen at end-of-life. Built into ACP is the understanding that directives will change and evolve as end of life nears. ACP is a process that can and must be adapted to meet the cultural, ethnic and spiritual needs of a diverse population. And, importantly, ACP is a process that is on-going and the decisions and documents that result will evolve and change over time. (Issues & Medicine, 2015)

So, knowing what works, where from here?

National and Statewide Initiatives

While research clearly points to the benefits of advance care planning, most people have not begun the process. ACP does not need to be done in a doctor's office or a lawyer's office. There are many websites from national organizations that have created toolkits, web based lessons and videos on how to discuss end of life wishes with family members and how to complete an advanced directive.

The National Hospice and Palliative Care Organization (NHPCO), a membership organization representing hospice and palliative care professionals, has been in the forefront in providing access to information and guidance in advance care planning. They created the *Caring Connections Conversation Guides* that include state-by-state specific information and forms. They also provide communities with information about building coalitions, outreach to stakeholders and community education. NHPCO is also an important source for information about state and federal policy; they create media campaigns and organize national events.

"It's about how you **LIVE**"
Learn about options for end of life services and care.
Implement plans to ensure wishes are honored.
Voice decisions to family, friends and health care providers.
Engage in personal or community efforts to improve end-of-life care.
--NHPCO

Journalist Ellen Goodman has created a web site, videos and toolkit called the *Conversation Project* to help individuals discuss their end of life wishes and complete advance directives. The website is self directed, well designed with clear instructions and the stories that are told are compelling and real. The *Conversation Project* is a collaboration with the Institute for Health Improvement (IHI) and is funded by several national foundations and health care organizations. The *Conversation Project* initiated a national event - *Death Over Dinner* - that encouraged families and friends to gather at a home, cook comfort food (national chefs created menus that could be copied) and discuss end of life.

The National POLST Paradigm works in each state to implement POLST (Physician Orders for Life Sustaining Treatment) programs in health care systems. POLST (or MOLST or MOST) is an end step in an ACP process. POLST are a type of advance directive specifically for those people with life limiting conditions. In many ways, POLST/MOLST is a more comprehensive version of the Do Not Resuscitate forms. POLST forms clearly state a person's desires for specific life sustaining treatments in three areas: Emergency response, that is resuscitation/CPR; medical interventions - from comfort measures (pain control) to everything possible to prevent death (ventilation, intensive care unit); and artificial hydration and nutrition (feeding tubes). These forms are meant specifically to give guidance to Emergency Medical Services providers (paramedics, emergency room doctors and nurses) if a person is brought to a facility at the end.

In New Mexico, NM MOST is leading the charge to engage health care systems and physicians in completing these forms with their terminal patients. The language is clear and the form is aligned with New Mexico's statutes. While simplified for the layperson, it is clearly a medical order and contains no language regarding personal values. According to Lorrie Griego, project leader, successful implementation of the MOST document is best through a whole system, scaffold approach: discussion of MOST begins with the person guiding a patient to the room and ends with the physician.

POLST/MOLST are clear, concise one page formats that are easily readable and accessible within a patient's medical record. POLST forms come from the health care system and are a systems response to finding ways to better understand what a patient wants at end of life. These forms require a physician's signature so are completed in a physician's office. These forms signify that end of life is near, that physicians have had this frank conversation with a patient and have taken the time to complete the forms. Most importantly, the forms must be accessible at the time of a health crisis.

At a more grass roots level, *Death Café*, a “social franchise” is an effort to provide opportunities for people to come together and discuss death. Begun in Switzerland, *Death Cafés* are being held

all over the world. The organizers are asked to follow a basic set of guidelines and provide cake and tea for participants. These are not grief groups nor are meant to lead to a specified conclusion or action. *Death Café* is meant as an open forum to discuss anything and everything related to death, to help improve understanding and acceptance of what is inevitable and looking for ways to make improvements in the systems around end-of-life.

The largest event so far is *National Health Care Decisions Day*. On or near April 16, is a day devoted to providing information and encouraging people to complete advance directives. All over the country health care organizations and community groups join with the national organization to create their own community appropriate formats that promote ACP and provide uniform tools to individuals. In New Mexico Christus St. Vincent and Presbyterian Health Care have been active participants in the NHDD Day.

While each of these organizations, web sites and grassroots events has their own flavor, they also share many commonalities. Each strongly encourages:

1. Discussing your wishes with family members, friends and your physician.
2. Choosing a health care representative (agent, proxy).
3. Completing forms as appropriate for the state you live in and any state you spend a lot of time in.
4. Reviewing advance directives every so often to be sure it truly reflects your beliefs and wishes.

State and County Initiatives

Across the country state medical societies and large health care systems recognize the need for increasing the use of advanced directives. Organizations in California, Oregon, New York and Minnesota have been at the forefront moving from direct service to state policy initiatives and have inspired other states to replicate their work. State level work is often focused on the larger policy issues but many began as community education initiatives within health care systems.

In the lead is Honoring Choices Minnesota. Begun as an initiative of the Twin Cities Medical Society, for the past seven years its coalition of health care systems and providers, insurance providers, faith leaders, public television and community activists have implemented training in systems, facilitated discussion groups in communities, created incredible videos and online guides and resources. They have adopted the Respecting Choices® program (more later in the report) and currently are working on policy to have common forms in statute.

Advice from Honoring Choices Minnesota

“Build your coalition, no one group can do this on their own. Involve everyone.”

Wisconsin, Washington State, Virginia, and Florida are all using the Honoring Choices model of multi-level engagement to increase the number of people with advance directives. This combination of an evidence based direct service training program for systems and individuals along side a focused media presence and policy agenda is proving successful.

There are many smaller communities who have undertaken initiatives to promote Advance care planning. Sonoma and Napa Counties in California have both been working on increasing advance directives for a number of years. Initiatives in both counties began through individuals initiating a project that was integrated into their respective health councils. Both counties provided educational workshops for community members and media campaigns.

These counties received funding support from the California Healthcare Foundation (CHF) to integrate POLST into the work they were already doing. In its report, *Advance Care Planning Takes Root: Best Practices from Four California Communities*, the foundation highlights these common practices within its successful coalitions:

- Identifying strategic leaders and existing champions;

- Creating an independent organizations
- Outreach to both providers and consumers
- Working with Faith Leaders
- Conducting multi-lingual and multi-cultural outreach (Rebkin, 2014)

Both Counties are now working with Minnesota's Honoring Choices model that includes using the Respecting Choices® community and medical system training program.

All initiatives appear to have common elements that lead them to adopting the Honoring Choices Model:

1. They began first by establishing a coalition as described above and are lead by health system, medical society or community health council'
2. They engage initially at the health care systems level, providing training to medical personnel, aligning documentation and developing systems for storing and accessing documents;
3. They create or adopt a community education program or strategy and train medical professionals, social workers and laypersons on how to facilitate discussion about advance care planning and guide people in completing documents.

At this time, there is little reason to recreate the wheel as many health care systems and national palliative care organizations have designed programs for facilitating discussion on advance directives. Those reviewed above from national organizations make it easy for an individual to access information on his/her own. But, communities and states have had more success with direct service to community members and have developed facilitator training programs that can be replicated in other communities. Conversations on Compassionate Care originated in Rochester, New York, has been used throughout the state with great success. CCCC is a one hour facilitated discussion that provides education on advance care planning teaches how to choose a health care agent and increases people's comfort in discussing death and dying. CCCC uses trained facilitators who may or may not be health care providers and each trainer provides the materials appropriate for the state in which one lives to complete an advance directive and health care proxy.

Most notably is Respecting Choices® Program from the Gunderson Health Systems of LaCrosse, WI. Respecting Choices is a four-part program that has successfully increased the number of people with advanced directives in their community to over 94% (Detering, 2010). It involves:

1. Community Engagement
2. Advance Care Planning facilitation skill development
3. Systems to honor people's choices
4. Continuous Quality Improvement

The Respecting Choices® program is designed to guide persons in a three staged approach to advance care planning. The first stage is for anyone 18 years and older with or without a

chronic disease. This stage is for preparing for the inconceivable, an unexpected life ending event. The goal of this stage is to begin the conversation and education about end-of-care, appoint a health care agent and complete a basic advance directive. The second stage is for people who have a worsening chronic condition. The goal for this stage is to provide accurate information about disease progress, and review and update advance care planning documents in the case of a bad outcome directly related to the chronic condition. The Last Steps stage is for those for whom end-of-life is near, within the next 12 months. At this stage, the POLST form is completed alongside a physician and is given to those who need them: health care agent, EMS system, Hospital System and physician.

According to Britt Welnetz, Business Development Consultant for Respecting Choices®, the first step in replicating the Respecting Choices® program is to develop a coalition and fully engage the health care system. Next, key persons from the coalition and others who may want to become facilitators would attend a 3-day “Respecting Choices® Organization and Community Advance Care Planning course.” In this training participants learn to engage community, develop systems and become certified facilitators of the Respecting Choices® Course. Respecting Choices® also holds an annual conference for all its replication sites. Respecting Choices® is the one model that is evidence-based and has outcomes that include increase in quality of life metrics for persons at end of life, decrease in stress, anxiety and depression amongst family members and reduces cost to the health care system.

Through efforts from the Palliative care department, Christus St Vincent Hospital recently approved the use of the NM MOST form within their facility. They worked with Lorrie Griego of NM MOST and received the train the trainers training in how to use the NM MOST. They went on to train many people in the hospital, in local nursing facilities and in local practices in using NM Most. While they still use the 5 Wishes form, the NM MOST simple and concise format works well within their environment.

Now Christus St Vincent has a committee working on promoting advance directives. The committee is made up of palliative care staff, nurses, members of the ethics committee, an ex board member, faith provider and a person with strong connections to the state legislature. The committee reports to the hospital ethics committee.

This year Christus St Vincent joined the National Health Care Decisions Day and held an event where they provided information and support to individuals interested in advance directives.

Taos County

So, is Taos ready to undertake such a project?

First, one must ask if this sort of initiative is needed? Demographically speaking, Taos is aging. The US Census' American Household Survey of 2013 tells us that there are 7432 persons over the age of 62 and 6125 persons over the age of 65. The median age in Taos County is 45.8, up from 44.1 years in 2010. Life expectancy is 87 (NMDOH 2011-13).

According to the Dartmouth Health Atlas, for those who have died in Taos:

- Fewer have gone into Hospice than the national average (44% vs 51%)
- More people are dying in the hospital than national average (34% vs 23%)
- Approximately 15% of people end their lives in the intensive care unit (lower than national average of 17%)
And those who die in hospital, spend on average a little over a day (1.19, lower than national average of 1.71 days) in the hospital before dying.

While the numbers do not paint a terrible picture, there is great room for improvement. And, as our populations' median age rises, end-of-life issues become more relevant to a greater number of people.

Quick facts about morbidity and mortality in Taos County

- Alcohol related chronic disease death rate 52/100K (NMDOH 2009 -13)
- Heart disease death rate 129/100K (NMDOH 2011-13)
- Stroke death rate - 26 NMDOH 2011-13)
- Diabetes death – 20/100K (NMDOH 2011-13)

More than 20 persons were interviewed about their experiences and ideas about advance care planning in Taos. The interviewees were medical professionals, front line caseworkers, attorneys, financial planners, and community activists. They were asked a variety of questions about what they know about advance care planning, their experiences with it, what they thought could be improved in the process and how best to increase the number of people in the community who have advance directives. Every person believed that a community wide initiative would be very beneficial in Taos County and all said they would take part in any way they could in promoting advance care planning.

So, how does it work in Taos? Who has Advance Directives?

Key informants in Taos believed that those who had advance directives had most likely completed them as part of a greater estate planning process. In fact, all local lawyers interviewed for this report believed it would be unethical for them to not include completing Advance Directives and Durable Power of Attorney for Health Care documents as part of their estate planning process. Completing these forms does not mean that their clients have participated in advance care planning, though some attorneys report having deeper conversations, all believed that medical providers are important to having a full understanding of the options.

And, attorneys were not the only ones who believed that the medical providers were essential to the process. All frontline providers, and social workers concurred, though with a caveat that primary care physicians do not have the time available to them for these conversations. Key informants concurred with much that was found in the research presented earlier in this report.

- Medical providers uniformly believe that the conversation needs to begin in the primary care setting, but this also requires at least one if not more lengthy conversation. The primary care doctors often do not have the time with patients.
- Providers say that many patients do not understand what an advance directive would or would not do or that it can be changed.
- Many believe that during a crisis is NOT the right time for the conversation. The patient and family are too caught up in the moment and too scared to be able to take in the information. The form often is left behind.

Because many informants (attorneys, planners and case workers) believe that advance directives are most often completed with lawyers they thought that one reason so few people have directives is that they do not believe they need estate planning services. And, some informants admitted that they do not have directives because they, too, believe it is part of a larger estate planning process and they have not undertaken it yet.

The Five Wishes
From Aging with Dignity.org

“Living Will with Heart and Soul”

Available in paper and online in multiple languages it helps people:

- Choose a health care agent
- Determine medical treatment
- Determine level of comfort treatment
- Determine level of contact with other people
- Determine what you want people to know

Key informants thought that the number of different options is confusing. In Taos, each major health care provider uses a form that meets their needs. While most offer *The Five Wishes* there were mixed feelings about the efficacy of this form. Attorneys and caseworkers agreed that people need guidance to complete *The Five Wishes*. The questions, while appearing simple and straightforward, require contemplation, discussion. While forms are widely available, guidance and education are not

All recognize that the level of conversation required to really delve into an advance care planning process is beyond what can be done in a primary care visit. But the majority did not believe

that this must happen in an attorney’s office. While many acknowledged that depending upon a persons situation a directive drawn up by an attorney and signed would be beneficial, it is not required in New Mexico and most thought having guidance from a knowledgeable person with direct experience with the process might be the best option. All believed that the primary care physician was essential for initiating the conversation and giving accurate information about disease progress and end-of-life treatment options. But working with a person who has the time to listen and help write down people’s wishes is important.

As a system, Taos health care providers are not aligned. As mentioned previously, while all have had experience using *The Five Wishes* form, most were not satisfied with the results. One informant commented that when it comes down to it, medical personnel need a single page that in a crisis they can access easily and read in a matter of seconds. Of the front line

and medical providers interviewed some had knowledge of the POLST form, but none had heard of the NM MOST project.

Attorneys were the only ones who reported receiving annual, formal training on advance directives. This they receive through annual conferences. Medical and front line caseworkers report receiving no formal training. All either use forms and processes directed to them or have completed a great deal of research on their own. Several pointed to the work done by the National Hospice and Palliative Care Organization as being very helpful.

Most health care organizations have a process they follow to try to collect a directive, though it is different for each institution. The one constant was that advance directives are mentioned at intake. At Holy Cross Hospital, all people are asked at registration if they have an advance directive. This is a requirement by Medicare for reimbursement. If they do not, then they are asked if they would like information and are given information. There continues to be apprehension about pushing this conversation much further as staff doesn't want patients to mistakenly think that the hospital is in some way trying to limit care, a direct result of the "death panels" political gaming.

In-patients are asked three times about advance directives: the admitting nurse asks patients again when they come onto the floor. If they do not have a directive, then they are asked if they would like more information. If they do want information, then a case manager is brought in to provide information and answer questions. Caseworkers do not complete forms with patients. Many providers report ethical questions about completing forms with patients, especially at a time of crisis. Unequivocally, these people believe a time of crisis is not the right time.

Hospice and the nursing facility are able to spend more time with people on this. They did agree that the best conversation occurs after the crisis is over and often give patients/client some time before the conversation. Again, they provide information as asked and allow time for people to think and ask questions.

Uniformly, attorneys and case workers agree: choose a person and ask them to be your agent, complete a Durable Power of Attorney for Health Care and then discuss with your representative what you will want at the end-of-life. While New Mexico has a statute in place for advance directives, the requirements are broad. But, for those without any directives the law is clear: without a Health Care Agent and Advance Directive the decision-maker is first the spouse. If there is no spouse, than an adult child will be the decision maker. Last, without spouse or child, living parents will make the decisions. If there is no one to make decisions than a patient is termed "full code" or every possible life extending measure is taken. So, while there is a process in place, without a directive those who become the decision makers are left without guidance from the patient.

So how can this be improved?

Most informants were certain that improvements are needed and that a community approach would be best. They were not certain about how to go about it. Most mentioned information at health fairs, writing newspaper articles, developing PSAs for radio and providing seminars and workshops. Some thought panel discussions at senior centers or community centers would be beneficial. While many thought these conversations could be lead by knowledgeable people who were not necessarily within the health care or law field, few could identify anyone whom they would want to enlisted to facilitate conversations. Two persons mentioned human resource directors, after all “they talk about life insurance, which is really death insurance.”

And, no one mentioned any ideas about possible system changes. This was interesting since most reported having received no training. One informant relayed that her own experience in a prior job at a very large health care system, all staff was required to complete advance directives. This had given her direct experience in the process, and she believes helps her empathize with her clients. She is able to say to them that she has a directive, has had one for ten years, and reviews and changes it regularly. She has been through it.

The one system level challenge that was acknowledged by several persons was that New Mexico doesn't have a document bank for advance directives. This is very important for Taos area people since people often end up in different hospitals and health care systems within the state. In order for advance directives to be followed, each system needs a copy of the directive, which means that individuals must make this happen on their own.

So, it isn't enough to complete the forms, people must give them to their families, health care agent, doctor and local hospital. Providers also encourage that people carry a card in their wallet to let EMS workers and emergency department providers know that they have a directive, especially since there is no unified state nor national system.

Analysis and Recommendations

The timing for an advance care planning initiative in Taos County appears to be good. Aside from the recent changes in billing codes for Medicare, there is also greater media attention to the challenges at end-of-life. Recent books by well-respected physicians Angelo Volandes, M.D. and Atul Gawande, M.D. provide well-written and researched information for the layperson. Articles in the New York Times and coverage on National Public Radio about Respecting Choices® and Minnesota's Honoring Choices® initiative have brought this to public attention. And, the recent publication of the IOM's report on end of life provides a comprehensive review of the recent literature and recommendations for strategies and actions for the health care system and communities to take to improve how we care for people at the end-of-life.

For the Taos Community Foundation and Taos Health Systems there are some points of convergence between communities that have initiatives and Taos. First, many initiatives are lead by health councils alongside with health care systems. This connection is already made in Taos.

Next, many initiatives began their efforts by connecting to state-wide movements to increase the use of the POLST form. This form has clear application for health care systems, especially those in the emergency medicine departments and community EMS. New Mexico MOST, while relatively new, is working toward integrating the MOST form into health care systems in Northern New Mexico. They have a basic training, support from knowledgeable individuals and a track record of changing systems in Santa Fe and Albuquerque. Currently they are working in Espanola, NM and are eager to connect with Taos.

But, there will be some challenges for Taos. In many of these initiatives a strong presence by a local medical society or group of primary care physicians has been critical to changing systems and initiating conversations with patients. While there is no “medical society” in Taos, Taos physicians do have a Physician-Hospital Organization, Taos Health Plan. While the group has not had much experience in working outside of their own businesses, this project might be one in which they can take steps toward engaging in community health actions. At the very least, it is a place where many physicians will show up and a way to disseminate information to this critical group of stakeholders.

The New Mexico Medical Society is also not involved in this issue, but are receptive to discussing the work with the Taos Community Foundation and Taos Health Systems. Their primary work appears to be in the legislative sector but with the new ruling from Medicare the Society may be a good ally. The Medical Society could support more formalized approach to advance care planning in physician practices, including more intentional training in the area.

Most of the counties that were researched were larger, urban and had been working on this issue for a number of years. Taos County is at a very low level of readiness with this issue so a great deal of work will need to be done to simply bring this to the attention of the medical community and other potential key stakeholders. And, much of their funding came from the health care system. Often health care systems provided staffing to lead the project and office space to house it. The communities researched also had strong support from state and local foundations and insurance providers. Efforts at the state level are scarce, though the New Mexico MOST project is being lead by Presbyterian Health Services and is a likely partner in this effort.

Taos County does have an active community and the majority of organizations that are important stakeholders for an advance care planning initiative are at the Health Council table. Below is a table that identifies the key stakeholder from research into initiatives and the potential entities or persons who might fill these roles.

Key Stakeholders - General	Potential Taos Stakeholders
Health Council	Taos Health Council

Medical Society	Taos Health Plan (Physician Hospital Organization)
Private Practice Physicians and/or Medical	Family Practice Taos Medical Group
Other Medical Providers and Social Workers	From a variety of organizations including Taos Pueblo Health and Community Services, New Mexico Cancer Institute, Local psychologists
Nursing Homes and Elder Housing	Taos Living Center Taos Retirement Village
Health System (Hospital)	Holy Cross Hospital
Hospice and Palliative Care	Mountain Home Health
Mental Health and Bereavement Groups	Golden Willow Retreat Tri-County Community Services
Faith Leaders	Generally, faith leaders have been brought in when the initiative is ready to find conversation facilitators. There are many faith communities in Taos and this will be determined as a target population is identified.
Attorneys	Kellan Emery Leslie Peterson Bill Hudson
Committed Community Members	Susan Carpenter and Death Café organizers, Hospice volunteers, Holy Cross Hospital Auxiliary and Patient Advocates Program

There is no doubt that a Taos initiative will need to work intently to understand how best to meet the needs of our rich culturally diverse population. Many initiatives have created videos in other languages that may be used as well has have translated documents and information in Spanish and other languages. Taos, though, is its own best resource. Advance Care Planning is about how to gain trust and have a conversation about a very difficult subject. Within our community there are health care providers, educators, mental health professionals and advocates and faith leaders who do this work daily. They will be the best resource for providing input on how any program or process might be best adapted to meet the needs of the Taos population.

One of the most successful communication tools from others' experiences has been video. There are videos created specifically for use within a health care facility, there are videos that have been created for community-based providers, there are videos that can simply be watched on one's home computer. Minnesota's Honoring Choices® partnered with their public television affiliate and together have created remarkable videos of people telling their stories. These can be used or potentially collaborate with UNM Taos media studies program to produce local stories that can be used.

An important task of an initiative will be identifying appropriate forms and written material. If using a program like Respecting Choices®, these will be provided and they will support the community in adapting them as is necessary. The National Hospice and Palliative Care Organization already provides New Mexico specific materials available online. This will be very important work as at this time each entity uses a different form. Each person interviewed from other communities were clear that it is essential to get the systems in place, including consistency in materials, prior to initiating discussion groups. Early adopters to advance care planning need to be successful in completing forms. Word of mouth has been the most successful means of engaging people into the advance care planning process.

A pilot project might begin within the Health Care system itself. How many health care providers have an advance directive? In a community like Taos, the health care system is one of the largest employers. And, within this family-centric community many people have a connection to Holy Cross Hospital because they have a family member who works there. Asking hospital employees to complete an advance directive has many potential outcomes

1. Those who are in the front lines asking people about directives will have the advantage of their own experience to share and empathize with patients,
2. There are a large number of hospital employees, simply getting 20% of employees to complete a directive will have an affect on overall numbers;
3. They will tell their families and friends about their experience and will be the best sources for beginning a conversation and “word of mouth” referrals.

Most of the initiatives have been funded by health care systems, insurance providers, statewide health focused foundations and local philanthropists. Initially, initiatives were coordinated by staff from health care system, usually from palliative and hospice care or case workers. As the initiatives have grown, local foundations and other funders have provided resources. Partnerships within the coalition also help staff and donate resources to the initiative. Working with an evidence based program like Respecting Choices® will make the Taos initiative more amenable to funding from government sources like the Health Resources and Services Administration.

A pilot project might also be of interest to a funder. While most initiatives have garnered funding from within their own coalition partners, a Health Care Foundation like Con Alma might be interested in a pilot project of this sort. This project would have many implications for rural communities where you see these familial bonds between larger businesses and the greater community. And, with limited local media and low computer literacy in older populations, direct contact will be the best way to bring people to the conversation.

An initiative in Taos could expect to make very positive changes. Below is a list of potential outcomes :

Process/Outputs

1. ACP information and planning documents specific to local and state regulation
2. Group of people trained to facilitate conversations and guide ACP process

3. Align the ACP processes and forms across the Taos Health Care system

Immediate Outcomes

1. Increase access and availability of ACP information and guidance to Taos Community members
2. Increase community members' knowledge and understanding of the importance of ACP.
3. Increase the number of persons with advance directives

Longer Term Outcomes

1. Increase use of hospice and palliative care services
2. Increase reported quality of life for persons at the end-of-life.
3. Decrease the stress and anxiety within families due to their experiences with their loved ones at the end-of-life.
4. Decrease the number of persons spending time in the ICU in the last week of their lives.
5. Decrease the costs to families and systems of end-of-life care.

Conclusion

This report sets out to research and analyze the potential for a community-based initiative to increase the number of Taos County residents who complete an advance directive.

Literature has shown that persons with advance directives are more likely to have fewer intensive medical interventions at end-of-life and enter hospice earlier resulting in a higher quality of life at end-of-life, family members reporting less stress and anxiety and decreases in cost of end-of-life care.

Literature also has found that a facilitated process called Advance Care Planning is the most effective means for increasing the number of persons with advance directives. There are a number of good guides and organizations that train persons to facilitate conversations with individuals and groups. The most notable is Respecting Choices®. It provides training to both change the health care systems' approach to ACP and facilitation training for laypersons to hold conversations with their neighbors and friends. The program is based in a three tiered system related to age and health status. This program is evidence-based and is being used as the direct service and systems changes component of the Honoring Choices® framework for larger state run initiatives.

Taos County is in a good position to successfully implement an initiative. While the communities readiness level is low, many of the essential components for infrastructure are present: health council, active community members involved in end-of-life issues, recognition amongst health care professionals and others that there is a need for this type of work, and active collaboration with the primary health care system.

Interviews with community members resulted in the following findings:

- Advance directives are being completed in lawyers offices, at intake in the Living center and with the hospice social worker
- While the 5 wishes was mentioned most often, each of entity uses a different form
- There are many forms with different names and different forms with different sort of uses: DNR or Do Not Resuscitate, Living Will, POLST and it is not clear to individuals the differences between them or why they many need multiple forms.
- Providers say that advance directives and advance care planning is important to be done but people don't always discuss this with the people who need to know that they have them: their families.
- All believe that people need a knowledgeable and supportive person to help people complete the form.
- Health care professionals have received no formal training on facilitating discussions on advance directives.

The timing for a directive in Taos seems optimal. Recent potential changes in Medicare means that physicians will be able to bill for the time they spend with patients discussing advance care planning. ACP is in the news, there is increasing interest in how we, as a nation, tend to end-of-life and what are the priorities for ourselves and our medical systems. New studies increasingly show that palliative and hospice care, featuring high levels of comfort care and low levels of medical intervention lead to higher quality of life at end of life, less stress and anxiety for family members and decreases in costs. And, a recent study has shown that earlier hospice care for lung cancer patients and others has lead to not just higher quality of life, but longer life than those who opt for life extending medical interventions. The time is right for this conversation, the time is right for THE Conversation.

GLOSSARY from Honoring Choices Wisconsin

activated power of attorney for health care – In the event a person has been declared incapacitated, their chosen health care agent assumes the duty or is “activated” to make health care decisions for that person, as stipulated in their power of attorney for health care document.

advance care directive - See *advance directive*

advance care plan – A person’s plan, formal or informal, for the medical treatments and life-sustaining measures he/she would or would not like if he/she cannot speak for him/herself. These often designate someone to speak on behalf of the person if they are not able to speak for themselves. Advance care plans typically are expressed in an *advance directive*.

advance care planning – A process across time of understanding, reflecting on and discussing future medical decisions, including end-of-life preferences. Advance care planning includes:

- · Understanding your health care treatment options
- · Clarifying your health care goals
- · Weighing your options about what kind of care and treatment you would want or not want
- · Making decisions about whether you want to appoint a health care agent and/or complete an advance directive
- · Communicating your wishes and any documents with your family, friends, clergy, other advisors and physician and other health care professionals

advance directive – A document in which a person states goals, values and beliefs about health care treatment decisions, including who should make those decisions, in the event that person can no longer make those decisions for him/herself.

An advance directive can be changed at any time by the patient and may include a Power of Attorney for Health Care, Living Will or other expressions.

Also known as advance health directive or health care directive, but advance directive is preferred.

code status – A term used by physicians and other health care professionals to describe procedures that can be performed if a person’s heart stops or lungs fail. Code status can include the terms DNR, DNI or CPR.

- · DNR (*do not resuscitate*): Do not use CPR if a person’s breathing or heartbeat has stopped
- · DNI (*do not intubate*): Do not put a breathing tube down the throat to assist with breathing

- · *Do not hospitalize:* Do not admit the person to the hospital overnight

comfort care – Medical care and treatment for immediate relief of pain and symptoms without intubation, artificial nutrition/hydration and re-hospitalization. Treatments and care usually are provided in a community setting or at home and can include oxygen and medications for pain and symptom relief.

CPR (cardiopulmonary resuscitation) – An emergency procedure to keep a person's heart pumping and oxygen flowing to the brain. The procedure involves another person breathing into the patient's mouth and pressing on the chest. Medicine and special equipment may be used to give electrical shocks to the person's heart to get it working. A tube may be placed down the throat to breathe.

DNR (do not resuscitate) – An order issued by a physician that communicates to emergency medical technicians, first responders or emergency department staff that a qualified patient has decided he/she does not wish to be resuscitated. A qualified patient is an adult who has a terminal condition or would suffer pain or harm from resuscitation or for whom resuscitation would be unsuccessful.

durable power of attorney for health care – See *power of attorney for health care*

end-of-life care – Care provided to a patient who is nearing the end of his/her life. End-of-life care is often provided by hospice.

facilitator – A person trained to help initiate and support the process of advance care planning among patients, families and the health care team. Provided proper training and certification, the facilitator can be any member of the health care team, a volunteer or someone from outside the immediate care team.

feeding tube – A medical tube through which nutrition or hydration is administered into a person's stomach, nose, mouth or other body opening. A feeding tube can be used to administer both nutrition and hydration, and can be used if a person cannot swallow normally or take in enough food or water. Some refer to an intravenous access (IV) as a feeding tube that goes into the vein, through which hydration and nutrition can be passed.

health care agent – The person chosen by a patient to make health care decisions in the event that the patient cannot make decisions for him/herself. A health care agent is named in a *power of attorney for health care*. Other equivalent terms include *health care proxy*, *substitute decision maker* or *surrogate decision maker*, but *health care agent* is preferred.

health care directive – See *advance directive*

March 2013

Honoring Choices Wisconsin (HCW) Statewide Steering Committee – An advisory group convened by the Wisconsin Medical Society (Society) to advise the Society on how best to pursue the mission of HCW, advocate in public for HCW and its mission and represent other HCW stakeholders.

hospice – A form of care that provides comfort and support to terminally ill patients and their families, where treatment focuses on the patient's comfort rather than on a cure for an illness and includes pain management and spiritual counseling.

hydration – The use of intravenous tubes to provide water to someone who cannot drink enough.

incapacity – Determination by two physicians, or one physician and a licensed psychologist, that a person is unable to receive and evaluate information effectively or to communicate decisions to such an extent that the individual lacks the capacity to manage his or her own health care decisions. This determination of incapacity is used to activate a Power of Attorney for Health Care.

IV (intravenous) line – A narrow, flexible plastic tube placed in a vein. An IV is a way to give hydrating fluids, blood and medicine and/or nutrition.

living will – A document that provides a set of instructions about care at the end of life . A living will is often a component of an advance directive.

MOLST (Medical Orders for Life-Sustaining Treatment) – See **POLST** **MOST** (Medical Orders for Scope of Treatment) – See **POLST**

nutritional support – The use of IVs or other tubes to provide nutrients to someone who cannot eat or drink.

palliative care – Specialized medical care for people with serious illnesses focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal of palliative care is to improve quality of life for both the patient and the family.

POLST (Physician Orders for Life-Sustaining Treatment) – A standardized form that documents a conversation between a physician and a seriously ill patient or the patient's surrogate decision maker. POLST is designed for patients for whom a physician would not be surprised if they died in the next year. POLST is not a component of Honoring Choices Wisconsin or the Respecting Choices First Steps, program for Honoring Choices Wisconsin.

power of attorney for health care – A legal document naming a health care agent (also known as a POA or durable power of attorney for health care). A Power of Attorney for Health Care is often a component of an *advance directive*.

proxy – See *health care agent*

storage and retrieval – In the context of advance care planning, the ability to include an advance directive in a person's electronic health record and easily access it when a Power of Attorney for Health Care is activated.

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Attachment 1: Resources

Coalition for Compassionate Care of California

<http://www.Coalitionccc.org>

Guides for healthcare professionals, families, coalitions working with the faith community, guides in multiple languages, public policy information Initiatives.

Compassion & Choices

<https://www.compassionandchoices.org>

Resource guides and information on advance care planning. Doc-to-Doc Consultation Program.

The Conversation Project

Ellen Goodman

<http://theconversationproject.org>

Stories, videos, self-directed guides

Honoring Choices Minnesota

Contact: Karen Peterson, BSN

Director of Program Operations

<612-362-3704> | kpeterson@metrodoctors.com

www.metrodoctors.com

www.honoringchoices.org

Honoring Choices Pacific Northwest

<http://www.honoringchoicespnw.org/learn/know-your-options/>

Good description of terms and medical practices important for end-of-life decision making.

Napa Valley Honoring Choices

414 S. Jefferson St., Napa, CA 94559

Kathie East, MSW | Program Coordinator

Phone: 707.254.4162

<http://hcnv.org/wp-content/uploads/2014/11/HCNV-Case-Statement-10-23-2014.pdf>

Case Statement presented to the community to gain support for the initiative

Honoring Choices Wisconsin

Wisconsin Medical Society

Main Phone: 866.442.3800 (toll-free)

Contacts: John Maycroft, 608.442.3766

Joyce Hart-Smerick, 608.442.3723

Erin Aagesen, 608.442.3746

<https://www.wisconsinmedicalociety.org/professional/orphan/honoring-choices-wisconsin-executive-summary/>

Well articulated summary of the project and process for Honoring Choices replication.

Medicare

<http://www.medicare.gov/manage-your-health/advance-directives/advance-directives-and-long-term-care.html>

Easily readable information for all about advance directives.

National Health Care Decisions Day

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

April 16, 2016

National Hospice & Palliative Care Organization

<http://www.nhpco.org/advance-care-planning>

Hospice and Palliative Care membership organization providing information and resources on variety of topics related to end of life including state specific advance directive information and forms at:

<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>

NM MOST

Contact: Lori Griego

lorrie.griego@nmmost.org

[505-559-6053](tel:505-559-6053)

NM MOST Form and training resources for implementing within healthcare systems

Respecting Choices®

Contact: Britt Welnetz

Respecting Choices, Business Development Consultant

Bereavement & Advance Care Planning Services

Direct: [608-775-4887](tel:608-775-4887) | [800-362-9567](tel:800-362-9567), ext. 54887

Gundersen Medical Foundation | www.gundersenhealth.org

www.bereavementservices.org | www.respectingchoices.org

1900 South Avenue, La Crosse, WI 54601 | Mailstop AVS-003

Evidence-based approach to systems change and direct service to increase advance care planning.

Advance Directive Forms

NM MOST Form

<http://www.nmmost.org/images/nmmostform2014.pdf>

NM Cancer Care

<http://www.nmcancercenter.org/files/2008/11/advanced.pdf>

San Juan Regional Medical Center Advance Directive Information

<http://www.sanjuanregional.com/upload/docs/Patient%20and%20Visitors/Advanced-Directive.pdf>

Books

The Conversation: A Revolutionary Plan for End-of-Life Care

Angelo E. Volandes, M.D.

New York, NY, USA: Bloomsbury.

Being Mortal

Atul Gawande

New York, NY, USA: Metropolitan Books Henry Holt and Co.

Articles

http://opinionator.blogs.nytimes.com/2015/07/11/aid-in-dying-laws-are-just-a-start/?ref=opinion&_r=1

Videos

<http://www.acpdecisions.org>

Videos created by physicians for patients about end-of-life and acp.

Honoring Choices Minnesota

www.honoringchoices.org

The Conversation Project

<http://theconversationproject.org>

Attachment 2: Advice from Honoring Choices Minnesota

A quick overview of the advice we typically give a community here in MN:

1. It's critical to have a planning team with carefully selected members, including leaders in various community roles – possibilities include leaders from local public health and/or the major health system(s) in the area, community and/or civic leaders (such as city council, League of Women Voters, Rotary Club, faith leaders, leaders of cultural/ethnic populations, etc), because you never want to be the “outside expert” who comes in to tell people how they should be doing things; instead you want to garner the support of leaders of the various groups so that THEY are the ones saying to their constituents “this message is important and this person is going to explain why.” Having these leaders on board (and educated about what you want to do) is critical to your success. Finally, you need at least one person who is an experienced “worker bee” – the person who GETS. THINGS. DONE. in your community. The person who chairs the local community events, or steps up to lead support efforts following a disaster, or who pulls together celebrations for a centennial anniversary – you know the type!
2. Know that it takes time. It's ideal to work both with health care and the community simultaneously if possible – ensuring the health care sites are ready with an ACP program ready to go (we highly recommend using the Respecting Choices model), and also working to educate the public so they know to ask for this at their clinic visits. Neither of these happen quickly; it's critical to know that from the outset that this is a long-term plan. You need to set modest benchmark goals and learn as you go along, making changes and adjustments in response to the feedback you receive as you start out.
3. There are a ton of tools and resources available online. Some of our favorites – in addition to the videos available on our website – are The Conversation Project, National Healthcare Decisions Day (they have a terrific 3-minute video which introduces the concept), Coalition for Compassionate Care of California, which has good resources for working with non-English speaking groups.
4. When starting the community efforts, utilize the leaders on your planning team. Start by giving presentations where you have captive audiences – groups that are already convening for other purposes, so you don't have to use your time and efforts to round up audiences. Have the community leaders do the introductions and share their endorsement of this topic. Incorporate the elements of ACP, but also elements of your community so the message resonates with the audience. Some of my favorite resources about why ACP matters are this book: Being Mortal, and this book: The Conversation. Excellent resources about making presentations and reaching your audience: this TED blog, this TED talk, this book: Made to Stick, this book: Good to Great.

Karen Peterson

Attachment 3: ACP Taos “one pager”

Purpose: To increase the number of Taos County Residents who complete advance directives and file these with their healthcare provider.

What: Advanced Directives are part of the Advance Care Planning (ACP) process. The conversations and documentation that results from the process ensures that a person’s end-of-life wishes are understood and honored. Advanced Care Planning can include:

- Engaging in conversations with family and friends that result in clear documented instructions for end-of-life care (Advanced Directive)
- Choosing a Health Care Agent (Power of Attorney for Healthcare) who will make decisions for an individual when he/she can no longer make decisions for him/herself.
- Completing, with a physician, when end-of-life is imminent, a Physicians’ Orders for Life Sustaining Treatment (POLST) to ensure that healthcare providers give the end-of-life treatment desired.

Outcomes: States and communities that have ACP initiatives have found that:

- Increases the likelihood that individuals receive the care that they prefer at the end of life
- Reduces depression and anxiety in family members
- Increases family satisfaction with the process of care.
- May contribute to decrease in health care costs for health care systems and the communities they support.

How: The Taos initiative is researching Honoring Choices®, an expansion by the Twin Cities Medical Society of Respecting Choices® an evidence-based program from the Gundersen Health Care System of LaCrosse, Wisconsin.

Honoring Choices® works:

- **With Communities** by using media and social media to engage and promote conversation amongst family members and neighbors about end-of-life planning.
- **With Systems** to train physicians, nurses and other healthcare providers to have conversations with their patients about end-of-life and provide resources and support for making plans. Trains faith leaders, business leaders and other volunteers to facilitate end-of-life conversations with individuals and groups.
- **With Individuals** by providing easy access to information and resources through websites, healthcare providers and community and faith organizations.
- **With Policy makers** in developing and advocating for policies that promote advance care planning and honoring individual choice at end-of-life.

Resources: State or City Medical Societies, Healthcare Plans, Health Care Systems and philanthropists and foundations fund Initiatives locally through grants or direct pay of initiative staff.