



MARYLAND
Department of Health

Advance Directive Outreach and Education with Faith-Based Organizations White Paper

November 2018



Prepared by Apiari LLC

Introduction

Advance care planning is a process that allows a competent individual, in conjunction with family, community, or health care providers, if desired, to make decisions about future health care preferences within the context of their current health.¹ Most Americans agree that advance care planning is important, however less than one in three adults have completed an advance directive.² African Americans and other minority groups have even lower rates of uptake.³ Reasons for low completion include lack of awareness, concerns about cost or complexity,⁴ confusion about what forms or signatures are required, and differing cultural or spiritual views and values on death and dying.⁵

Over the last several years, the State of Maryland has prioritized greater participation in advance care planning through 1) the creation of an Advance Directive Program at the Maryland Department of Health; 2) targeted outreach and education activities to increase awareness of advance directives; and 3) expanded access to electronic advance directives. Electronic advance directives are created and stored online, and they have the advantage of being more accessible to health care providers at the point-of-care (e.g., emergency rooms). In Maryland, this accessibility is enhanced by an initiative that makes available electronic advance directives created with State Recognized vendors through the State-designated health information exchange. State Recognition is voluntary and demonstrates a vendor meets certain criteria and standards for privacy and security, independent audits, education, reporting, and technical provisions, some of which are required by State and/or federal law.⁶

In 2017, the Maryland Advance Directive Program launched its first outreach and education initiative, beginning in the faith community, where partnerships present an important opportunity to raise awareness about end-of-life decision-making.^{7,8} Three faith-based organizations (“grantees”) were competitively awarded funds to deliver a robust series of community engagement activities in three geographic regions of the state — the Central (Baltimore Metro), Capital, and Western Regions.⁹ This paper provides a summary of the project and its key findings from 2017 to 2018.

Background

An advance directive is a legally-recognized paper, electronic, or video-taped statement describing desires and preferences for future health care. Typically, an advance directive also

¹ Henry, C. (2008) "Advance care planning: a guide for health and social care staff." National Health Service, Retrieved 29 July, 2018 <<http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf>>.

² Rao JK et al. (2014) Completion of Advance Directives Among US Consumers. *Am J Prev Med*, 46(1): 65-70.

³ Huang, IA et al. (2016) Racial and ethnic differences in advance directive possession: role of demographic factors, religious affiliation, and personal health values in a National Survey of older adult, *Journal of Palliative Medicine*, 19.2, 149-156.

⁴ Id.

⁵ Bullock K. (2006) Promoting advance directives among African Americans: A faith-based model, *Journal of Palliative Medicine*, 9.1, 183-195.

⁶ State Recognition is granted by the Maryland Health Care Commission. For more information, visit:

https://mhcc.maryland.gov/mhcc/pages/hit/hit_advancedirectives/hit_advancedirectives.aspx.

⁷ Green, MA et al. (2014) Carrying the burden: Perspectives of African American pastors on peer support for people with cancer, *Journal of Religion and Health*, 53.5, 1382-1397.

⁸ Pereira-Salgado, A. et al. (2017) Religious leaders' perceptions of advance care planning: a secondary analysis of interviews with Buddhist, Christian, Hindu, Islamic, Jewish, Sikh and Bahá'í leaders. *BMC Palliative Care* 16.79.

⁹ Apiari LLC (Western Region), Community Ministry of Prince George's County (Capital Region), Maryland Faith Health Network (Central Region)

identifies a health care agent who may legally give or withhold informed consent for medical care when an individual lacks capacity to do so.

Research has shown that advance directives improve the quality of care at the end of life, decrease burden on family and health care providers, and reduce administration of unwanted, life-sustaining treatments.¹⁰ Advance care planning is recommended across the health care continuum, not just late in life or when diagnosed with a serious illness.

Advance directives are voluntary, changeable, and can be completed at no cost. While Maryland makes forms available to residents through the Attorney General's website,¹¹ specific forms are not required to validate an advance directive. Maryland law requires these documents to be signed in the presence of eligible witnesses,¹² but it does not require them to be notarized.¹³

Project Activities

Over the project period, from October 2017 to June 2018, the grantees conducted 21 community engagement activities, reaching approximately 1,200 participants from 22 faith groups. Activities were held in 24 zip codes across nine jurisdictions — Garrett, Allegany, Washington, Frederick, Montgomery, Prince George's, Carroll, and Baltimore Counties, as well as Baltimore City (see *Heat Map*). Activity structure and format varied considerably, with some activities connected to worship services or embedded into pre-existing classes, while others were held as stand-alone events. Activity size varied from small group seminars and mid-size prayer breakfasts to large health fairs held in houses of worship. All grantees used the Maryland Department of Health's one-page information sheet, "Five Reasons to complete an Advance Directive today" (see *Appendix I*) and introduced the concept of electronic advance directives, providing resources, and a rationale for their use. Finally, the grantees collected data at each engagement activity, although the format and structure of this data collection differed by grantee.

All grantees reported meaningful increases in participant knowledge about the purpose and intent of advance directives. Additionally, they noted increased awareness of where to find paper and electronic forms and resources, indicated by correct responses to a short survey offered at the end of most sessions. Anecdotal responses also suggested positive shifts in attitudes toward advance directives. Instead of continuing to "kick the can down the road" and avoid an unpleasant topic, many participants indicated a willingness to share what they learned with family and friends, and to continue the advance directive discussion outside of the engagement activity. A few participants indicated a readiness to complete their advance directive on-site. Note: Collecting participants' advance directives on-site was not a goal of the engagement activities.

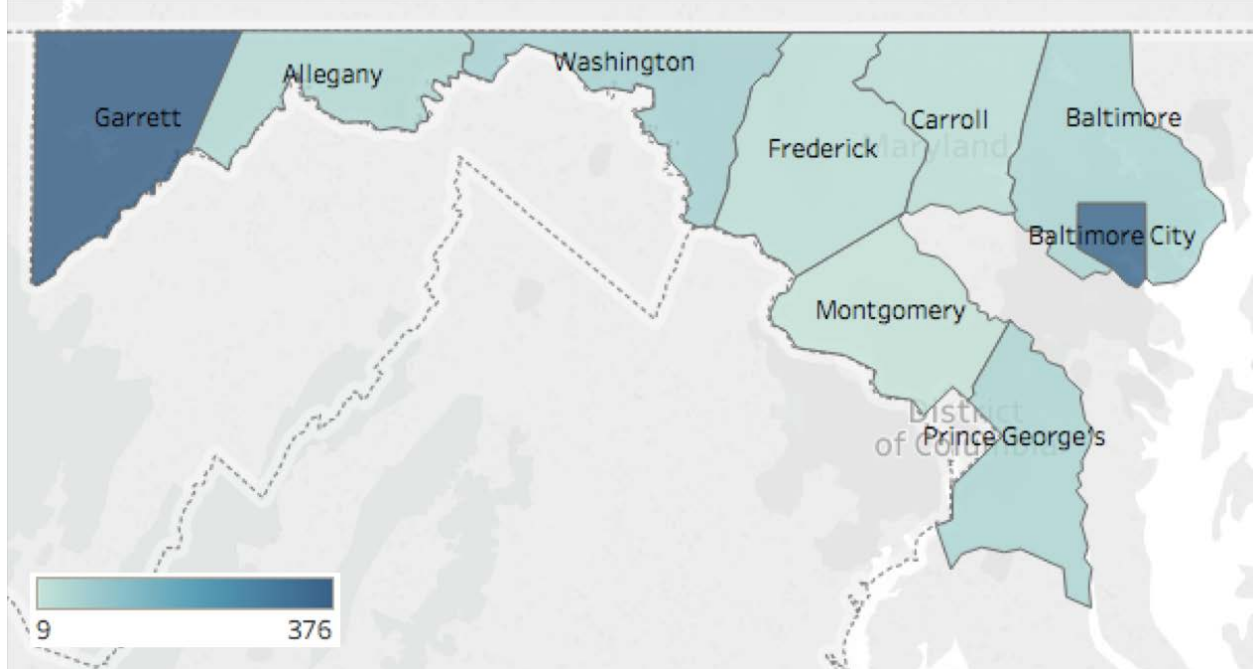
¹⁰ Benson WF et al. (2012) "Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself," [Critical Issue Brief] Centers for Disease Control and Prevention, Retrieved 7/29/2018
<<https://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf>>

¹¹ Maryland Office of the Attorney General, Retrieved 24 August 2018,
<http://www.marylandattorneygeneral.gov/Pages/HealthPolicy/AdvanceDirectives.aspx>

¹² A witness is not required for an electronic advance directive if the declarant's identity has been authenticated per National Institute of Standards and Technology Special Publication 800-63-2: Electronic Authentication Guideline, available at <https://nvlpubs.nist.gov/nistpubs/specialpublications/nist.sp.800-63-2.pdf>

¹³ Chapter 667 of the Acts of 2017 (HB 188).

Heat Map: Advance Directive Faith-Based Outreach, Participants by Jurisdiction



Key Findings

1. Advance care planning is relevant and important to faith groups.

Grantees reported that advance care planning is timely and important to faith groups. Many faith leaders described personal experience with parishioners and families at the end of life and articulated how having an advance directive in place eases this process. More than once it was stated: “The hospital is not the place to be making these decisions.”

The president of the Ministers Conference of Baltimore and Vicinity stated, “[Advance Care Planning] affects our membership. Our oldest members are the most vulnerable.” Another pastor in Washington County stated, “We are very good at preparing our congregations for the ends of their lives spiritually. We have a lot of work to do in learning how to help them prepare practically.” While faith leaders believe the topic is important, they cite competing priorities as the most common reason for not addressing advance care planning with their congregations. Many also do not feel confident in their ability to answer technical questions for their congregations or lead others through the advance directive documents themselves.

2. Faith leaders serve as trusted and credible messengers.

Grantees noted the importance of faith leaders in guiding the conversation and generating a shift in attitude. In particular, faith leaders were successful in helping dispel persistent and unhelpful myths about advance directives—they hasten death; they are equivalent to “do not resuscitate” or “do not treat” orders; that naming a proxy decision-maker causes a person to lose control over their care. Faith leaders explained that advance directives might enhance rather than conflict with their religious belief system. And, faith leaders also successfully led by example with powerful testimony, which was described by grantees as a key enabler in

shifting attitudes.

When a leader or trusted member of the faith community described how having (or not having) an advance directive personally affected them, or another parishioner, this helped participants connect the abstract concept of advance directives to a relatable situation, increasing the sense of importance and urgency in advance care planning. In one case, a pastor from Zion Hill Baptist Church in Baltimore provided testimonial about serving as his father's health care agent. The pastor described how he appreciated his father letting him know what his wishes were, thereby avoiding family discord and ensuring he was doing what his father wanted.

3. *Faith groups are receptive to electronic advance directives.*

Over the years, a paper-based document known as *Five Wishes*¹⁴ has become popular in faith-based advance directive settings. Most grantees discussed *Five Wishes* as a resource at their outreach activities, however they also noted that many participants were interested in an electronic format, especially if it “walks you through the process” and can be updated easily. Several participants asked how to convert existing paper advance directives into electronic ones. Others raised concerns about privacy and security with electronic advance directives, as well as questions about how an electronic advance directive completed at home differed from what they may be asked to complete in the hospital.

4. *Advance care planning involves spiritual, medical, and legal considerations.*

Faith groups were very successful at introducing the concept of advance directives within a spiritual framework — utilizing scripture, prayer, and personal anecdotes. However, advance directive conversations sit at the intersection of the spiritual, medical, and legal realm, often with indistinct borders. Many grantees noted confusion among participants, caused by unfamiliar forms and terminology (e.g., MOLST versus living will) as well as numerous questions about how to execute an advance directive document (see *Appendix 2, Frequently Asked Questions*).¹⁵ Distinguishing between medical decision-making and comprehensive estate planning was a common theme among participants. To address this, two grantees regularly collaborated with medical and legal advisors at their engagement activities.

5. *Advance care planning is a process, not a checklist item.*

Grantees observed a wide range of “readiness” for advance care planning. Participants needed both spiritual and practical preparation, as well as ample time to discuss with family. This finding is supported by the literature; “The [advance directive] form is only as good as the conversation and the shared understanding that goes along with it.”¹⁶

In many cases, grantees found it helpful to host multiple activities in a series — with one building on the next — to fully explore the topic first from a spiritual lens, and later from a

¹⁴ Aging with Dignity, Retrieved 24 August 2018, <https://fivewishes.org/five-wishes/advance-care-planning>

¹⁵ MOLST refers to Medical Orders for Life-Sustaining Treatment. MOLST is medical record completed by a health care professional to document discussions on life-sustaining medical treatment preferences for a person with advanced illness. Advance directive refers to a broad category of legal instructions that include 1-a living will (the document detailing medical treatment wishes) and 2-the appointment of a health care agent.

¹⁶ Crist, C. (2017) “Over one third of U.S. adults have advanced medical directives,” Reuters Health News, Retrieved July 19, 2018, <<https://www.reuters.com/article/us-health-usa-advance-directives/over-one-third-of-u-s-adults-have-advanced-medical-directives-idUSKBN19W2NO>>.

practical perspective, detailing the key steps involved. Some grantees asked faith leaders to prepare participants by discussing the spiritual side of end of life in sermons leading up to the outreach activities. Then, at the outreach activities themselves, more emphasis was placed on the practical aspects of advance care planning -- terminology, forms, and signature requirements.

Next Steps

In April 2018, the program expanded its advance directive education and outreach project to include additional community organizations and a broader geographic reach. The Maryland Department of Health competitively awarded year-long grants to 13 highly diverse community and faith-based organizations to deliver education and outreach with events planned across the state. The Maryland Department of Health expects this “second wave” of engagement activities to include more than 125 distinct outreach events in all regions of the state, reaching over 6,000 Marylanders. Informed by findings from the faith-based outreach project, second wave grant recipients will utilize a survey tool for standardized data collection. A second paper will further analyze the project’s expansion, capturing key themes, barriers, enablers, and messages that resonate with Marylanders.

The program plans to use lessons learned from this project to develop messages for future communication efforts. Beginning in 2019, the Maryland Department of Health anticipates launching a communication campaign to encourage participation in advance care planning.



An Advance Directive is a written statement that allows you to decide what type of medical treatment you do (or do not) want, particularly in an emergency or near end-of-life situation.

QUICK FACTS

Advance Directives are:

- Voluntary. You are not required to complete one.
- Changeable. You can edit or revoke at any time.
- For adults of all ages.
- Most effective when completed in consultation with family, religious and/or legal advisors.
- Available in a variety of formats, including electronically.

Why use an electronic advance directive?

Electronic advance directives are more readily available at the point-of-care. Paper forms may not be retrievable in an emergency.

How can I create one?

Visit any electronic advance directive vendor online to sign up and fill out an advance directive.



Appendix 2: Frequently Asked Questions

Collected at faith-based community engagement activities 2017-2018

Signature Requirements

- What are the requirements for an advance directive to make it legal?
- Who can serve as the two witnesses to the patient's signature?

Definitions and basic information

- When do I fill out an advance directive?
- How old do I need to be?
- Don't I fill out an advance directive every time I go to the hospital? How is this different?
- Is the advance directive paperwork filled out at one hospital transferable to another?
- Won't (my home care nurse/assistant/family) take care of this for me?
- Who qualifies as a "domestic partner?"
- Who is the best person to choose for my health care agent?

Submission

- Who do I file an advance directive with?
- Where does my advance directive go when I am done filling it out?
- Do I need to give my advance directive to my life insurance agent?

Electronic Advance Directives

- Who can see my electronic advance directive online?
- How do electronic vendors that don't charge the user make a profit?
- How do I convert a completed paper advance directive into an electronic one without retyping the content?

Details

- If there are multiple copies or conflicting advance directives, how does the medical team decide which one to follow?
- What if I change my mind? How do I update it?

State Lines

- What if my health care agent is in another state?
- What if I get sick out of state? Are electronic and paper advance directives accepted outside of Maryland?

Obligations

- Does being someone's health care agent make you responsible for their medical bills?