

Empowering Tomorrow

Navigating The Future With Advance Care Planning



My Family Story &
Our Advance Care
Planning Journey

“I have an
advance directive,
not because
I am seriously
ill, but **because**
I have a family.”

– Ira Byock, MD



ADVANCE CARE PLANNING:

**Isn't It Time
We Talk?**

What is Advance Care Planning (ACP)?

**We all make decisions every day,
and we plan ahead for all sorts of expected events.**

It is just as important to plan ahead for the health care you would want as you age.

**Advance Care Planning (ACP)
involves making decisions about that care**

- **It is about giving your family the gift of conversation and planning for care in advance.**
- **Making decisions regarding who will speak for you if you can't speak for yourself.**
- **Putting your plans in writing in a legal document, i.e. HC POA, Living Will, etc.**

We Already Know...

Not enough people are talking about their advance care planning.

- 90% of people believe it is important to discuss end of life care with loved ones, but only 30% have done so.¹
- 82% of people say it's important to put their wishes in writing, only 23% have done so. (Californian Survey 2013)
- Documentation of those wishes is not accessible when needed.

Many people store them in locked boxes or other inaccessible locations

- Fewer than 13% of patients 65+ admitted to UNC's ED had Advance Care Documents available in the EHR according to a 2017 journal article.²

Why Are We Not Talking

We have family & cultural myths.

- **If I talk about it, I will make dying happen to soon.**
- **Only old people** need an advance directive.
- An advance health care directive means **I won't get any more treatment.**
- **"My doctor, or my family, knows what I want."**
- **"If I name someone as my health care agent, I will lose control of my care."**

Barriers to Talking About ACP

- Fear of dying
- Lack of knowledge
- Lack of experience
- Cultural/Spiritual considerations
- Lack of Trust
- The physician doesn't have time and is in a hurry
- Disagreement about decisions
- Desire to maintain hope
- Family role issues
- Ethical dilemmas

The Simple 4-Step ACP Plan

- 1. Think about your choices** in light of what is important to you.
- 2. Talk about your decisions** with loved ones, spiritual advisers, and your doctor.
- 3. Put your plans in writing** by completing advance directives, and so that they will be ready when needed.
- 4. Store Your documents** in a safe place such as Mind My Health.

Advance Care Planning: The Past

- Limited or no training for physicians, nurses, social workers, etc. re how to initiate advance care planning conversations
- No emphasis on cultural competency/cultural humility and advance care planning with patients and caregivers
- Silos existed between the health care teams and community-based organizations and the faith community

Advance Care Planning: The Present

- Training our present clinicians and those who are in training who aspire to work in the field of serious illness care delivery (i.e. Ariadne, Vital Talk, Respecting Choices, etc.)
- Partnerships with Community Based Organizations and faith organizations to reach
- Utilization of Community Health Workers as ambassadors as extensions of the health care team to educate lay persons on the benefits of having
- Funding Support for grass roots campaigns to reach our vulnerable populations in rural and underserved communities (Duke Endowment, Harmon Foundation, Rita & Alex Hillman Foundation, BCBS SC Foundation, etc.)
- ACP payment by CMS, commercial payers, ACO's, etc.
- Health System EMR's storage of Advance Directives for easy access
- Cloud based Advance Directive registries (i.e. Mind My Health, Five Wishes, etc.)

Program Funding



State of North Carolina's
License to Give Trust Fund Commission





Mind My Health



 **Mind My Health**
BETA VERSION
Keeping your advance care in check.

[Why Plan?](#) [How It Works](#) [FAQs](#)

[Log In](#)

[START NOW](#)

Own your care. Plan in advance.

Your online tool to keep your advance care plan in check.

[START NOW](#)

Our Goals

- ▶ **Develop an online platform that makes AD available at the point of care**
- ▶ **Work with healthcare systems to transfer an AD stored on the platform into the electronic health record**
- ▶ **Increase the number of people who complete the AD and document their organ donation preference**


Advance Care Planning: The Future

Expanding Our Reach

- Expansion of advance care planning conversation training in post secondary training curriculums
- Increase of ACP conversations in primary care offices
- Care Models that encourage upstream access to advance care planning
- Increase in Collaborations and Partnerships with Community Based Organizations and faith organizations and faith communities (nationally and regionally)
- Utilization of Community Health Workers as ambassadors as extensions of the health care team to educate lay persons on the benefits of having
- Funding Support for grass roots campaigns to reach our vulnerable populations in rural and underserved communities
- Inoperability with technology for storage and rapid access to Advance
- National and state legislative and payor alignment that enhances and increases opportunities for ACP conversations and advance directive execution. (i.e. eliminate Co-pays for ACP, MCD palliative care benefits, etc.)

Community Engagement & Lessons Learned

- Prioritize building relationships with credible influencers and experts in the communities you desire to serve.
- Give the experts a “seat” at your planning table to give feedback and advise you on the process (i.e. Advisory Councils)
- If doing research, include them in your budget, value their time and engagement and compensate them accordingly
- Listen to their stories and incorporate what you learn into your practice (what works and what doesn't work)
- Be intentional and accountable to follow up and keep your word
- Practice cultural humility and train your team to follow your example.




“Trust is earned in the smallest of moments. It is earned not through heroic deeds, or even highly visible actions, but through paying attention, listening, and gestures of genuine care and connection”

Brene Brown





The Final Word On Care Delivery

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- “People are people..they are not just a collection of molecules and tissues and organs. We have to understand what the person with the disease or illness wants to accomplish” Dr. Richard Payne

Q & A

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