ADVANCE CARE PLANNING: WHY, HOW, AND IMPACT ON THE TRIPLE AIM

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OBJECTIVES

- What are our legal obligations to provide advance care planning?
- What is the evidence supporting the health benefits of ACP? Is there any harm in asking?
- What if palliative care were a drug?
- What role does a community-based ACP program play in the Triple Aim?

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DEFINITIONS

LIFE SUPPORT ~ "JUST PULL THE PLUG"

- Cardiac/vascular monitors
- 10 IV pumps
- 1 Pain pump
- 1 Dialysis machine
- 1 ventilator
- 1 forced air warmer
- Feeding tube by default

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DURABLE POWER OF ATTORNEY (DPOA)

- Written document in which *you* appoint a trusted person to *act on your behalf*, continuing the relationship beyond your incapacity.
- Includes decisions such as financial and legal affairs.

LEGAL DICTIONARY (2014). HTTP://LEGAL-DICTIONARY.THEFREEDICTIONARY.COM/DURABLE+POWER+OF+ATTORNEY

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DURABLE POWER OF ATTORNEY FOR HEALTHCARE (DPOAH)

- Appoints your **Patient Advocate (PA)** or Durable Power of Attorney for Healthcare (DPOAH)
- Gives your Advocate the right to participate in discussions about your care and ensures your wishes are followed

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ADVANCE DIRECTIVE
VERSUS
LIVING WILL

ADVANCE DIRECTIVE:

- *Appoints* the person(s) you choose to speak for you if you cannot speak for yourself (patient advocate)
- The patient advocate(s) must accept the role in writing

LIVING WILL:

- Focuses on your *goals for care*/treatment preferences
- Does NOT stand alone in the state of Michigan.
- It can be attached to your advance directive

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ADVANCE CARE PLANNING (ACP)

A CONVERSATION, A PROCESS, A DOCUMENT, OR ALL THREE?

ADVANCE DIRECTIVE DOCUMENTS ARE *ONLY AS GOOD AS THE CONVERSATIONS AND THE PROCESS* THAT GOES INTO THEM.

Wise & Aldrich, 2013

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GAPS AND HARMS

WHAT WE WANT TO DO

VERSUS

WHAT WE DO

THE GAPS AND THE HARMS

60% OF PEOPLE SAY THAT MAKING SURE TOUGH DECISIONS DO NOT BURDEN IS "EXTREMELY IMPORTANT"

56% HAVE NOT COMMUNICATED THEIR END-OF-LIFE WISHES

80% SAY THAT IF SERIOUSLY ILL, THEY WOULD WANT TO TALK TO THEIR DOCTOR ABOUT END-OF-LIFE CARE

7% REPORT HAVING HAD AN END-OF-LIFE CONVERSATION WITH THEIR DOCTOR

82% SAY IT'S IMPORTANT TO PUT THEIR WISHES IN WRITING

23% HAVE ACTUALLY DONE IT

70% SAY THEY PREFER TO DIE AT HOME

70% DIE IN A HOSPITAL, NURSING HOME, OR LONG-TERM CARE FACILITY

LEGAL OBLIGATIONS

LETTER OF THE LAW VERSUS INTENT OF THE LAW

PATIENT SELF-DETERMINATION ACT (PSDA)

- Protects the right of the patient for preferences at end-of-life
- Educates the patient about choices
- Protects the health-care provider

OMNIBUS BUDGET RECONCILIATION ACT (1990)

CMS PROVIDER REQUIREMENTS

- Provide written information to patients re: rights to create an AD
- Maintain written policies & procedures re: ADs and make them available to patients upon request
- Document whether or not the patient has an AD
- Comply with Michigan state law respecting the AD
- Educate the staff and community about Advance directives

WHAT THE PSDA DOES *NOT* DO:

- Require conversation between the healthcare provider and patient about treatment preferences and intent
- Require incorporation of the ACP into the Plan of Care

Fischer, S. M., Sauaia, A., Sung-Joon, M., & Kutner, J. (2012)

2016 CMS FINAL RULE FOR ACP

- **99487**: ACP including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician *or other qualified health care professional; first 30 minutes, face-to-face* with the patient, family member(s), and/or surrogate.
- **99498:** ACP including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; *each additional 30 minutes* (List separately in addition to code for primary procedure).

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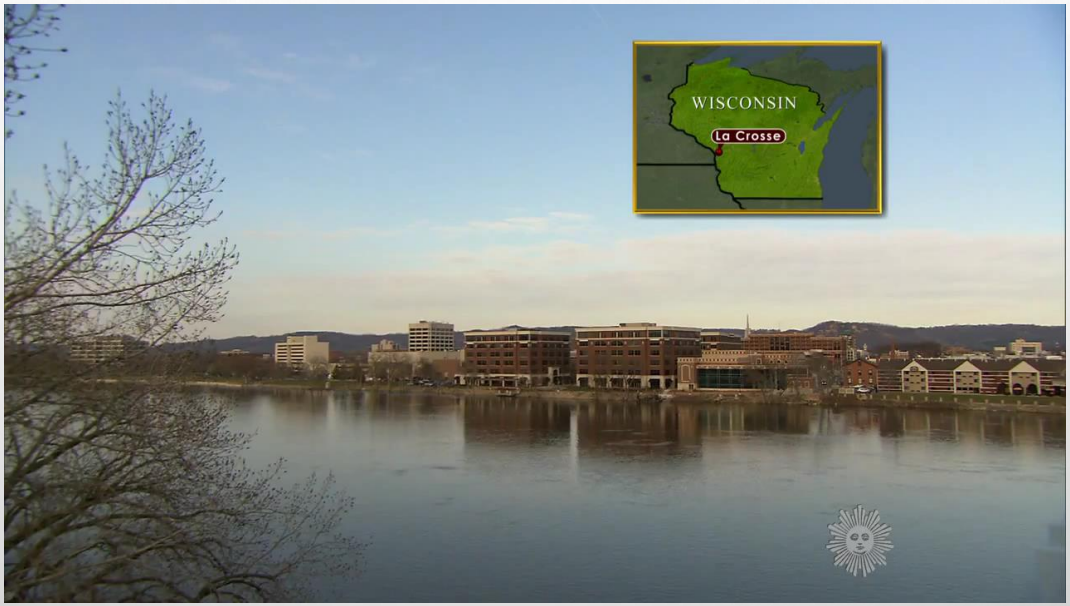
HEALTH BENEFITS OF ACP: BEST EVIDENCE

IS THERE HARM IN ASKING?

BEING PREPARED FOR THE FINAL DAYS

Respecting Choices®



CBS Sunday Morning News (2014_April 27). http://www.cbsnews.com/news/being-prepared-for-the-final-days/

GUNDERSEN LUTHERAN RESPECTING CHOICES® MODEL

First Steps®

Healthy Adults in community-MCM

Topics:
Clarify values
Designate Patient Advocate

Next Steps®

Chronic or Life-limiting disease with complications

Triggered at diagnosis. Focused on care & tx specific to disease

Last Steps®

Life expectancy
< 12 months

Topics:
DNR, hydration/nutrition.
Complete MI-POST

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THE LACROSSE, WI EXPERIENCE RESPECTING CHOICES®

Retrospective comparison of medical record and death certificate data of adults who died:

- over a 7 month period (2007/08)
- over an 11 month period (1995/96).

Hammes, B. J., Rooney, B. L., & Gundrum, J. D. (2010). A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. *Journal of the American Geriatric Society, 58*, 1249-1255.

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COLLABORATIVE EFFORT

- PARTICIPANTS INCLUDED COUNTY HEALTHCARE ORGANIZATIONS:
  - Adults were invited to reflect on and plan AD
  - Participants assisted by trained *non-physicians* for ACP
  - Written plans are accurate, specific and understandable
  - Written plans are stored and retrievable wherever person is treated
  - Plans are updated and become more specific with illness progression
  - Plans are reviewed and honored at the right time

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LACROSSE RESULTS

- All healthcare facilities (including long-term care, home health with hospice and county health management organization) participated in the review
- 519 (78%) of adult decedents were included
- *Prevalence* of AD: **90%**
- *Documented* specific preferences about CPR: **93%**
- C*onsistency* between preferences for CPR, hospitalization and treatment: **99.5%**

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LACROSSE: LESSONS LEARNED

- Implementing an effective ACP system is challenging
- Requires resources and a redesign of local systems
- Requires sustained commitment of resources
- Requires sustained leadership
- The *healthcare culture must shift* to knowing and honoring a patient's preferences to care *with the same priority as documenting allergies, knowing a patient's medical problems* and *what medications they take*.

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WHAT IF PALLIATIVE CARE WAS A DRUG?

WHAT *IS* PALLIATIVE CARE, ANYWAY?

- Philosophy of care
- Spectrum of care delivery, ranges from primary care to specialized teams
- "an approach that improves the quality of life for patients an their families facing the problems of life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

(World Health organization, 2016, HTTP://WWW.WHO.INT/CANCER/PALLIATIVE/DEFINITION/EN/)

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All hospice patients need palliative care.

Not all palliative care patients need hospice!

THE MOST IMPORTANT ELEMENTS OF END-OF-LIFE CARE~ PATIENT & FAMILY VIEWS

KNOWLEDGE:

KNOW WHEN DEATH IS COMING, AND TO UNDERSTAND WHAT CAN BE EXPECTED

HAVE ACCESS TO INFORMATION AND EXPERTISE OF WHATEVER KIND IS NECESSARY

ACCESS:

TO ANY SPIRITUAL OR EMOTIONAL SUPPORT REQUIRED

TO HOSPICE CARE IN ANY LOCATION, NOT ONLY IN THE HOSPITAL

CONTROL:

BE ABLE TO ISSUE ADVANCE DIRECTIVES, TO ENSURE WISHES ARE RESPECTED

BE ABLE TO RETAIN CONTROL OF WHAT HAPPENS

HAVE CONTROL OVER WHO IS PRESENT AT THE TIME WHEN THE END COMES

HAVE PRIVACY AND DIGNITY

HAVE CONTROL OVER PAIN RELIEF AND OTHER SYMPTOM CONTROL.

HAVE CHOICE AND CONTROL OVER WHERE DEATH OCCURS (AT HOME OR ELSEWHERE)

BE ABLE TO LEAVE WHEN IT IS TIME TO GO, AND NOT HAVE LIFE PROLONGED.

Debate of the Age Health and Care Study Group (1999).*The future of health and care of older people: the best is yet to come*. London: Age Concern; 1999.

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SHARED DECISION MAKING

- Increased knowledge
- More accurate risk perceptions
- Reduced internal conflict about decisions
- Greater likelihood of receiving care aligned with their values
- Fewer people are undecided or passive in the decision-making process

Lee, E.O., & Emanuel, M.D. (2013). Shared decision making to improve care and reduce cost. *New England Journal of Medicine, 368*, (1), p.6.

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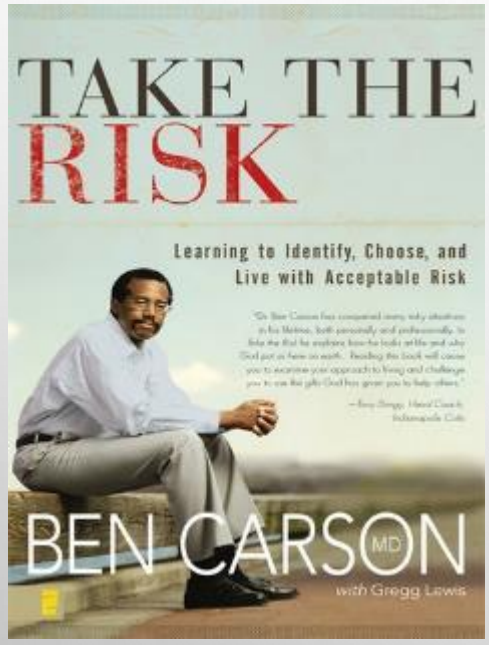
TAKE THE RISK: BEN CARSON MD



IF I CHOOSE

TO *HAVE* THE TEST/PROCEDURE/SURGERY:

- WHAT IS THE BEST OUTCOME I CAN EXPECT?
- WHAT IS THE WORST OUTCOME I CAN EXPECT?

- ***NOT TO HAVE* THE TEST/PROCEDURE/SURGERY:**
  - WHAT IS THE BEST OUTCOME I CAN EXPECT?
  - WHAT IS THE WORST OUTCOME I CAN EXPECT?

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Being Mortal: Treatment Preferences in Chronic Illness

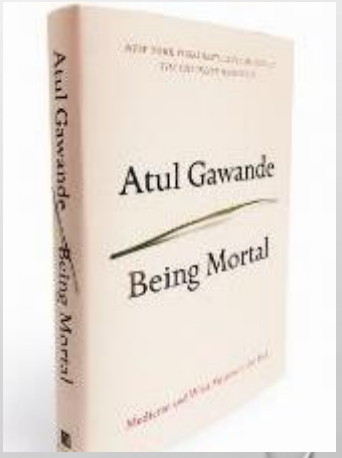
Atul Gwande MD

Gwande, A. (2015_Feb 10). Being Mortal. *PBS Frontline*. http://www.pbs.org/wgbh/frontline/film/being-mortal/

“HOPE IS NOT A PLAN…” ATUL GWANDE MD

1. IF YOUR CURRENT CONDITION WORSENS, WHAT ARE YOUR GOALS?
2. WHAT ARE YOUR FEARS?
3. ARE THERE ANY TRADEOFFS YOU ARE WILLING TO MAKE?

LATER: WHAT WOULD A GOOD DAY LOOK LIKE?



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COMMUNITY-BASED ACP AND THE TRIPLE AIM

ACP ADVANTAGES

- Community ACP opens the door to "Goals of Care" discussions
- Leads to easier transition for palliative care
- Supports the IHI Triple Aim:
  - ✓Greater patient satisfaction with care
  - ✓Lower total health care costs
  - ✓Improved community health – proactive!

- 501 (c)(3) non-profit
- Vision: foster a community culture where it is acceptable to *talk about* health care choices, including end of life, and to *respect* and *honor* those choices.
- Mission: encourage and *facilitate* advance *health* care planning by the people of West Michigan.

BASIC HEALTH CARE PLANNING INCLUDES…

- Who would make medical decisions for you?
- What medical care would you want if you were unlikely to know who you are, where you are, or who you are with?
- What religious, cultural or personal values might influence your decisions?

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1-616-421-4840
Email Us
HOME
WHO WE ARE
PROGRAMS
RESOURCES
TESTIMONIALS
FAQ
DONATE
CONTACT
Do you have a Patient Advocate who truly knows your preferences for care?
Encouraging and facilitating advance health care planning by the people of West Michigan.

PATIENT ADVOCATE QUALITIES:

- Someone you can talk to and discuss your values and goals
- Willing to accept this responsibility
- Able to follow your wishes
- Able to make decisions in stressful situations

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PREPARE TO DISCUSS:

- Treatment Preferences ~Neuro Illness/Injury~
- Spiritual/religious and cultural issues:
  - Living with meaning and hope
  - Relationships/connections to others
  - Faith
  - Sense of empowerment and confidence
- Organ donation, autopsy
- Burial/cremation/green funeral

http://www.honoringchoices.org/videostories/#!1001536

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CONSIDER THE FOLLOWING…

- You have a sudden, unexpected event (a car accident, or a complication from your illness)
- You are unaware, and it is not likely you will recover

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LIFE-PROLONGING TREATMENT

- Would you want life-prolonging treatment to continue?
- Would you want life-prolonging treatment to be stopped (allow natural death)?

CONSIDER THE BENEFITS AND BURDENS OF LIKELY TREATMENTS, E.G. CPR

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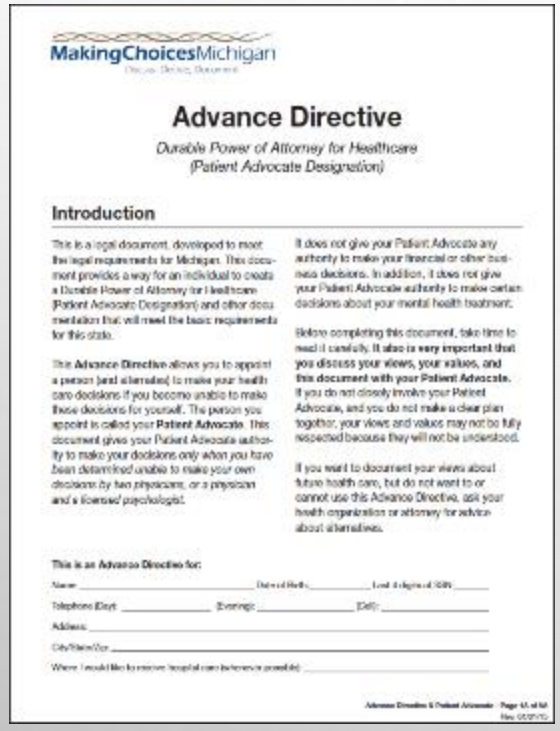
DOCUMENT!

Put your wishes in writing



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Advance Directive

Durable Power of Attorney for Healthcare
(Patient Advocate Designation)

Introduction

This is a legal document, developed to meet the legal requirements for Michigan. This document provides a way for an individual to create a Durable Power of Attorney for Healthcare (Patient Advocate Designation) and other documentation that will meet the basic requirements for this state.

This **Advance Directive** allows you to appoint a person (and alternates) to make your health care decisions if you become unable to make these decisions for yourself. The person you appoint is called your **Patient Advocate**. This document gives your Patient Advocate authority to make your decisions only when you have been determined unable to make your own decisions by two physicians, or a physician and a licensed psychologist.

It does not give your Patient Advocate any authority to make your financial or other business decisions. In addition, it does not give your Patient Advocate authority to make certain decisions about your mental health treatment.

Before completing this document, take time to read it carefully. **It also is very important that you discuss your views, your values, and this document with your Patient Advocate.** If you do not closely involve your Patient Advocate, and you do not make a clear plan together, your views and values may not be fully respected because they will not be understood.

If you want to document your views about future health care, but do not want to or cannot use this Advance Directive, ask your health organization or attorney for advice about alternatives.

This is an Advance Directive for:

Name: _____ Date of Birth: _____ Last 4 digits of SSN: _____

Telephone (Day): _____ Evening: _____ Cell: _____

Address: _____

City/State/Zip: _____

Where I would like to receive hospital care (where one is available): _____

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WHEN YOUR WRITTEN PLAN IS COMPLETED

- Talk to your family members
- Make Copies for…
  - Your Patient Advocate(s)
  - Other family members
  - Your physician/hospital

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- MCM provides free upload to GLHC
- MCM serves as link between GLHC and other agencies (law firms, CCRCs, etc.) to obtain upload capabilities
- MCM will scan AD and send (upon request) to participant

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THE "5 D'S"

REVIEW AND *UPDATE* YOUR PLAN:

- **D**ecade (five years for older participants)
- New **D**iagnosis of a serious illness
- **D**ecline related to a current illness
- **D**ivorce of you or your patient advocate
- **D**eath of someone close to you ~did it change your values or beliefs?

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HONORING THE ADVANCE DIRECTIVE WHEN THE TIME COMES

- 437 ADs completed 2014-2015
- 6 people have passed away (to our knowledge)
- AD was incorporated into the plan of care in all 6 individuals

MCM: LESSONS LEARNED

- "The Conversation" takes time
- People are open to the topic of "end of life" discussions
- Many people expressed appreciation for helping them discuss a topic that they had been unable to discuss with family on their own
- Having an advance care planning session often assisted participants and physicians to have a more open dialogue related to prognosis, treatment plan, and quality of life issues

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CONSIDER…

- What is important to you to live well?
- Who else do you need to talk to?
- Contact Making Choices Michigan to schedule a FREE facilitated conversation

WWW.MAKINGCHOICESMICHIGAN.ORG

616-421-4840

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“The Conversation” is going to happen, *with or without you*.

Jaume Plensa. *I, you, she or he (*2006). Meijer Gardens

Do you want to be part of it?

RESOURCES

The Conversation Project. *Helpful questions to help you clarify your wishes, and begin the conversation with family and friends*. http://theconversationproject.org

Downs Burgar, J., Rogers, B. (2015*). Summary of 2016 CMS Final Rule for Advance Care Planning*. Retrieved from http://www.agg.com/files/Publication/7fa202d1-41f5-4ab3-9f8d-a2a540183beb/Presentation/PublicationAttachment/506fca51-4506-4f7b-97d7-a9bf1e96e816/Burgar-Rogers-Summary-of-2016-CMS-Final-Rule-for-%20Advance-Care-Planning.pdf

Dunn, H. (2009). *Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness, 5th Edition*. A &A Publishers, Lansdowne, VA.

Enage with Grace *The One Slide Project.* Retrieved from *http://engagewithgrace.org/Default.aspx*

Making Choices Michigan (2015). *Making Choices Information Booklet and Planning Guide*. available free on the Making Choices Michigan website, or call 616-421-4840

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