INTEGRATING PALLIATIVE CARE INTO THE PCMH-N MODEL

Ethical and Legal Aspects of Care

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Welcome

- Thank you for attending this event.
- For the in-person presentation, I will be using Active Learning Strategies, such as break out sessions, open discussion, and question and answer opportunities. Your active participation will enrich and enhance this presentation.
- Please ask questions and seek clarification whenever you have a concern.
- Please complete the evaluation. Your feedback is important.

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Disclosures

Ewa Matuszewski, BA (Speaker and Planner)
No Commerical Relationships

Continuing Education

Social Work
This course is approved by the NASW-Michigan Social Work Continuing Education Collaborative Approval # 121621-01, # CE Hours approved: 2

Presenter

Ewa Matuszewski, BA
MedNetOne Health Solutions

Step Back and Think Upstream

"If I had understood
(when down the river you and I went swirling in that boat)
that there were those who knew the ways of water
and how to use the oars to keep afloat …"

(Bruce Dawe, "White-Water Rafting and Palliative Care," 2007, 18–19)

Defining Palliative Care

An approach that improves the quality of life of patients and their families facing the problems associated with 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.

Like few other areas in health care, palliative care is a phase of care and includes both primary care and specialty care.

https://www.who.int/news-room/fact-sheets/detail/palliative-care

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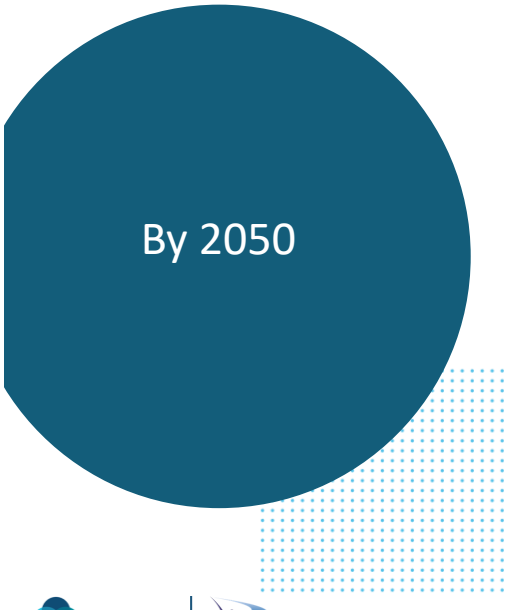

Aging American Society

- 45 to 64 years old will **increase 40%** (61 to 85 million)
- 65 and older **more than double** (34 to 79 million)
- 85 and older **more than quadruple** (4 to 18 million)

https://www.census.gov/

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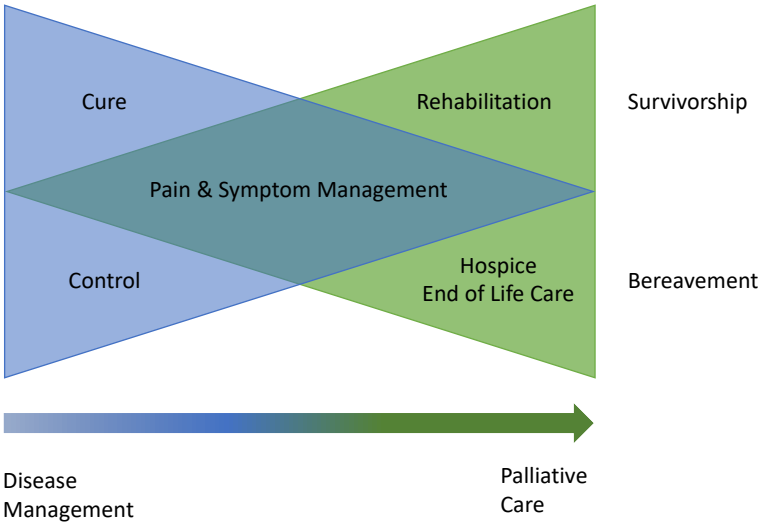
Palliative Care – Enhanced Care Model

Hawley, P,H. (2014). The Bow Tie Model of 21st Century Palliative Care. *Journal of Pain and Symptom Management*. Retrieved from http://dx.doi.org/10.1016/j.jpainsymman.2013.10.009



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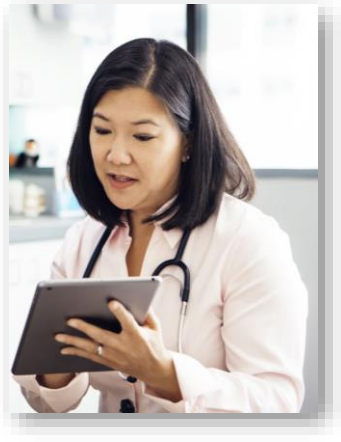
Palliative Care: Challenges for Healthcare Providers



- Minimal planned sequence of instruction on the topic of palliative care
- Not enough time to get to know patients, families and /or caregivers
- Palliative care may be discouraged; futile treatments may be encouraged
- Use of life sustaining therapies, whether appropriate, may be encouraged
- Fear of litigation

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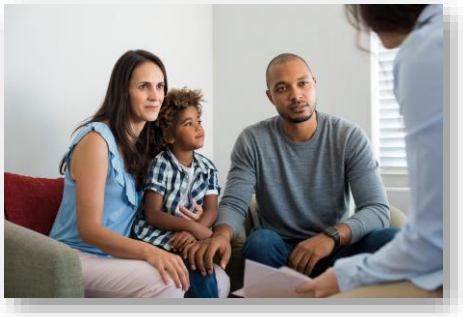
Palliative Care: Challenges for Patients and Families

- Do not know primary care services can be provided in the patient's home
- Do not understand palliative care
- Patient's wishes are unknown or not honored
- Patients may feel pressured to receive therapies they don't want
- Patients don't know they can decline treatment even if they seek care in the emergency department



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Why Seek Palliative Care in a PCMH?

- Access to a multidisciplinary team
- Coordinate care
- Address social, emotional and spiritual concerns
- Option for pain and symptom management and higher quality of life while still pursuing curative measures

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Ethical and Legal Aspects of Care

Interprofessional Team Awareness

Applies ethical principles to the care of patients with serious illness	Including honoring patient preferences as well as decisions made by legal proxies or surrogate decision makes
Acknowledges that the surrogate's obligations	Are to represent the patient's preferences
Familiarizes oneself with state and local laws	Regarding advance care planning, decisions regarding life sustaining treatment, and evolving treatments with possible legal ramifications
Is aware of the needs of vulnerable populations	Such as minors, those with developmental disabilities or psychiatric illness

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6371670/

Ethical and Legal Aspects of Care

Ethical Aspects of Serious Illness

Learning Objectives

- Explain the importance of medical ethics in palliative care
- Identify six values of medical ethics
- Discuss the integration of medical ethics into serious illness care

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Personal and Professional Ethics

- A personal set of ethics refers to an individual's beliefs and values in any area of life
- Professional ethics refers to a person's values within the workplace or occupation

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Medical Ethics

- A set of *moral principles, beliefs and values* that guide healthcare professionals in making choices about medical care
- At the core of health care ethics is the *sense of right and wrong* and our beliefs and duties we owe others about rights we possess
- *Thinking carefully* about ethical aspects of health care decisions helps us make choices that are right, good, fair and just

Medical Ethics

Goals

Deal	Recognize	Think	Apply
Deal effectively with ethical issues in clinical practice	Recognize ethical issues as they arise in clinical care and identify hidden values and unacknowledged conflicts	Think clearly and critically about ethical issues in ways that lead to an ethically justifiable course of action	Apply practical skills to implement an ethically justifiable course of action, and skills

Medical Ethics

Core Principles

- Autonomy: Honor the patients right to make their own decision
- Beneficence: Help the patient advance his/her own good
- Nonmaleficence: Do no harm
- Justice: Be fair and treat like cases alike

Cornerstone of Medical Practice: Four Plus Two

1. Autonomy	patient has the right to choose or refuse treatment
2. Beneficence	doctor should act in the best interest of the patient
3. Nonmaleficence	first do no harm
4. Justice	distribution of health resources equitably
5. Dignity	patient and the persons treating the patient have the right to self-respect
6. Truthfulness and honesty	informed consent and truthfulness

- The ability to understand one's illness in physiological terms and to conceptualize current illness as an irreversible phenomenon
- The capacity to reason and consider future implications
- The ability to act autonomously and not consent to the authority of doctors and family members

Autonomy

Self-rule

- Presumption that the decision-maker has necessary information, capacity and circumstances to make rational decisions
  - Patient has the capacity to act freely in accordance with a self-chosen plan
  - Patient is free from both controlling interference by others and from limitations

Autonomy

Principles

- Tell the truth
- Protect confidential information
- Respect privacy of others
- Obtain consent for services from patients

- Sympathetic concern for the well being of others: respect for the patient, family and caregiver
- Looking at advanced chronic illness, the value of beneficence requires that the patient's changing needs and preferences about care and treatment options and sites of care are recognized, regularly reviewed and acted upon, so that the person may live as comfortably as possible with their indisputable human dignity always respected
- Patients assume a health care provider is there for their benefit and will act with compassion, charity and kindness toward them
- Health care decisions are based on sound clinical judgements

Beneficence

Principles

- Provide benefits of care
- Balance benefits with risks/harms
- Protect and defend rights of others
- Prevent harm from occurring to others
- Remove conditions that may cause harm
- Help persons with disabilities
- Rescue persons in danger

Nonmaleficence
first do no harm

- Health care professionals have an obligation to inflict no harm or allow harm to be done to a patient
- Sister to beneficence and is an inseparable pillar of medical ethics
- Extraordinary versus ordinary care
- Complicated by advanced technology

Nonmaleficence

Principles

- Do not cause offense
- Do not incapacitate
- Do not cause pain or suffering
- Do not kill

- Most wide ranging of all ethical values
- Requires that those who are ill, and all other people involved in their care - families, caregivers, and even the wider community - are treated fairly
- Limited resources are used responsibly and wisely

Justice

Principles

- Equitable distribution of benefits, risks, costs and resources
- To each person
  - an equal share
  - according to merit
  - according to need
  - according to effort
  - according to contribution

"Time, sympathy and understanding must be lavishly dispensed… for the secret of the care of the patient is in caring for the patient."

Francis W. Peabody, MD Harvard Medical School instructor, in a famous 1926 speech

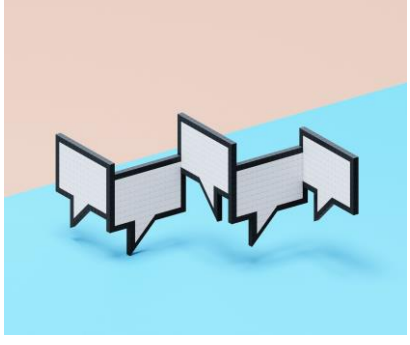
- The state or quality of being worthy of honor or respect
- Treating the patient, the way you would want to be treated
- Feeling a sense of worth or respect

Truthfulness and honesty

informed consent and truthfulness

- Total openness concerning diagnosis and prognosis
- Providing honest information about the patient's condition
- Disclosing “bad news”
- Addressing the requests from relatives “not to tell” and the conspiracy of silence

Why Integrate Ethics into Serious Illness Care



- Ensure coordination of care
- Recognize the extent and limits of the services available in the PCMH based on the care team’s own expertise and contribution of other professionals
- Develop and maintain a relationship with a community palliative care specialist
- Consider inviting a community palliative care specialist to join your PCMH-N

Learning Objectives Recap

- Explain the importance of medical ethics in palliative care
- Identify six values of medical ethics
- Discuss the integration of medical ethics into serious illness care

Ethical and Legal Aspects of Care

Legal Aspects of Serious Illness

Learning Objectives

- Identify common legal issues patients face in serious illness care
- Describe the three components of the Advance Care Planning (ACP) process
- Explain types of Advance Directives (AD)

"The good physician treats the disease.

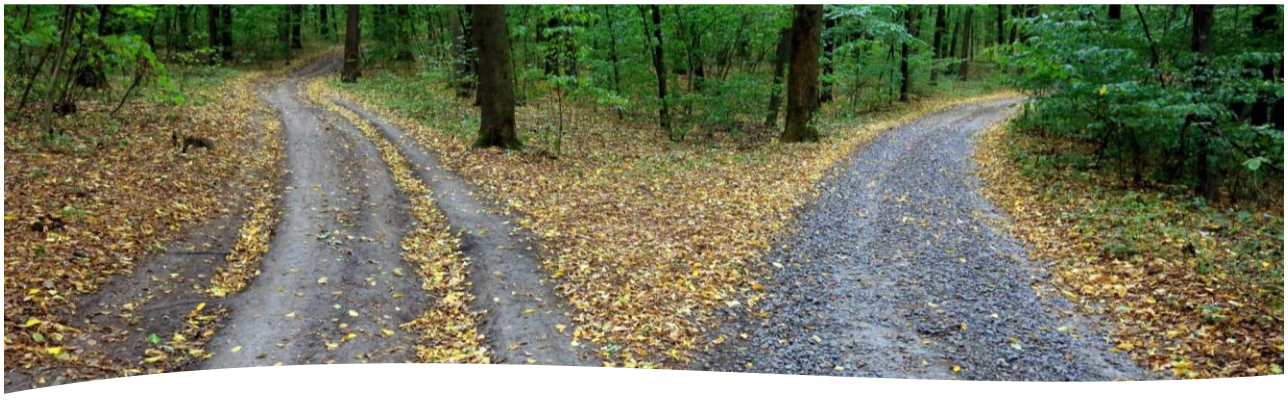
The great physician treats the patient

who has the disease."

William Osler MD

"Founder" of modern medicine

Berman (2012)



Legal Issues and Serious Illness Care

- Planning and providing care for a person with serious illnesses can involve ethically complex decision-making
- Complex decision making can occur at any point along the illness trajectory
- Healthcare providers should be prepared to address potential ethical dilemmas
- Treatment decisions can challenge a provider's values and beliefs

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Examples of Legal Issues Patients and Families May Face

- Dealing with debt
- Securing specific retirement or social benefits
- Navigating obstacles in the justice system
- Addressing discrimination
- Drafting wills
- Creating a trust
- Disposing of property
- Family law matters
- Planning for under-age children or those with disabilities

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Legal and Ethical Challenges in Healthcare Decision-Making

- Unmarried partners with no legal paperwork
- No written wishes regarding life sustaining treatment
- Children and/or stepchildren get involved and disagree on care
- Patient was not encouraged to share wishes
- Mental capacity and refusal for treatment
- Young adults (18 and older) without an Advance Directive:
  - Michigan is one of 6 states without a default surrogate consent law
  - Parents can be consulted, but may disagree on care
  - Petition to Probate Court to appoint a Guardian ad Litem (may not be related to the patient in any way, *EPIC Act, Section 700.5305 (1998)*

Common Concerns in Serious Illness

Medical Debt	Discontinuity with previous way of life
▪ More than 25% of U.S. adults struggle to pay their medical bills ▪ Medical debt is the #1 source of personal bankruptcy filings in the U.S. ▪ 20% of Americans under 65 with health insurance had trouble paying their medical bills ~ 63% used up all or most of their savings on healthcare expenses	▪ Loss of control ▪ Disruption in sense of time ▪ Loss of independence ▪ Feeling of helplessness ▪ Fear of relapse

Brown, M.E. (2014)

Patient is Ready to Engage in ACP

Interprofessional care team member recognizes the patient's desire to explore advance care planning

Voluntary Advance Care Planning

- Advance care planning is not an event but the process of planning
- Voluntary ACP is a face-to-face encounter between a qualified health care professional and a patient to discuss the patient's health care wishes if they become unable to make decisions about their care
- As part of this discussion the patient may talk about advance directives with or without completing legal forms
- An AD appoints an agent and/or records the person's wishes about their medical treatment based on their values and preferences.

Advance Care Planning (ACP) Components

Structured discussion between patient, proxy, family and qualified healthcare professional

Discuss
- Patient reflects on his/her values and beliefs

Decide
- Patient chooses a Patient Advocate(s)
- Considers choices for Goals of Care/Treatment Preferences

Document
- Record the Patient Advocate(s) choice and treatment preferences in an Advance Directive (Durable Power of Attorney for Healthcare)

The patient should share the plan!

Advance Directive vs. Living Will

Advance Directive	Treatment Preferences/Goals of Care (a.k.a. "Living Will")
▪ Appoints your Patient Advocate(s) (PA)	▪ Gives medical instruction to the Patient Advocate
▪ Gives the PA the right to participate in discussions about the patient's care and share treatment preferences with the healthcare team	▪ *The GIFT a patient gives to their selected advocate!*
▪ ***Required document by state of Michigan***	▪ *It is not a required legal document in Michigan*
	▪ ***It does not "stand alone" by state statute*** *State of MI (2000)*

Advance Directive: Patient Advocate Designation

- A legal document that allows a person to appoint a person to share their healthcare decisions
- Document used when a person loses decision making ability (capacity)
- Document is signed, dated and witnessed (not notarized)
- Most helpful to the healthcare team if the patient has discussed their wishes with their Patient Advocate
- Document is captured in the health record

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Capacity and Competence

Capacity

- A ***clinical*** term referring to the ability to exercise decision making autonomy that reflects personal preferences, values, and judgments
- Ability to understand relevant information about his or her condition
- Able to process probable outcomes of the disease and of various potential interventions and alternative therapies
- Able to make an informed decision using the information, based on own beliefs, values and understanding of the consequences of the decision
- Able to communicate a decision

Competence

- A ***legal*** term, declared only by a judge and refers to a person's mental and cognitive capabilities to execute a legally recognized act.
- If the judge rules a person to be incompetent, a guardian is assigned
- If a person has designated a Durable Power of Attorney for Healthcare/Patient Advocate prior to being declared incompetent, the designated health care advocate will remain in the position to have medical decision-making authority, even if a guardian is assigned

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Discuss A Good Death

Preventive Approach in Primary Care

- A sense of control - site, further treatment, who is in attendance
- A sense of dignity and privacy - respect for decisions
- A sense of relief from pain and symptoms – state of the art pain and symptom control
- Revisiting Advance Directives and Advance Care Planning
- Visioning the future with the patient

Who Should Have the ACP Conversation?

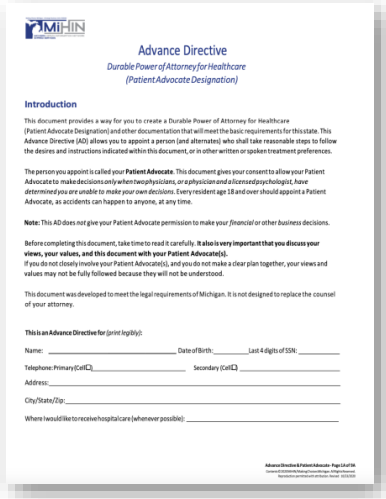
- It is important for *all* adults ages 18 and older
- Prepares the Patient Advocate(s) to speak for the patient if he/she cannot
- Patient Advocates suffer less depression, anxiety and post-traumatic stress disorder if they have a meaningful conversation with the person *in advance of a healthcare crisis*

Hickman, Daily & Lee (2012); Placovic (2016)

Choosing Your Patient Advocate

- Accepts the role/job in writing
- Willing to talk NOW with the patient about this/her goals, values, and preferences for care
- Will follow the patient's choices, *even if he or she does not agree with them*
- Able to make decisions, *even if he or she feels stressed*

ACP Documentation Tools



Advance Directive

Durable Power of Attorney for Healthcare
(Patient Advocate Designation)

Introduction

This document provides a way for you 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 (AD) allows you to appoint a person (and alternates) who shall take reasonable steps to follow the desires and instructions indicated within this document, or in other written or spoken treatment preferences.

The person you appoint is called your **Patient Advocate**. This document gives your consent to allow your Patient Advocate to make decisions *only when two physicians, or a physician and a licensed psychologist, have determined you are unable to make your own decisions.* Every resident age 18 and over should appoint a Patient Advocate, as accidents can happen to anyone, at any time.

Note: This AD does not give your Patient Advocate permission to make your *financial* or other *business* decisions.

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(s).** If you do not closely involve your Patient Advocate(s), and you do not make a clear plan together, your views and values may not be fully followed because they will not be understood.

This document was developed to meet the legal requirements of Michigan. It is not designed to replace the counsel of your attorney.

This is an Advance Directive for *(print legibly)*:

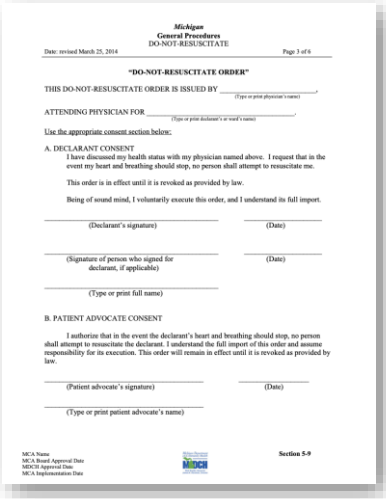
Name: _____ Date of Birth: _____ Last 4 digits of SSN: _____

Telephone: Primary (Cell ☐) _____ Secondary (Cell ☐) _____

Address: _____

City/State/Zip: _____

Where I would like to receive hospital care (whenever possible): _____



Michigan
General Procedures
DO-NOT-RESUSCITATE

Date: revised March 25, 2014 Page 3 of 6

"DO-NOT-RESUSCITATE ORDER"

THIS DO-NOT-RESUSCITATE ORDER IS ISSUED BY _____,
(Type or print physician's name)

ATTENDING PHYSICIAN FOR _____,
(Type or print declarant's or ward's name)

Use the appropriate consent section below:

A. DECLARANT CONSENT

I have discussed my health status with my physician named above. I request that in the event my heart and breathing should stop, no person shall attempt to resuscitate me.

This order is in effect until it is revoked as provided by law.

Being of sound mind, I voluntarily execute this order, and I understand its full import.

_____ _____
(Declarant's signature) (Date)

_____ _____
(Signature of person who signed for declarant, if applicable) (Date)

_____
(Type or print full name)

B. PATIENT ADVOCATE CONSENT

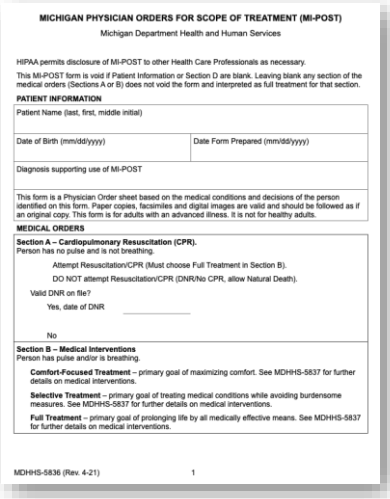
I authorize that in the event the declarant's heart and breathing should stop, no person shall attempt to resuscitate the declarant. I understand the full import of this order and assume responsibility for its execution. This order will remain in effect until it is revoked as provided by law.

_____ _____
(Patient advocate's signature) (Date)

_____
(Type or print patient advocate's name)

MCA Name
MCA Board Approval Date
MDCH Approval Date
MCA Implementation Date

Section 5-9



MICHIGAN PHYSICIAN ORDERS FOR SCOPE OF TREATMENT (MI-POST)

Michigan Department Health and Human Services

HIPAA permits disclosure of MI-POST to other Health Care Professionals as necessary.

This MI-POST form is void if Patient Information or Section D are blank. Leaving blank any section of the medical orders (Sections A or B) does not void the form and interpreted as full treatment for that section.

PATIENT INFORMATION

Patient Name (last, first, middle initial)	
Date of Birth (mm/dd/yyyy)	Date Form Prepared (mm/dd/yyyy)
Diagnosis supporting use of MI-POST	

This form is a Physician Order sheet based on the medical conditions and decisions of the person identified on this form. Paper copies, facsimiles and digital images are valid and should be followed as if an original copy. This form is for adults with an advanced illness. It is not for healthy adults.

MEDICAL ORDERS

Section A – Cardiopulmonary Resuscitation (CPR).
Person has no pulse and is not breathing.

Attempt Resuscitation/CPR (Must choose Full Treatment in Section B).

DO NOT attempt Resuscitation/CPR (DNR/No CPR, allow Natural Death).

Valid DNR on file?

Yes, date of DNR _____

No

Section B – Medical Interventions
Person has pulse and/or is breathing.

Comfort-Focused Treatment – primary goal of maximizing comfort. See MDHHS-5837 for further details on medical interventions.

Selective Treatment – primary goal of treating medical conditions while avoiding burdensome measures. See MDHHS-5837 for further details on medical interventions.

Full Treatment – primary goal of prolonging life by all medically effective means. See MDHHS-5837 for further details on medical interventions.

MDHHS-5836 (Rev. 4-21) 1

Treatment Preferences
Personalizing care

- **Important considerations**
  - Location: home, hospital or care facility?
  - Children and/or stepchildren: how involved should they be in the care?
  - Visitors: immediate family only or all friends welcome?
  - Finances:
- **What would provide comfort (no matter the location)?**
  - Rituals: prayer, readings, meditation, guided imagery?
  - Environment: lighting, quiet or noise and laughter, certain music, certain foods, pets?
- **What does the patient know/understand about Palliative Care & Hospice Services?**

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What Should You Counsel the Patient To Do Now

- Do their homework
  - https://theconversationproject.org
  - https://prepareforyourcare.org/welcome
- Talk with a potential Patient Advocate(s)
- Complete the Advance Directive
  - https://mihin.org/advance-care-planning-resources/
  - https://prepareforyourcare.org/advance-directive
  - https://www.nhpco.org/advancedirective/

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Document Storage and Retrieval

"It doesn't do you any good if no one can find it..."

1. **Talk** to family and close friends and give them the Patient Advocate name(s) and tell them treatment preferences
2. **Keep** the original Advance Directive (AD) where it can be *easily* found
3. **Give** a copy to the Patient Advocate(s); an electronic PDF sent by email can be stored in a smart phone
4. **Give** a copy to the healthcare team to scan into your electronic health record (EHR)
5. **Take** a copy to the hospital or care facility and ask them to place it in the health care record (EHR)

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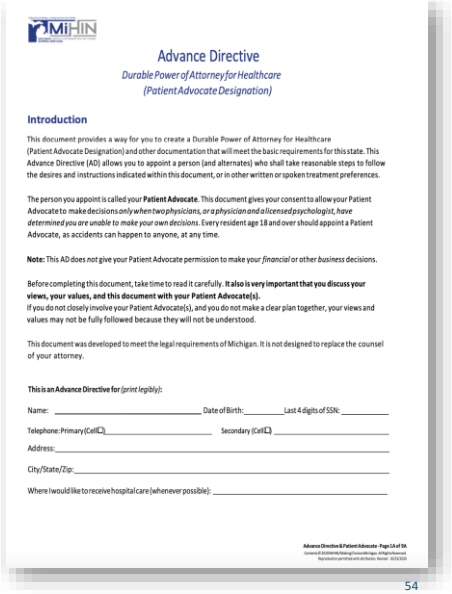
Review the AD Periodically

- Advance care planning is a *process*, not a one-time event!
- A person may change their mind over time and situations
- If the AD is updated, be sure the Patient Advocate(s) and Healthcare Provider have the revised copy

Making Choices Michigan (2021)



MiHIN

Advance Directive

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Telephone: Primary (Cell ☐) _____ Secondary (Cell ☐) _____

Address: _____

City/State/Zip: _____

Where I would like to receive hospital care (whenever possible): _____

Advance Directive & Patient Advocate - Page 1 & of 5A

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Summary

"How a person faces serious illness

will obviously require a broader cultural change,

so death itself will not be considered as something to ignore,

but accepted as part of life itself, something to talk about,

and a crucial theme for every healthcare professional's training."

https://ethnomed.org/resource/cultural-relevance-in-end-of-life-care/

Learning Objectives Recap

- Identify common legal issues patients face in serious illness care
- Describe the three components of the Advance Care Planning (ACP) process
- Explain types of Advance Directives (AD)

Questions?

Thank you

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