Conversations to Promote Advance Care Planning in the LGBTQ+ Community

Northeast Ohio Aging & DisABILITY Summit
09/29/2023

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Nothing to disclose.

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Marcie Lambrix, MA

Anna Goff, MA

Inamori International Center for Ethics and Excellence

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Objectives

- Encourage self-reflection about your values and preferences when LGBTQ+ individuals are faced with difficult health issues.
- Promote conversations with others to understand the healthcare values and preferences of LGBQT+ individuals.
- Provide necessary documents to provide LGBQT+ individuals that outline desired healthcare preferences.

Who gets involved when you're sick and can't participate in medical decisions?

Adults (over 18 years)

- Health Care Power of Attorney or Guardian
- Spouse
- Majority of adult children
- Parent(s)
- Majority of siblings
- Nearest adult relative by blood or adoption

Children (under 18 years)

- Parent(s)/guardian
  - This can get very complicated
    - Separations/divorces/establishment of paternity
- Mature minors* can consent to the following without parent/guardian:
  - Emergency care
  - Limited outpatient mental health care
  - Alcohol and drug abuse treatment
  - Testing and treatment for HIV/AIDS
  - Some family planning services

*no law for emancipated minors –can occur when they marry or join armed forces

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Starr

Starr

- 45-year-old transgender female admitted via ED after being found down on a sidewalk
- apparent accidental overdose
- history of epilepsy and alcohol and substance use
- hospital course included two cardiac arrests and infections
- no listed emergency contacts, no advance directives
- previous hospital notes indicate she is estranged from her family, though had recently been reconnecting with a son

What does (should) a hospital due in the case?

- The short answer: find family.

- How?
  - thoroughly review medical records
  - use search engines
  - social media
  - court records
  - other

- Why?
  - Legal and ethical obligation to do so.

But …

Unfortunately, not every (*dare I say most?)* hospital system spends the time looking for surrogates.

They have an internal process, a *committee*, that determines medical treatment.

Statistics

- 5.5% of patients who died in intensive care units lacked decision making capacity and did not have a surrogate
  - 0-27% across 7 centers (White et al 2007)

- 16% of patients admitted to ICUs lacked decision making capacity and did not have a surrogate for the entire stay (White et al 2006)

Statistics

- Patients who lacked decision making capacity and did not have a surrogate were in the ICU twice as long as other ICU patients (median of 6 days versus median of 3 days)

- Patients who lacked decision making capacity and did not have a surrogate received more (questionable) life-sustaining treatments

White et al 2006

End-of-life wishes

- 340 patients in one study rated the following as very important at the end of life:
  - 90% Say goodbye to important people
  - 86% Resolve unfinished business with family or friends
  - 85% Share time with close friends
  - 85% Believe that family is prepared for one's death
  - 81% Presence of family
  - 75% Not die alone

Steinhauser et al 2000

A second study

Heyland, et al

Patients (434)

1. To have trust and confidence in the doctor looking after you
2. Not to be kept alive on life support when there is little hope for a meaningful recovery
3. That information about your disease be communicated to you by the doctor in an honest manner
4. To complete things and prepare for life's end (life review, resolving conflicts, saying goodbye)

Family Members (160)

1. To have trust and confidence in the doctor looking after the patient
2. To not have your family member be kept alive on life support when there is little hope for a meaningful recovery
3. That information about your family member's disease be communicated to you by the doctor in an honest manner
4. To have an adequate plan of care and health services to look after him or her at home, after discharge from the hospital

8. To complete things, resolve conflicts, and say goodbye to your family member

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  - court records
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What did we find?

- Starr had a lot of Facebook friends
- We were able to locate extended family via obituaries and mention of Starr's given name
- Extended family, uncle in particular, was willing to be involved

- *But is this who Starr would have chosen as her surrogate?*

Advance Care Planning

What is Advance Care Planning (ACP)?

- ACP is concerned with people proactively thinking and communicating about what their health care wishes would be if they are unable to speak for themselves at any time in the future.

- Two Types:
  1. Formal ACP – the completion of legal documents that outline a patient's wishes in the event they lose capacity.
  2. Informal ACP – conversations and discussions with loved ones about health care preferences.

ACP in the LGBTQ+ Community

- Research has shown that only 10% of LGBTQ+ people have had an ACP discussion with their primary health care provider (Kcomt et al., 2019).
  - Fear regarding identity
  - Fear their wishes and surrogate would not be respected (Reich, et al., 2022)

- Transgender people were 50–70% less likely than their LGB counterparts to have a living will or to have appointed a healthcare proxy (Kcomt et al., 2019).

Disparities in the LGBTQ+ Community

- LGBTQ+ individuals face **barriers** that can complicate health care, particularly around aging and end-of-life issues:
  - Aging LGBTQ+ individuals are more likely to live alone and less likely to have children or legal spouses.
  - Some LGBTQ+ individuals have experienced rejection from their family of origin and have a greater reliance on chosen family which can present legal challenges.
  - ACP discussions between LGBTQ+ people and their primary health care providers are less common.

(Kcomt, L., & Gorey, K. M., 2019)

Simon

Simon

- 85-year-old male with end-stage dementia and COPD admitted for respiratory failure and poor prognosis
- Live-in caregiver indicates patient's 84-year-old-wife also had dementia and could not participate in patient's medical decisions
- Live-in caregiver indicates she is patient's health care power of attorney, but she cannot find the paperwork
- Live-in caregiver states patient has an estranged adult son

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- The short answer: find family.

- How?
  - thoroughly review medical records
  - use search engines
  - social media
  - court records
  - other

- Why?
  - Legal and ethical obligation to do so.

What did we find?

- The patient's son
  who was now living as a female.

- *Is this who Simon would have chosen as his surrogate?*
- *With whom do we share our findings?*

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Formal ACP

What are Advance Directives?

- Advance Directives are legal documents that let others know who you want participating in your medical care and what type of medical care you want. They will be used if you become too ill to participate in medical decisions on your own behalf.

Some Advance Directives in Ohio

Health Care Power of Attorney (HCPOA)

Declaration for Mental Health Treatment

Living Will

Organ Donation Form

Disposition of Bodily Remains

And, guess what?

YOU DON'T NEED A LAWYER TO COMPLETE ANY OF THEM!

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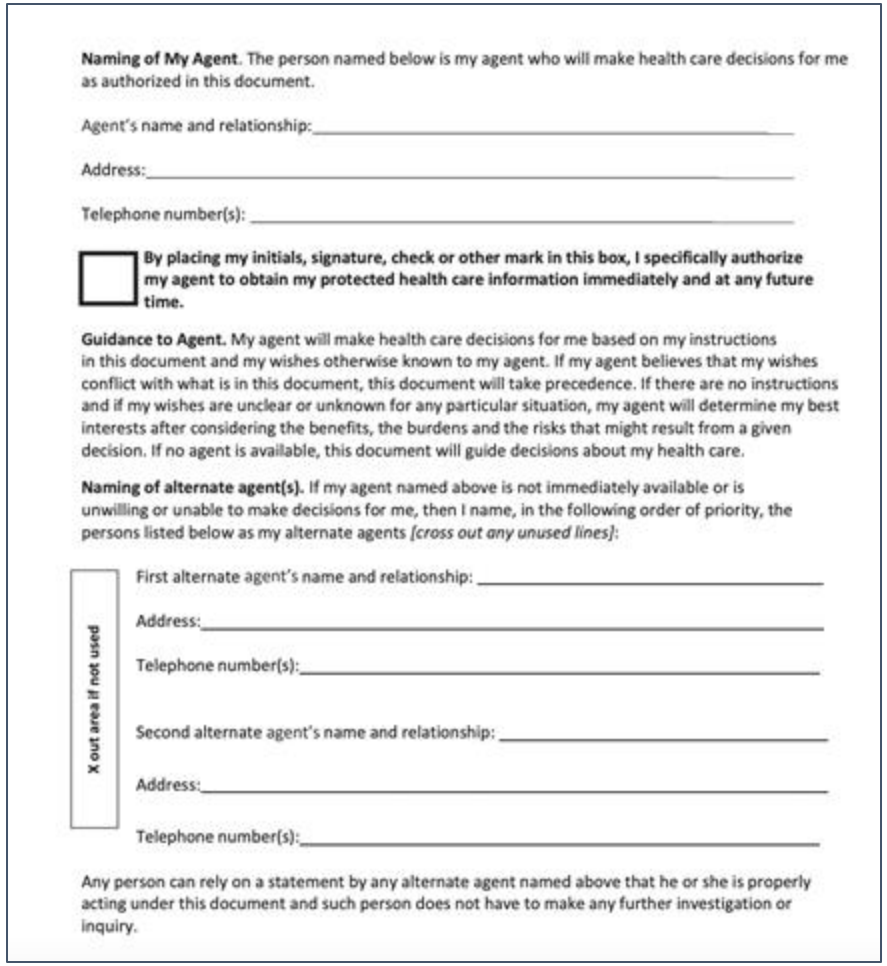
Health Care Power of Attorney (HCPOA)

- This document allows you to name someone to participate in medical decisions on your behalf.
- This individual will be tasked with telling the medical team what treatments you do and do not want.
- Choose someone you trust and discuss your medical wishes with them!

NOTE: This is different than a financial power of attorney!



Naming of My Agent. The person named below is my agent who will make health care decisions for me as authorized in this document.

Agent's name and relationship:_____

Address:_____

Telephone number(s): _____

☐ **By placing my initials, signature, check or other mark in this box, I specifically authorize my agent to obtain my protected health care information immediately and at any future time.**

Guidance to Agent. My agent will make health care decisions for me based on my instructions in this document and my wishes otherwise known to my agent. If my agent believes that my wishes conflict with what is in this document, this document will take precedence. If there are no instructions and if my wishes are unclear or unknown for any particular situation, my agent will determine my best interests after considering the benefits, the burdens and the risks that might result from a given decision. If no agent is available, this document will guide decisions about my health care.

Naming of alternate agent(s). If my agent named above is not immediately available or is unwilling or unable to make decisions for me, then I name, in the following order of priority, the persons listed below as my alternate agents *[cross out any unused lines]*:

X out area if not used

First alternate agent's name and relationship: _____

Address:_____

Telephone number(s):_____

Second alternate agent's name and relationship: _____

Address:_____

Telephone number(s):_____

Any person can rely on a statement by any alternate agent named above that he or she is properly acting under this document and such person does not have to make any further investigation or inquiry.

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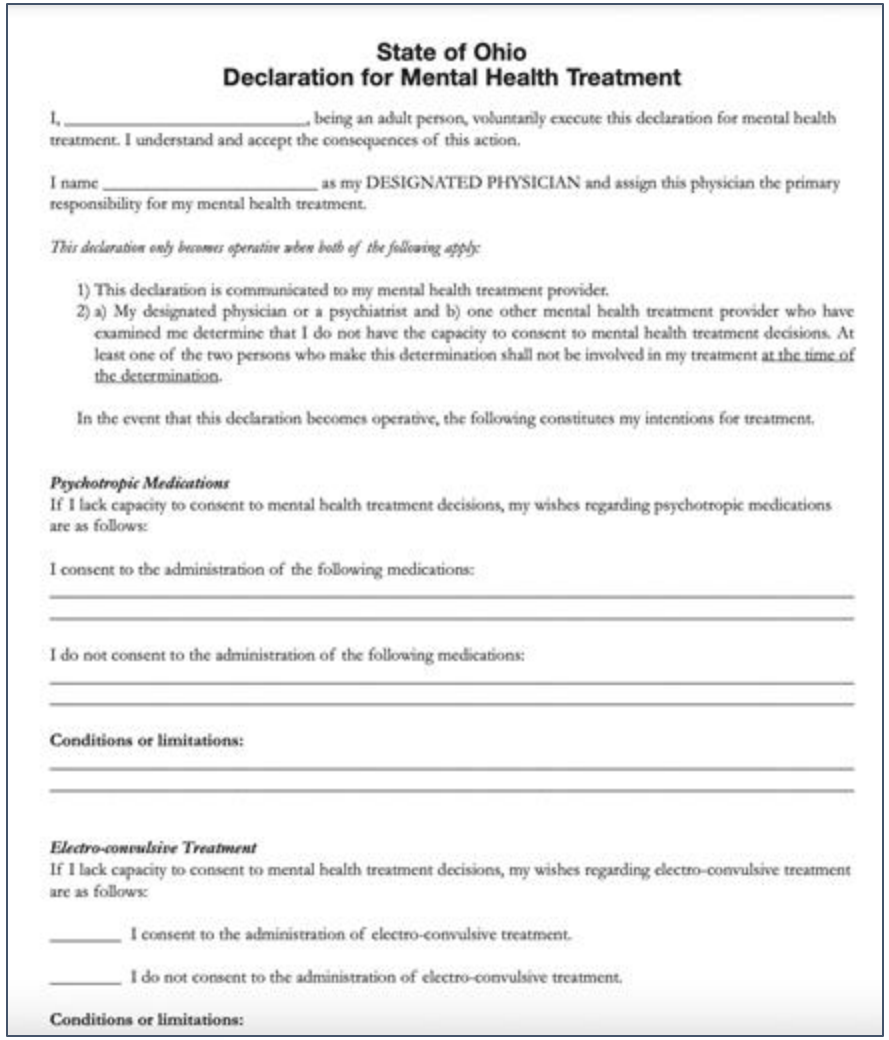
Declaration for Mental Health Treatment



State of Ohio
Declaration for Mental Health Treatment

I, _____, being an adult person, voluntarily execute this declaration for mental health treatment. I understand and accept the consequences of this action.

I name _____ as my DESIGNATED PHYSICIAN and assign this physician the primary responsibility for my mental health treatment.

This declaration only becomes operative when both of the following apply:

1) This declaration is communicated to my mental health treatment provider.
2) a) My designated physician or a psychiatrist and b) one other mental health treatment provider who have examined me determine that I do not have the capacity to consent to mental health treatment decisions. At least one of the two persons who make this determination shall not be involved in my treatment at the time of the determination.

In the event that this declaration becomes operative, the following constitutes my intentions for treatment.

Psychotropic Medications
If I lack capacity to consent to mental health treatment decisions, my wishes regarding psychotropic medications are as follows:

I consent to the administration of the following medications:
_____
_____

I do not consent to the administration of the following medications:
_____
_____

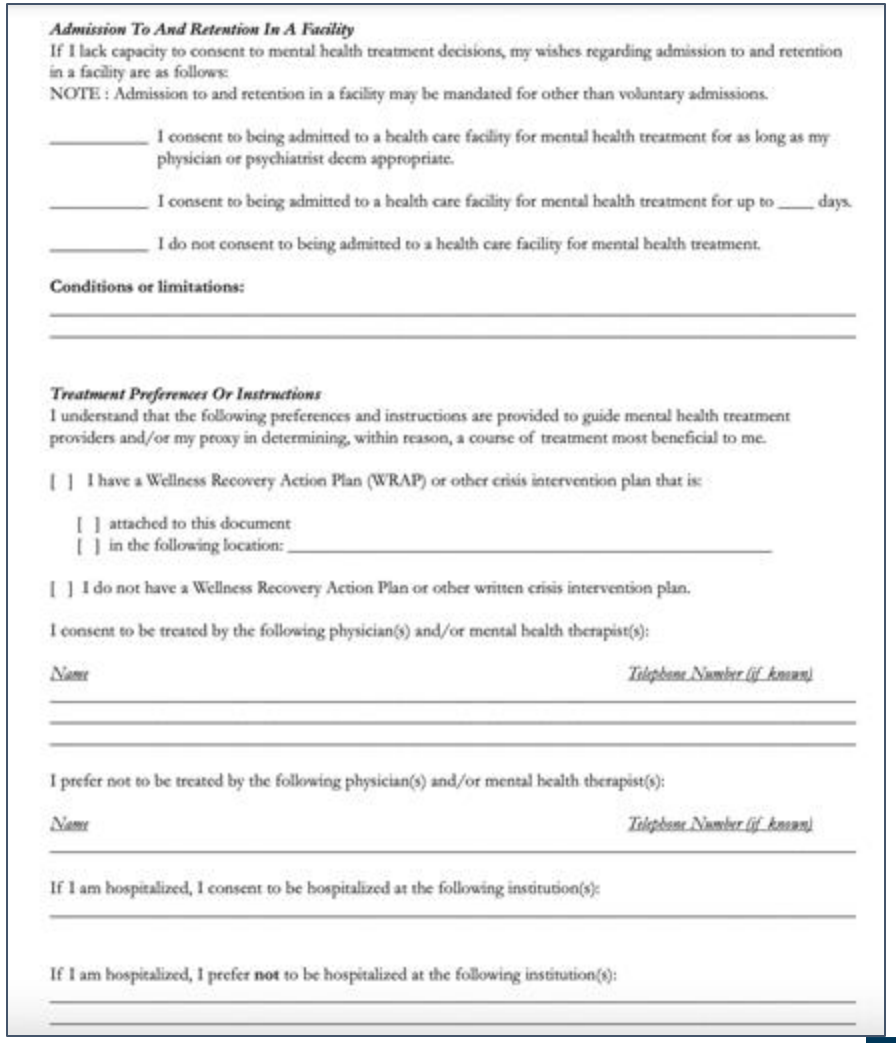
Conditions or limitations:
_____
_____

Electro-convulsive Treatment
If I lack capacity to consent to mental health treatment decisions, my wishes regarding electro-convulsive treatment are as follows:

_____ I consent to the administration of electro-convulsive treatment.

_____ I do not consent to the administration of electro-convulsive treatment.

Conditions or limitations:



Admission To And Retention In A Facility
If I lack capacity to consent to mental health treatment decisions, my wishes regarding admission to and retention in a facility are as follows:
NOTE : Admission to and retention in a facility may be mandated for other than voluntary admissions.

_____ I consent to being admitted to a health care facility for mental health treatment for as long as my physician or psychiatrist deem appropriate.

_____ I consent to being admitted to a health care facility for mental health treatment for up to ____ days.

_____ I do not consent to being admitted to a health care facility for mental health treatment.

Conditions or limitations:
_____
_____

Treatment Preferences Or Instructions
I understand that the following preferences and instructions are provided to guide mental health treatment providers and/or my proxy in determining, within reason, a course of treatment most beneficial to me.

[ ] I have a Wellness Recovery Action Plan (WRAP) or other crisis intervention plan that is:

[ ] attached to this document
[ ] in the following location: _____

[ ] I do not have a Wellness Recovery Action Plan or other written crisis intervention plan.

I consent to be treated by the following physician(s) and/or mental health therapist(s):

Name *Telephone Number (if known)*
_____
_____
_____

I prefer not to be treated by the following physician(s) and/or mental health therapist(s):

Name *Telephone Number (if known)*
_____

If I am hospitalized, I consent to be hospitalized at the following institution(s):
_____

If I am hospitalized, I prefer **not** to be hospitalized at the following institution(s):
_____
_____

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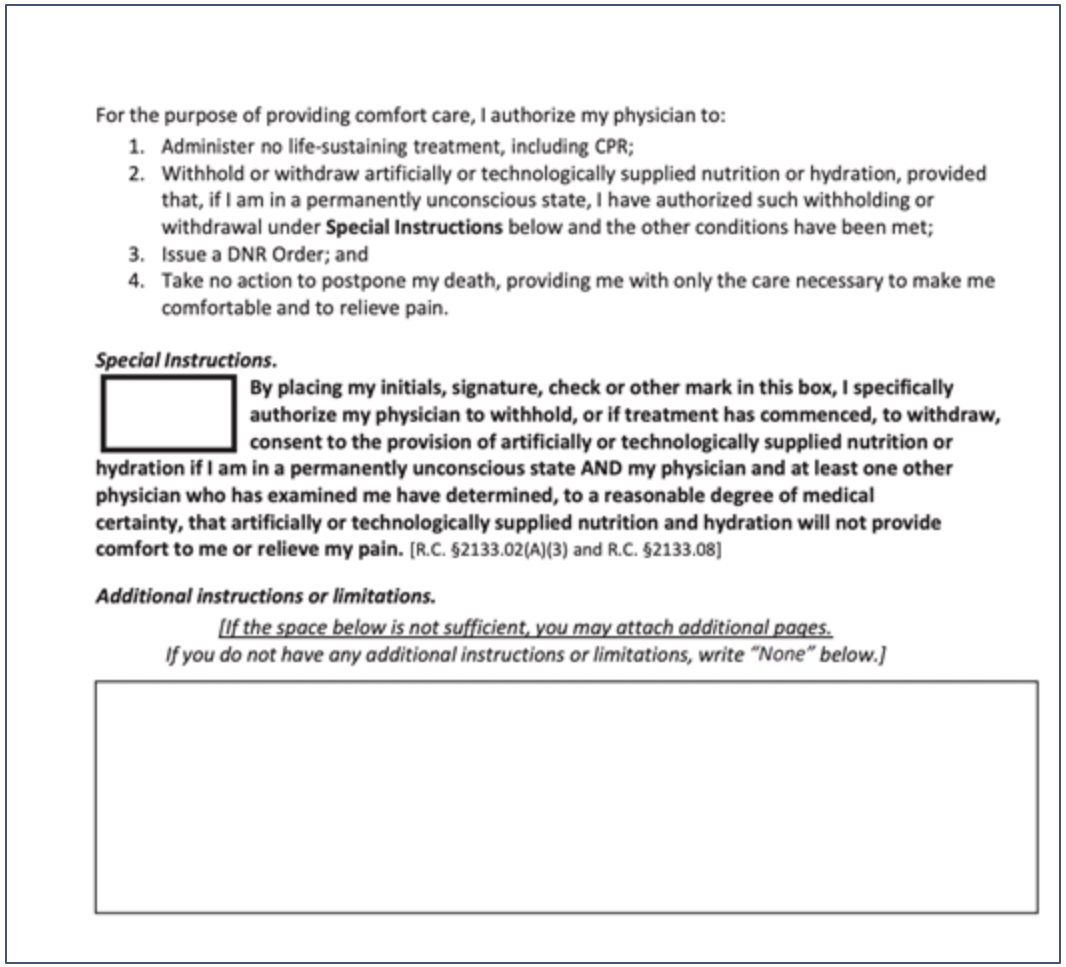
Declaration for Mental Health Treatment

- This document allows you to do the following:
  - Name someone to talk with your medical team about your mental health care on your behalf.
  - Designate a preferred physician.
  - Share your wishes about specific mental health treatments including psychotropic medication and electroconvulsive treatment.
  - *Name someone to care for your pets if you are in the hospital!*
- This document requires renewal after three years as well as a signature from the person you name in the declaration to participate in treatment decisions on your behalf.
  - *NOTE: This requirement is specific to the Declaration for Mental Health Treatment!*

Living Will



For the purpose of providing comfort care, I authorize my physician to:

1. Administer no life-sustaining treatment, including CPR;
2. Withhold or withdraw artificially or technologically supplied nutrition or hydration, provided that, if I am in a permanently unconscious state, I have authorized such withholding or withdrawal under **Special Instructions** below and the other conditions have been met;
3. Issue a DNR Order; and
4. Take no action to postpone my death, providing me with only the care necessary to make me comfortable and to relieve pain.

Special Instructions.

☐ **By placing my initials, signature, check or other mark in this box, I specifically authorize my physician to withhold, or if treatment has commenced, to withdraw, consent to the provision of artificially or technologically supplied nutrition or hydration if I am in a permanently unconscious state AND my physician and at least one other physician who has examined me have determined, to a reasonable degree of medical certainty, that artificially or technologically supplied nutrition and hydration will not provide comfort to me or relieve my pain.** [R.C. §2133.02(A)(3) and R.C. §2133.08]

Additional instructions or limitations.

[If the space below is not sufficient, you may attach additional pages.
If you do not have any additional instructions or limitations, write "None" below.]

- Your living will comes into effect when:
  1. You are terminally ill and incapacitated

     OR

  2. You are permanently unconscious
- This document allows you to share your preferences about life-sustaining treatments.
  - Breathing machines
  - Feeding tubes
- You should also communicate these wishes with your HCPOA and/or loved ones!

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Organ Donation Form

- This document allows you to share your wishes regarding organ and tissue donation.
  - Transplantation
  - Therapy
  - Research
  - Education
- You should also communicate these wishes with your HCPOA and/or other loved ones!
- *If you check the box at the BMV you are agreeing to all of these!*

To register, please complete and mail this enrollment form to:
Ohio Bureau of Motor Vehicles
Attn: Records Request
P.O. Box 16583
Columbus, OH 43216-6583

PLEASE PRINT

LAST NAME	FIRST	MIDDLE
MAILING ADDRESS		
CITY	STATE	ZIP
PHONE ( ) -	DATE OF BIRTH / / /	STATE OF OHIO DL/ID CARD # **OR** SOCIAL SECURITY #

DONOR REGISTRY ENROLLMENT OPTIONS

OPTION 1

☐ Upon my death, I make an anatomical gift of my organs, tissues, and eyes for any purpose authorized by law.

OPTION 2

☐ Upon my death, I make an anatomical gift of the following organs, tissues, and/or eyes selected below:

☐ All organs, tissues and eyes

ORGANS

☐ Heart ☐ Intestines
☐ Lungs ☐ Small Bowel
☐ Liver (and associated vessels)
☐ Kidneys (and associated vessels)
☐ Pancreas/Islet Cells

TISSUES

☐ Eyes/Corneas ☐ Veins
☐ Heart Valves ☐ Fascia
☐ Bone ☐ Skin
☐ Tendons ☐ Nerves
☐ Ligaments

For the following purposes authorized by law:

☐ All purposes ☐ Transplantation ☐ Therapy ☐ Research ☐ Education

OPTION 3

☐ Please take me out of the Ohio Donor Registry.

SIGNATURE OF DONOR REGISTRANT	DATE
X	

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Disposition of bodily remains

OHIO APPOINTMENT OF REPRESENTATIVE FOR DISPOSITION OF BODILY REMAINS, FUNERAL ARRANGEMENTS, AND BURIAL OR CREMATION GOODS AND SERVICES

Authorized by House Bill 426, Effective October 12, 2006

I, (legal name and address) _____ _____, a n adult being of sound mind, willfully and voluntarily appoint my representative, named below, to have the right of disposition, as defined in section 2108.70 of the Revised Code, for my body upon my death. All decisions made by my representative with respect to the right of disposition shall be binding.

REPRESENTATIVE(S):
(If the representative is a group of persons, indicate the name, last known address and phone number of each person in the group. Attach additional sheet if necessary.)

Name: _____ _____

Address:_____ _____

Telephone Number: _____

SUCCESSOR REPRESENTATIVE(S):
If my representative is disqualified from serving as my representative as described in section 2108.75 of the Revised Code, then I hereby appoint the following person or group of persons to serve as my successor representative.

(If the representative is a group of persons, indicate the name, last known address and phone number of each person in the group. Attach additional sheet if necessary.)

Name: _____ _____

Address:_____ _____

Telephone Number: _____

PREFERENCES REGARDING HOW THE RIGHT OF DISPOSITION SHOULD BE EXERCISED, INCLUDING ANY RELIGIOUS OBSERVANCES THE DECLARANT WISHES A REPRESENTATIVE OR A SUCCESSOR REPRESENTATIVE TO CONSIDER (attach additional sheets if necessary):

_____

_____ _____

_____

_____

ONE OR MORE SOURCES OF FUNDS THAT COULD BE USED TO PAY FOR GOODS AND SERVICES ASSOCIATED WITH AN EXERCISE OF THE RIGHT OF DISPOSITION:

_____

1 _____

_____

_____

_____

DURATION:
The appointment of my representative and, if applicable, successor representative, becomes effective upon my death.

PRIOR APPOINTMENTS REVOKED:
I hereby revoke any written declaration that I executed in accordance with section 2108.70 of the Ohio Revised Code prior to the date of execution of this written declaration indicated below.

AUTHORIZATION TO ACT:
I hereby agree that any of the following that receives a copy of this written declaration may act under it:
- Cemetery organization;
- Crematory operator;
- Business operating a columbarium;
- Funeral director;
- Embalmer;
- Funeral home;
- Any other person (such as the representative named herein) asked to assist with my funeral, burial, cremation, or other manner of final disposition.

MODIFICATION AND REVOCATION - WHEN EFFECTIVE:
Any modification or revocation of this written declaration is not effective as to any party until that party receives actual notice of the modification or revocation.

LIABILITY:
No person who acts in accordance with a properly executed copy of this written declaration shall be liable for damages of any kind associated with the person's reliance on this declaration.

Signed this _____ day of _____, 2 _____

_____
(Signature of declarant)

WITNESSES:
I attest that the declarant signed or acknowledged this assignment of the right of disposition under section 2108.70 of the Revised Code in my presence and that the declarant is at least eighteen years of age and appears to be of sound mind and not under or subject to duress, fraud, or undue influence. I further attest that I am not the declarant's representative or successor representative, I am at least eighteen years of age, and I am not related to the declarant by blood, marriage, or adoption.

(CONTINUED NEXT PAGE)

2 _____

First witness:
Name (printed) _____

Residing at:_____

Signature:_____ Date:_____

Second witness:
Name (printed) _____

Residing at:_____

Signature:_____Date:_____

~OR~

NOTARY ACKNOWLEDGMENT:
State of Ohio, County of_____ SS.

On _____ before me, the undersigned notary public, personally appeared _____ known to me or satisfactorily proven to be the person whose name is subscribed as the declarant, and who has acknowledged that he or she executed this written declaration under section 2108.70 of the Revised Code for the purposes expressed in that section. I attest that the declarant is at least eighteen years of age and appears to be of sound mind and not under or subject to duress, fraud, or undue influence.

Signature of notary public:

_____

My commission expires on: _____

For further reference, see ORC 2108.70 et seq. Consult your attorney for specific questions.

3 _____

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Disposition of bodily remains

- Name a successor to oversee the disposition of your body upon your death
- Share wishes regarding funeral, memorial services, religious observances

Disposition of bodily remains

Next of kin hierarchy if you don't complete this form (HCPOA does NOT apply)

- Spouse
- Adult children, collectively
- Parent(s)
- Adult siblings, collectively
- Grandparent(s)
- Grandchildren, collectively
- Lineal descendants of decedent's grandparents
- Guardian
- Any other person willing to assume right of disposition

Sarah and Michelle

Sarah & Michelle

- Sarah is a 75-year-old with history of dementia and admitted with COVID pneumonia
- She is not able to participate in medical decisions
- Her long-time partner, Michelle, is at the bedside and provides a hard copy of the health care power of attorney form Sarah completed 5 years ago naming Michelle as her health care power of attorney
- The social worker documents that she received it, but it gets lost and is never scanned
- It was the only copy …

Who should have a copy of your Advance Directive(s)?

- Your primary care provider (PCP)
- The hospital(s) that you're most likely to receive care at
- Your HCPOA (if relevant)
- Other loved ones
- You should also have an easily accessible copy somewhere at home!
- **You can also upload your Advance Directive(s) to your MyChart account!**

To update an advance directive, you simply need to complete a new form, share it with the individuals above, and destroy the outdated version.

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Informal ACP

Informal ACP Resources (CDC)

- The Conversation Project
- Caring Conversations Workbook
- Five Wishes
- National Resource Center on LGTBQ+ Aging

sage | Advocacy & Services for LGBT Elders
National Resource Center on LGBT Aging

Simple Steps in Supporting Older LGBTQ Friends and Loved Ones at End of Life

the conversation project

Institute for Healthcare Improvement

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Social gatherings!

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Conversations with Loved Ones

- Because I love you …

I want you to know…
I want to know …

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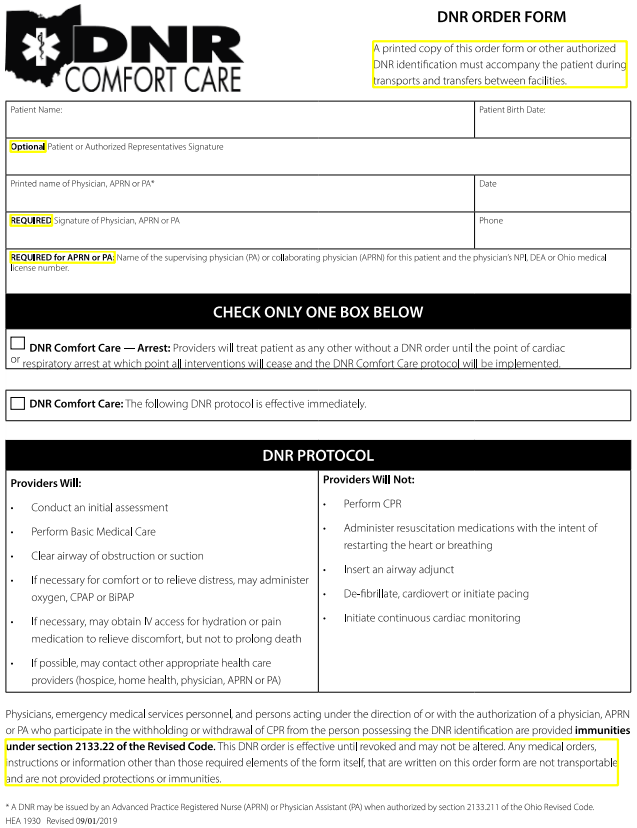
Side note

- Do Not Resuscitate (DNR) orders are NOT advance directives.
- They are medical orders.
- Must be signed by a physician, APRN, or PA.



DNR COMFORT CARE

DNR ORDER FORM

A printed copy of this order form or other authorized DNR identification must accompany the patient during transports and transfers between facilities.

Patient Name:	Patient Birth Date:
Optional Patient or Authorized Representatives Signature	
Printed name of Physician, APRN or PA*	Date
REQUIRED Signature of Physician, APRN or PA	Phone
REQUIRED for APRN or PA Name of the supervising physician (PA) or collaborating physician (APRN) for this patient and the physician's NPI, DEA or Ohio medical license number.	

CHECK ONLY ONE BOX BELOW

☐ **DNR Comfort Care — Arrest:** Providers will treat patient as any other without a DNR order until the point of cardiac or respiratory arrest at which point all interventions will cease and the DNR Comfort Care protocol will be implemented.

☐ **DNR Comfort Care:** The following DNR protocol is effective immediately.

DNR PROTOCOL

Providers Will:	Providers Will Not:
• Conduct an initial assessment	• Perform CPR
• Perform Basic Medical Care	• Administer resuscitation medications with the intent of restarting the heart or breathing
• Clear airway of obstruction or suction	• Insert an airway adjunct
• If necessary for comfort or to relieve distress, may administer oxygen, CPAP or BiPAP	• De-fibrillate, cardiovert or initiate pacing
• If necessary, may obtain IV access for hydration or pain medication to relieve discomfort, but not to prolong death	• Initiate continuous cardiac monitoring
• If possible, may contact other appropriate health care providers (hospice, home health, physician, APRN or PA)	

Physicians, emergency medical services personnel, and persons acting under the direction of or with the authorization of a physician, APRN or PA who participate in the withholding or withdrawal of CPR from the person possessing the DNR identification are provided **immunities under section 2133.22 of the Revised Code.** This DNR order is effective until revoked and may not be altered. Any medical orders, instructions or information other than those required elements of the form itself, that are written on this order form are not transportable and are not provided protections or immunities.

* A DNR may be issued by an Advanced Practice Registered Nurse (APRN) or Physician Assistant (PA) when authorized by section 2133.211 of the Ohio Revised Code.

HEA 1930 Revised 09/01/2019

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Takeaways for patients

- ACP presents a way for patients to express wishes regarding their medical care should they be unable to participate in decisions on their own behalf.

- If you don't feel ready to complete formal documents or you prefer not to, having conversations with your loved ones and health care providers about your wishes is a great place to start.

- MetroHealth is **here to help!** If you have questions after today's event or need help with the advance directive forms, you can contact our Social Work department at 216-778-5551.

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Takeaways for providers

- Initiate ACP conversations with your patients.
- Make your space a safe space for your patients to be and discuss their wishes/concerns.
  - LGBTQ+ individuals have significant fears of medical facilities, including long-term care facilities. (Caceres et al and Putnety et al)
- Have documents available!
- Understand the documents (or have someone available who does).
- MetroHealth's Center for Biomedical Ethics: 216-778-8497 or bioethics@metrohealth.org.

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Starr

Simon

Sarah and Michelle

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Thank you!

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Links to documents

- Health Care Power of Attorney, Living Will, Organ Donation
  - https://ohiohospitals.org/OHA/media/OHA-Media/Documents/News_and Publications/Publications/Ohio-Forms-and-Choices-Brochure.pdf
- Declaration for Mental Health Treatment
  - https://www.disabilityrightsohio.org/assets/documents/mhdeclare.pdf?pdf=Ohio_Declaration_for_Mental_Health_Treatment
- Disposition of Bodily Remains
  - https://www.narfe.net/site/chapter1927/files/fullName2979.pdf
- DNR
  - https://odh.ohio.gov/know-our-programs/do-not-resuscitate-comfort-care/resources/ohiodnrorderform

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