**HOUSE HEALTH COMMITTEE**

**INFORMATIONAL MEETING**

Wednesday, May 6th, 2026

9:00am

Room 60, East Wing

Harrisburg, PA

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1. Call to Order

**First Panel**

Nina A. Kohn, *Distinguished Professor of Law, Syracuse University*

Teresa Osborne, *State Advocacy Director, AARP*

Caroline L. Doherty, *DNP, AGACNP-BC, FACC, University of Pennsylvania*

**Second Panel**

Jennifer Garman, *Chief Executive Officer, Disability Rights Pennsylvania*

Marian Grant, *DNP, ACNP-BC, ACHPN, FPCN, FAAN, RN, Coalition to Transform Advanced Care*

2. Adjournment

Chair Frankel and members of the Committee:

My name is Nina Kohn. I am a law professor at Syracuse University and am also affiliated with the Solomon Center for Health Law and Policy at Yale Law School.

Thank you for the opportunity to provide testimony about the Uniform Health-Care Decisions Act, for which I served as Reporter. I appreciate the Committee's interest in examining whether this Act would be a viable and beneficial framework for Pennsylvania.

In 1992 the Pennsylvania General Assembly saw the wisdom of providing a statutory framework for creating and implementing advance directives. Much has changed since it revised that framework two decades ago. Fortunately, the 2023 Uniform Healthcare Decisions Act is designed to support states that, like Pennsylvania, are interested in modernizing their laws to reflect the reality of modern healthcare practice, and to better support the healthcare providers, patients and families navigating healthcare decision-making.

The 2023 Act revises the original 1993 Uniform Health-Care Decisions Act. The 1993 Act was a first-generation approach to health-care decision making developed at a time when states were first adopting statutes in this subject matter area. The 30 years since have witnessed significant technological advancements, changes in how health care is delivered, increases in the number of non-traditional familial relationships and living arrangements, popularization of electronic documents, and a growing use of separate advance directives exclusively for mental health care. The 2023 Uniform Health-Care Decisions Act learns from these advances, offering a modernized, second-generation approach to health-care powers of attorney and advance directives.

At its heart, the Uniform Health-Care Decisions Act is about ensuring that people have a voice in their own medical care, even when they cannot speak for themselves. The Act governs powers of attorney for health care, through which individuals appoint an agent to make health care decisions on their behalf if they become unable to make those decisions for themselves, and health-care instructions, which allow individuals to communicate the care they do or do not want, and the priorities and values they want to guide future decisions. The Act also authorizes certain people to make health-care decisions for individuals who cannot make their own decisions and have not appointed an agent. In addition, the Act establishes certain duties and powers of health-care agents and professionals and shields them from liability if they act reasonably and in good faith.

To highlight some of the key benefits of the Act:

First, the Act ***reduces barriers to creating and using advance directives***. It sets execution requirements at a reasonable level. To appoint a health-care agent, the Act requires a signature and one witness. It recognizes electronic forms and signatures, and it permits a witness to appear remotely. For health-care instructions, the Act generally avoids rigid formalities. Our collective experiences during the recent pandemic highlight both the need for these measures as well as the difference they can make in the health care setting.

Second, the Act ***clarifies when a surrogate decision-maker may make health-care decisions for a patient***. It sets forth a clear capacity standard focused on the person's functional abilities, including whether the person could make the decision with support. The Act recognizes that capacity is decision-specific: a patient may have capacity to make some decisions but not others. It also provides a mechanism for a patient to object to a determination that they lack capacity to make their own health-care decisions.

Third, consistent with the recognition that capacity is domain-specific, the Act ***differentiates between the capacity to make a health care decision and that to make an advance directive***. In doing so, it recognizes that an individual may have capacity to appoint an agent, even if the individual lacks the capacity to make a complex health care decision.

Fourth, the Act ***authorizes advance directives exclusively for mental health care***. Such specialized advance directives offer individuals with chronic mental health challenges the opportunity to provide tailored instructions for their own future mental health care. The Act also includes a provision that a state could adopt to give individuals the option of making these specialized advance directives binding during an acute mental health crisis.

Fifth, the Act ***clearly sets forth duties and powers that surrogate decision-makers and health-care professional have regarding advance directives***. One of note: the Act authorizes a health-care surrogate to apply for health insurance for a patient without another fiduciary who can do, thus reducing the likelihood that the patient's needs will go unmet due to financial barriers.

Sixth, the Act ***updates default-surrogate provisions to reflect the range of family structures and support systems that exist today***. When a patient cannot make health-care decisions and has not appointed an agent, the Act directs health-care professionals to take direction from a default surrogate. That surrogate is drawn from a priority list designed to

approximate who the patient would likely want to make decisions on their behalf. To better reflect modern families and support networks, the Act includes domestic partners, cohabitants, individuals involved in supported decision-making, and people who have shown special care and concern for the patient.

Finally, the Act ***includes a model form designed to work well for diverse populations***. The form uses plain language, which is especially valuable because many people create advance directives without help from a trained professional. It also allows individuals not only to state preferences for specific types of care, but to identify the goals and values they want to guide future health-care decisions. This information guides agents and health-care providers to make decisions consistent with the person's values when unanticipated situations arise.

Thank you for the opportunity to submit this testimony.

**Pennsylvania House Health Committee**
**Informational Meeting**
**on the**
**Uniform Healthcare Decision Act**

**Wednesday - May 6, 2026**

AARP® Pennsylvania

Good morning. My name is Teresa Osborne. I am the State Advocacy Director for AARP Pennsylvania. On behalf of the five million Pennsylvanians age 50 and over and their families, thank you, Chairman Frankel, Chairwoman Rapp, and members of the House Health Committee for convening this informational meeting as you further explore the Uniform Law Commission's Uniform Health-Care Decisions Act. We appreciate the opportunity to participate in today's discussion.

In May 2023, the family of former President Jimmy Carter and former First Lady Rosalynn Carter announced that Mrs. Carter was living with dementia and continuing to live "happily at home with her husband, enjoying spring in Plains and visits with loved ones. In their statement – released through The Carter Center – the family reminded the nation that Mrs. Carter had been the country's leading mental health and caregiver advocates for much of her life: first, in Georgia's Governor's Mansion, then in the White House, later at The Carter Center, and as founder of the Rosalynn Carter Institute for Caregivers.

It that role, Mrs. Carter often observed that there are only four kinds of people in this world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers. Providing care for a loved one is one of the most important – and challenging - roles any of us will play in our lives. By sharing their personal story, the Carter family underscored the universal nature of caregiving and expressed hope that it would prompt important conversations at kitchen tables and in doctors' offices across the country.

While it is something few of us want to think about, serious illness and death are realities that every family will eventually face. As uncomfortable as these conversations may be, talking with loved ones about the medical care you do or do not want can make life – and ultimately death – less stressful and more manageable for everyone involved.

Too often, people find themselves stepping into a caregiving role as the result of a crisis. In the most serious situations, before a caregiver can act, legal or financial arrangements may be required so they have the authority and information needed to provide care. By planning ahead – whether by authorizing a medical provider or financial institution to share information with a trusted family member, or by executing powers of attorney and advance health care directives – individuals can make the caregiving process clearer and less burdensome for their loved ones.

AARP believes that every adult should have an advanced directive that outlines the type of health care they do or do not want if they can no longer make their own decisions. We also believe that every adult should appoint someone they trust to speak on their behalf to ensure those wishes are respected and carried out.

This matters because one's own informed health care decisions is a fundamental principle of the American health care system. While most states have laws addressing how patients can express their wishes even after incapacity - and how decisions are made when no advance directive exists – these laws vary widely. What one state calls an "advance directive" may be referred to in another as a "living will," "health care power of attorney," or "health care proxy." Those differences can make it especially challenging to honor a person's wishes when they have connections to more than one state.

That is why the Uniform Law Commission – a bipartisan body made up of legal experts from around the country - takes on the task of developing non-partisan, carefully considered model legislation for states to consider in areas where consistency across state lines is desirable and practical. The Commission does not enact laws or advocate for specific policy outcomes; instead, it provides states with well-researched frameworks they can adopt, adapt, or modify to fit their own needs. One such area is health care decision-making. The original Uniform Health-Care Decisions Act - drafted thirty-three years ago, was intended to bring greater consistency to state laws governing health care powers of attorney and advance directives. Since the Act's publication in 1933, however, the world has changed in meaningful ways. There have been advances in medical technology; developments in legal technology, including the use of electronic estate-planning documents; greater understanding and treatment of mental illness; evolving concepts of decision-making capacity; and changing definitions of family, just to name a few.

In response to these changes, the Uniform Law Commission convened a drafting committee in 2021 to review and update the 1993 Act. The committee included legal experts and stakeholders from across the country. AARP participated throughout the drafting process as an official observer. The final updates to the Uniform Health-Care Decisions Act were approved by the Uniform Law Commission in 2023.

The 2023 Uniform Health-Care Decisions Act allows individuals to appoint an agent to make healthcare decisions for them in the event they are unable to make themselves. It ensures that a person's values and priorities regarding healthcare - including mental health care - are provided to a person's healthcare team and agent. It also provides a mechanism for selecting individuals outside of a court proceeding to act

as default surrogate decision-makers, or individuals with the authority to make decisions on behalf of another person.

The shift to the term 'default surrogate decision-makers' is important. The Act updated the list of who may serve in this role when an individual cannot make their own health-care decisions and has not named a health-care agent by looking first to the people closest to the individual - those most likely to understand their values, preferences, and wishes. This approach recognizes the realities of modern families and caregiving relationships, while preserving respect for personal autonomy and existing advanced directives. It helps ensure that necessary health-care decisions can be made promptly, thoughtfully, and by someone the individual trusts—without unnecessary delay or court involvement.

The Act also grants default surrogates limited authority to apply for health insurance on a patient's behalf. While that authority is narrow, it is meaningful because one of the most common reasons a guardianship is petitioned for is simply to obtain the legal authority needed to apply for Medicaid. Although Medicaid applications often require access to financial information or actions - such as spend-downs - that a default surrogate may not be able to take based solely on that status, this change could still significantly reduce the need for guardianship. For example, if a default surrogate is already a joint owner on a parent's bank account and has access to the financial documentation required for a Medicaid application, there would be no need to pursue guardianship solely to obtain the authority to enroll that parent in Medicaid.

The Act modernizes health-care decision-making statutes to better reflect how Pennsylvanians live, plan, and receive care today. While Pennsylvania has long recognized the importance of advance directives and health-care agents, gaps remain when individuals have not executed formal planning documents or when decision-making authority must shift temporarily due to changes in capacity. The Uniform Health-Care Decisions Act helps address those gaps in a thoughtful, balanced way by:

**Modernizing health-care decision-making**

The Act updates outdated statutory frameworks by recognizing modern realities. It allows for the electronic execution of advance planning documents, improving both accessibility and usability. It also recognizes that many individuals rely on family members, partners, and close friends who fall outside traditional nuclear family definitions. By doing so, the Act more accurately reflects real-world caregiving relationships and support systems. It also provides clarity for appointed agents or default surrogates

who may live in a different state than the patient. Clear guidance on authority and responsibility helps ensure that decision-makers understand their role, particularly during stressful medical situations. Importantly, because the Act is uniform, adoption across states reduces uncertainty when individuals travel or receive care outside their home state, helping ensure that a person's health-care wishes are respected wherever care is delivered.

**Recognizing the spectrum of decision-making capacity**

The Act reflects a modern and realistic understanding of capacity. Capacity is not an all-or-nothing condition. A person's ability to make health-care decisions may vary based on the complexity of the decision, physical or emotional stress, the effects of medication, or even the time of day. As a result, an individual may have the capacity to make some decisions but not others, and that capacity may fluctuate over time. The Act recognizes this reality by allowing decision-making authority to be tailored accordingly, rather than requiring an all-or-nothing transfer of authority through guardianship. This approach helps preserve individual autonomy while still ensuring that necessary decisions can be made when they are needed.

**Providing clarity through uniform default surrogacy rules**

The Act includes clear and uniform default surrogate provisions that apply when a patient lacks decisional capacity and has not appointed a health-care agent. In these situations, the law identifies who may act as a default surrogate by looking first to those closest to the individual - such as trusted family members or others familiar with the person's values and preferences. While most states, including Pennsylvania, have some form of default surrogate law, those statutes vary significantly from state to state. The Act promotes consistency by clarifying who may act as a surrogate, when that authority begins and ends, and how decisions should be guided by the patient's known wishes and values. It also clarifies when agents and surrogates may act - and when they may not - providing greater certainty for families and health-care providers alike.

**Reducing unnecessary reliance on guardianship**

A significant benefit of the Act is that it reduces the need for court involvement when compared to guardianship. The tools provided in the Act do not require judicial petitions, hearings, or ongoing court supervision to temporarily transfer decision-making authority when an individual lacks capacity - or to return that authority once the medical situation resolves. This approach makes it easier for individuals to

regain their decision-making authority and avoids the time, cost, and loss of autonomy that often accompany guardianship proceedings - particularly when incapacity is temporary or decision-specific.

**Allowing individuals to clearly define and limit authority**

The Act allows individuals to provide clear direction to their appointed agents or default surrogates. Individuals may grant specific powers, offer general guidance, or limit authority to particular decisions. Importantly, the Act limits an agent's authority to those powers expressly granted by the individual, helping ensure that agents are not unexpectedly responsible for decisions neither they nor the patient anticipated. This clarity benefits both patients and decision-makers by setting appropriate expectations and reducing confusion during medical emergencies.

**Resolving disputes and avoiding delays in care**

Not all states provide guidance for resolving disagreements among individuals at the same decision-making priority level. The Act does. It establishes a framework for addressing disputes among agents or default surrogates, helping avoid uncertainty and delays that can interfere with timely and appropriate medical care. These clear dispute-resolution provisions support both families and health-care providers by promoting quicker, more orderly decision-making.

**Addressing health-insurance applications without guardianship**

Finally, the Act grants default surrogates limited authority to apply for health insurance, including Medicaid, on behalf of an incapacitated patient. This provision does not determine eligibility. Instead, it eliminates the need to appoint a guardian solely for the purpose of submitting an insurance application - a step that is not uncommon under current practice. Allowing default surrogates to apply for health insurance reduces administrative burden, avoids unnecessary guardianships, and helps ensure continuity of coverage during medical crises.

Taken together, the Act modernizes health-care decision-making law in a way that preserves individual autonomy, reflects modern family and caregiving relationships, reduces unnecessary court involvement, and provides clearer guidance during medical crises. It builds on Pennsylvania's strong foundation for advanced directives by addressing real-world gaps – such as temporary incapacity, modern family structures, interstate care, and unnecessary guardianship – that patients, families, caregivers, and health-care providers face every day.

For families and other caregivers - many of whom never planned to take on this responsibility and find themselves navigating complex decisions under stress - the Act offers clarity, consistency, and reassurance. It helps ensure that caregiving decisions can be made thoughtfully, promptly, and in accordance with an individual's wishes, rather than delayed by uncertainty or unnecessary legal hurdles. Thank you for the opportunity to participate in today's informational meeting. We look forward to continuing to work with the Committee on this critical issue for patients, families, and caregivers across the Commonwealth.

Dear Members of the Health Committee:

Thanks to all of you for allowing me the opportunity to provide public comment on the Uniform Health-Care Decisions Act. My name is Caroline Lloyd Doherty. I hold a Doctor of Nursing Practice (DNP) and I have over 35 years of nursing experience that includes clinical, teaching, and research in cardiovascular and palliative care at the University of Pennsylvania.

There are many reasons for which I would like to advocate for the passage of this Act in Pennsylvania.

I am impressed that although the last update (Chapter 54) in Pennsylvania was completed in 2006, it includes many of the key elements in the Uniform Health-Care Decisions Act. One key element is that Pennsylvania does not require notarization which can be a significant barrier to the creation of an Advance Directive. Another is that Pennsylvania already has a mental health Advance Directive which is not the case in many other states. Pennsylvania also has language about protecting the healthcare team from liability if they act reasonably and in good faith. Furthermore, Pennsylvania includes a section regarding wishes related to organ donation.

But there are several areas where the Uniform Health-Care Decisions Act could help to further modernize Pennsylvania law.

First, current laws related to the selection of a healthcare proxy as well as Advance Directives vary significantly from state to state, which contributes to confusion for patients, their loved ones, and the healthcare team. Considering that healthcare proxies and advance directives become essential when a patient is significantly ill, vulnerable and cannot speak for themselves-clarity is paramount.

Second, this Act is a huge step forward for patients and their loved ones, as it provides clear and consistent guidelines as to how to create an Advance Directive and suggests the inclusion of priorities and preferences such as the importance to the individual of being independent or staying alive-even in the event of substantial physical limitations. These guidelines are more helpful than merely a checklist of interventions (such placement of a breathing tube) that one does or does not want and can be hard to envision when one is healthy. The Act also clarifies whom the patient may choose to serve as a healthcare proxy, and the relational order of whom the state appoints to serve in this role if a patient has not selected one. It modernizes default surrogate provisions in that it reflects a broader array of relationships, family structures, and living arrangements than previous laws did.

Third, this Act has an impact on all members of the healthcare team who have roles in which they travel to different states to provide care. Of note, Pennsylvania is one of the 41 states that has adopted the nursing license compact which enables nurses to practice across state lines without having to apply for a license in each one. To facilitate nurses' and all team members comfort with and understanding of the law as it relates to healthcare proxy selection and advance directives, it would be best for states to enact the Uniform Health-Care Decisions Act

to remove the variation that currently exists. Imagine the stress of being a traveling nurse, preparing a patient for major emergency surgery, and not knowing if the state requires notarization for an Advance Directive. That situation could result in undue stress for everyone-most importantly the patient and family.

Last, an advantage of this act is that it includes the expertise and participation of various members of the healthcare team to determine patients' capacity. Very few states have updated their laws to include these essential roles. In places where current laws use physician-specific language, the Uniform Health-Care Decisions Act has adopted the term health-care professional where appropriate.

I hope that you will strongly consider the value of the Uniform Health-Care Decisions Act and the difference it will make in the lives of patients, their loved ones, and the healthcare team. Thank You.

DISABILITY RIGHTS PENNSYLVANIA

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Disability Rights Pennsylvania
Pennsylvania House Health Committee Informational Hearing on the Uniform Healthcare Decisions Act

Provided by:

Jennifer Garman
Chief Executive Officer
Disability Rights Pennsylvania
May 6, 2026

Good Morning Chairman Frankel, Chairwoman Rapp and members of the House Health Committee.

My name is Jennifer Garman. I am the Chief Executive Officer at Disability Rights Pennsylvania. Disability Rights Pennsylvania is the federally mandated protection and advocacy agency designated by the Commonwealth of Pennsylvania. We provide legal and advocacy services to people with disabilities in Pennsylvania. On behalf of Disability Rights Pennsylvania, and the individuals that we serve, I would like to thank you for soliciting our views on healthcare decision making by people with disabilities in the Commonwealth.

**Disability History and Autonomy:**

Over the past forty years, the United States has moved away from institutionalization and segregation of people with disabilities. Today, people with disabilities are integrated in and participate in their communities. Integration and independence strengthen decision making skills. Integration provides more opportunity for trusting relationships which can offer support and guidance in decision making- like it does for all people. All people with disabilities, regardless of where they live or the supports they receive, should be presumed capable of

making decisions about their own lives, with support when needed. Disability should never be treated as a reason to assume incapacity.

However, far too many adults with disabilities do not retain decision making authority due to misconceptions and concerns about their ability to manage financial resources or meet their own health and safety needs. According to a 2019 report from the National Council on Disability, 58% of people with intellectual and developmental disabilities between ages 18 and 22 are under guardianship.[1] Parents of young adults with disabilities are often misinformed by schools, health care providers, or disability service providers that guardianship is necessary when their child turns 18. Instead, they should be informed about the full range of healthcare decision making tools and less restrictive options available to Pennsylvanians.

**Health Care Decision Making**

Adults with disabilities have the right to the dignity of risk. Losing the authority to make decisions about your own life has profound consequences and runs counter to the principles of the disability rights movement.

Pennsylvania law currently has many tools in place to support people with disabilities in making decisions about their healthcare treatment. These tools include advance directives that allow people to designate someone to make decisions for them in the event of incapacity. Under Act 169, certain family members or close friends can help make health care decisions when an adult cannot make those decisions and has not already chosen someone else to make them. Mental Health Advance Directives are available for people with mental illness. People also rely on informal supports utilizing concepts such as supported decision making with trusted friends and family.

Unfortunately, people with disabilities still face bias in access and maintaining autonomy when accessing health care. Despite these tools being available, people with disabilities still face providers who assume that disabled individuals cannot make healthcare decisions. We still have individuals and families who are unaware of the tools available in Pennsylvania and who are likely not using them because they may assume that they cannot or because they have been told that guardianship is the only option. In healthcare, experiencing bias by

[1] https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf at page 31.

medical providers makes people with disabilities less likely to seek healthcare, leading to worse health outcomes.

## Education and Accessible Materials for Health Care Decision Making

People with disabilities should be encouraged and supported to self-advocate, and learn to advocate for their healthcare, financial and other personal needs. People with disabilities need opportunities to build peer support and learning throughout their school careers and early adulthood to build circles of trust and implement informal supports such as Supported Decision Making and decide who they want to help make important life decisions, including health care decisions.

Teachers, service providers, medical professionals and attorneys need training and support to learn about decision making for people with disabilities. Teachers and families need to teach decision making skills that support children and young adults in making decisions expressing preferences and understanding their rights. Materials should also be developed to reach all individuals, including plain language materials that explain health care decision-making rights.

Training and education for individuals and families to understand how to promote informed choice and supported decision-making skills, starting during childhood and continuing through adulthood will also help individuals to maintain autonomy. This education should reinforce that needing help to understand information, communicate a choice, or weigh options does not mean a person should lose the right to make decisions. With the right support, people with disabilities can make meaningful choices about their health care and their lives.

We appreciate the opportunity to share our perspectives on healthcare decision making for people with disabilities. Any updates to Pennsylvania law should be centered on increasing autonomy in decision making, ensuring that competence is presumed, and to ensure that inclusive materials are developed for the disability community.

## About Disability Rights Pennsylvania

Disability Rights Pennsylvania has been the federally mandated protection and advocacy system in our state for over 45 years. Our mission is to protect and advocate for the rights of persons with disabilities so they may live the lives they

choose, free from abuse, neglect, discrimination, and segregation.  Our vision is a Commonwealth where people of all abilities are equal and free.

April 27, 2026

To: Chair Frankel and distinguished members of the Pennsylvania House Health Committee

Re: Support for Consideration of the Uniform Health-Care Decisions Act (UHCDA)

Thank you for the opportunity to submit written testimony in support of consideration of the UHCDA and the opportunity to modernize Pennsylvania's health-care decision-making laws.

I am Dr. Marian Grant, a certified palliative care nurse practitioner for 20 years who is also a national policy consultant for the Center to Advance Care, the Coalition to Transform Advanced Care and the National Partnership for Health and Hospice Innovation. I participated in the UHCDA update process and regularly see the consequences when the law does not give patients, families, and clinicians clear guidance about who can decide, how medical decisions should be made, and how patients' values can be honored when they cannot speak for themselves. For instance:

- An elderly man in the hospital whose dementia has progressed to where his family is considering inserting a feeding tube but whose 10-year-old advance directive doesn't address this issue.
- A young

As you know, Pennsylvania currently recognizes advance directives, including durable powers of attorney for health care and living wills, as key tools for care planning. Yet many residents still lack such documents, as do others across the country, and decision-making at the bedside often depends on an informal patchwork of family involvement, institutional policies, and case-by-case legal interpretation. The result can be avoidable conflict, delayed care, and decisions that do not reflect the patient's own wishes. (I once had an elderly patient who was too sick to speak for himself. He had 5 daughters who couldn't agree and it took days to bring them to consensus.)

The UHCDA is a comprehensive model law developed by the national Uniform Law Commission to standardize and modernize state rules for health-care decision-making. It builds on and updates the original federal 1993 Uniform Act to reflect today's health-care system, including the realities of complex chronic illness, diverse family structures, and care delivered across multiple settings. By adopting this framework, Pennsylvania would:

- Provide a single, coherent structure for advance directives, health-care agents, and default surrogate decision-makers, replacing fragmented or outdated provisions that can confuse families and clinicians.

- Clarify who may decide when a patient lacks capacity and has not appointed an agent, reducing delays at the bedside while still respecting appropriate priority for close family and others who know the patient well.
- Encourage more Pennsylvanians to complete advance directives by simplifying forms and requirements, while preserving strong protections for patients' rights and informed consent.
- Align Pennsylvania law with modern best practices in serious-illness and end-of-life care, including an emphasis on shared decision-making and honoring individual values rather than relying solely on rigid clinical criteria.

The 2023 revision of the UHCDA was specifically crafted to offer states a modern, comprehensive template for advance-care planning and surrogate decision-making laws. Several states are now considering adoption, recognizing that the older 1993 framework was never widely implemented and no longer fits current practice. Pennsylvania could be one of the next states after neighboring Delaware to implement it.

In my experience, I see several recurring problems with the current framework:

1. Uncertainty about decision-makers. When a patient lacks capacity and has no formal health-care power of attorney, families often struggle to understand who is "in charge," particularly in blended families or in situations involving unmarried partners or estranged relatives. Clear default surrogate provisions, as in the UHCDA, reduce conflict and help clinicians identify an appropriate decision-maker quickly.
2. Inconsistent respect for patient values. Even when families are available, they may not know the patient's wishes, especially regarding life-sustaining treatment, artificial nutrition and hydration, or transitions to hospice and palliative care. A consistent statutory framework that emphasizes prior expressed wishes, values, and goals of care—and that encourages early advance-care planning—supports decisions that better reflect what the patient would have chosen.
3. Legal and ethical anxiety at the bedside. Clinicians often fear liability when statutes are ambiguous or when policies vary across institutions. The UHCDA's clearer rules can reduce unnecessary transfers, repeated "capacity" battles, and overuse of aggressive treatments that neither improve outcomes nor align with patient goals.

Pennsylvania has a strong foundation in Act 169 of 2006, which modernized Chapter 54 of Title 20 and established a clearer framework for living wills, health care powers of attorney, and health care representatives. Even so, the 2023 Uniform Health-Care Decisions Act offers a timely and practical opportunity to build on that foundation by updating surrogate decision-making for the realities of current health care, family structures, disability rights, and serious-illness care.

One of the clearest reasons to consider a UHCDA-based update is its improvement of the surrogate process. Under Act 169, Pennsylvania provides a statutory list of default decision-makers, but the framework remains relatively traditional and gives default surrogates narrower authority than an appointed health care agent, especially for decisions about withholding or withdrawing life-sustaining treatment. By contrast, the 2023 UHCDA is designed to create a more modern and consistent surrogate process, with broader recognition of close personal relationships, more patient-centered standards, and a structure in which default surrogates generally have authority closer to that of a named agent.

That matters in practice. Many patients never complete a formal health care power of attorney, even though they have trusted people in their lives who understand their values and goals. In those situations, a modernized surrogate law can reduce delays, lessen conflict, and improve the likelihood that treatment decisions reflect the patient's own wishes rather than the happenstance of family hierarchy or institutional uncertainty.

The 2023 UHCDA also improves on Act 169 by better reflecting contemporary family and caregiving arrangements. States implementing the updated uniform framework have recognized domestic partners, cohabitants, and other close associates more explicitly than older statutes often did. That approach is especially important for Pennsylvanians whose primary support person may not fit neatly within older legal categories but is nonetheless the individual most familiar with the patient's values, preferences, and prior expressed wishes.

Another important improvement is the way the 2023 UHCDA strengthens patient control over the surrogate process. UHCDA-based reforms have been described as allowing clearer notice of incapacity findings, a more structured opportunity for the patient to object, and lower-threshold mechanisms for choosing, revoking, or disqualifying a surrogate as capacity fluctuates. Those features make the system more rights-protective and more compatible with the lived reality of many serious illnesses, in which decision-making capacity may vary over time rather than disappear all at once.

Pennsylvania's existing law also places relatively narrow statutory conditions on when a default surrogate may authorize withdrawal of life-sustaining treatment, while a named agent has broader authority. A UHCDA-based approach would better align treatment decisions with the patient's values and goals of care by reducing the gap between agent authority and surrogate authority, while still preserving safeguards and documentation requirements.

For these reasons, the strongest path forward may be to treat the UHCDA not as a rejection of Act 169, but as its next stage of modernization. Pennsylvania already has a useful framework; the opportunity now is to refine it so that the law more clearly supports inclusive surrogate recognition, patient autonomy, better conflict resolution, and decision-making that reflects current clinical and ethical practice.

As you consider legislation, I recommend you:

- Adopt a comprehensive UHCDA-based framework rather than piecemeal amendments, so that provisions on health-care agents, advance directives, default surrogates, and dispute resolution are coherent and aligned.
- Ensure robust protections for patient autonomy and rights, including clear standards for honoring prior expressed wishes, guidance on substituted judgment and best-interest decision-making, and safeguards against discrimination, abuse, or neglect of vulnerable individuals.
- Provide a prioritized list of default surrogates that reflects modern families (spouses and partners, adult children, parents, adult siblings, and others with a close relationship), while including mechanisms to resolve disputes and to bypass individuals who are clearly unsuitable or unavailable.
- Integrate strong communication and documentation requirements, including expectations that clinicians explore values and goals of care, document discussions in the medical record, and revisit decisions as conditions change, rather than treating the advance directive as a one-time form.
- Support public and professional education, so that Pennsylvanians understand their options for advance directives and health-care agents, and clinicians receive training on the new law, cultural humility, and shared decision-making.

Every Pennsylvanian deserves to have their values and preferences respected when they cannot speak for themselves, and every family and clinician deserves clear, workable rules to guide difficult choices. The UHCDA offers a thoughtful, modern foundation to achieve that goal. I urge the Committee to advance legislation that adopts a UHCDA-based framework for the Commonwealth and to pair it with robust implementation, education, and safeguards for vulnerable populations.

Thank you for your attention to this important issue and for holding the May 6 informational meeting on the UHCDA. A thoughtful UHCDA-based update would help ensure that Pennsylvania law better serves patients, families, and clinicians when health care decisions are most consequential.

Respectfully yours,

Marian Grant

Dr. Marian Grant, DNP, ACNP-BC, ACHPN, FPCN, FAAN, RN

Sources

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## Improvements to the Uniform Health-Care Decisions Act (UHCDA), 2023
# For People with Disabilities

The Uniform Law Commission's **Uniform Health-Care Decisions Act**, updated in 2023, recognizes that people with disabilities deserve dignity, choice, and safety in their health care. It ensures that a person remains at the center of their own health care decisions and guards against unwanted treatment or exploitation. Here are some highlights:

- The Act assumes that everyone has the mental capacity to make their own health care decisions, unless proven otherwise. It also recognizes Supported Decision Making, allowing people to get the help they need to understand and make choices, without losing the right to make decisions for themselves.

- If a health care professional determines that a patient does not have the ability to make their own health care decisions, the patient must be notified. The patient can object and trigger another evaluation. Importantly, even a second determination that a patient lacks the ability to make health care decisions cannot override a patient's wish to continue life-sustaining treatment. If a patient disagrees with a health care professional's evaluation, they can also petition a court for help.

- Patients can remove or replace a default or appointed decision-maker who is not acting in their best interests or in line with their wishes. Courts must disqualify decision-makers who pose a risk to the patient or, in certain circumstances, if the decision-maker's role as a health care provider creates a conflict of interest.

- To prevent unnecessary placement in nursing homes when community-based supports are available, the Act places restrictions on a decision-maker's ability to make long-term nursing home placements.

- Decision-makers have limits on what they can do when it comes to life-sustaining care and other serious medical decisions for people with disabilities.
    - For individuals with long-term disabilities who rely on medical technology as part of their everyday care, decision-makers cannot withdraw life-sustaining care—like feeding tubes, hydration, or ventilators—unless specific conditions are met, including the patient's own authorization if the patient is able to give it.
    - Decision-makers also cannot make certain irreversible or highly personal choices if other state law prohibits a guardian from making those decisions without court authorization. This prohibition protects individuals who might otherwise be subject to sterilization, the withdrawal of life-sustaining treatment, or other unwanted health care decisions.

- An individual or someone acting in the individual's interest may ask the court for help if there are concerns about a decision-maker's actions or withdrawal of health care. This creates an added safeguard against the misuse of power.

The full UHCDA of 2023 has many more improvements from the perspective of people with disabilities. For the full text and additional resources, visit the Uniform Law Commission's UHCDA website.

10/24/25

Uniform Law Commission
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# WHY YOUR STATE SHOULD ADOPT THE UNIFORM HEALTH-CARE DECISIONS ACT

The Uniform Health-Care Decisions Act ("UHCDA") enables individuals to appoint agents to make health care decisions for them should they become unable to make those decisions for themselves, to provide their health-care professionals and agents with instructions about their values and priorities regarding their health care, and to indicate particular medical treatment they do or do not wish to receive. It also authorizes certain people to make health-care decisions for individuals incapable of making their own decisions but who have not appointed agents, thus avoiding the need to appoint a guardian or otherwise involve a court in most situations. In addition, it sets forth the related duties and powers of agents and health-care professionals, and provides protection in the form of immunity to both under specified circumstances.

Like the 1993 Act that preceded it, the Act's goals include: (1) acknowledging the right of a competent individual to make decisions about the provision, withdrawal or withholding of health care; (2) providing a single statute to govern both the appointment of a health-care agent and the recording of an individual's wishes regarding their health care; (3) simplifying and facilitating the making of an advance health-care directive; (4) ensuring that decisions about an individual's health care will be governed, to the extent possible, by the individual's own desires; (5) addressing compliance with an individual's instructions by health-care institutions and professionals; and (6) providing a procedure for resolution of disputes.

Some of the key benefits of the act are that it:

***Reduces unnecessary barriers to the execution of advance directives***: By making it easier to create an advance directive, the Act seeks to reduce the number of Americans who lack an advance directive. The Act also authorizes the use of mental health care, or psychiatric, advance directives in a way that helps resolve conflicts between competing advance directives.

***Clarifies when agents may act*:** The Act adds provisions clearly indicating when a surrogate's power commences and addresses what happens if a patient objects to a surrogate making a decision for them. It also allows an individual to specifically authorize their appointed agent to obtain health information while the individual has capacity, thus allowing the agent to assist the individual in making health-care decisions.

***Includes a new optional form:*** The revised form is designed to be readily understandable and accessible to diverse populations. Unlike more traditional forms, it creates an opportunity not only for individuals to provide instructions about specific treatment preferences, but to also share information about their broader goals and values to help guide future health-care decisions.

***Clarifies agents' powers and gives individuals the option to authorize special powers.*** For example, to reduce the likelihood that an individual's health-care needs will go unmet due to financial barriers, the Act authorizes a surrogate to apply for health insurance for a patient who does not have another fiduciary authorized to do so. It also provides that an agent has only those powers that are expressly authorized in the power of attorney that appointed the agent.

***Modernizes default surrogate provisions*:** The Act updates the priority list in the 1993 Act to reflect a broader array of relationships, family structures, and living arrangements.

***Brings the definition of capacity and approaches to capacity determinations in line with modern practice:*** A surrogate's authority to make health-care decisions for a patient typically commences when the patient lacks capacity to make decisions for themselves. The Act modernizes the definition of capacity to focus on an individual's *functional* abilities and clarifies that an individual may lack capacity to make one decision yet retain capacity to make others. The Act also expands the list of health-care professionals who may determine that an individual lacks capacity.

For further information about the Uniform Health-Care Decisions Act, please contact Legislative Counsel Haley Tanzman at (312) 450-6620 or htanzman@uniformlaws.org.

# Improve Your State's Law on Advance Directives

**Background**

- People living with serious illness, and their families, often face difficult choices about medical treatment. These decisions frequently happen in moments of crisis, when patients can't speak for themselves and loved ones are left without clear guidance.
- Advance directives like living wills help people share what medical treatments and interventions they would or would not want if they are unable to speak for themselves. In 2023, the Uniform Law Commission approved the **Uniform Health-Care Decisions Act (UHCDA)**, which reduces barriers to advance health care planning, strengthens support for mental health care, and recognizes today's diverse family structures.

**Why it matters now** – Families look different today, and growing recognition of mental health and dementia care means states need clearer, more inclusive ways to guide medical decision-making.

**5 reasons why your state should consider adopting the UHCDA**

- The Act authorizes new advance directives focused specifically on mental health, filling a critical gap for those living with dementia or behavioral health conditions.
- The Act expands who can serve as a default decision-maker, reducing the need for burdensome and costly guardianship proceedings.
- The Act includes a plain language form that allows people to share both treatment preferences and their overall goals and values.
- The Act sets a clearer standard for determining when someone lacks the mental ability to make their own medical decisions.
- The Act removes outdated execution requirements that have discouraged people from creating advance directives.

**What to do next**

- Sponsor and support legislation to adopt the UHCDA in your state.
- Work with your state's serious illness coalition or advance care planning community to revise your state's advance directive laws in line with the UHCDA.

C-TAC is dedicated to improving the lives of the 12 million people impacted by serious illness, including their families and caregivers. We are their voice.

We are a coalition of leaders advocating for those impacted by serious illness. Join us in opening the doors to a new future for patients and those that care for them.

**SUBCHAPTER D**
COMBINED FORM

**Sec.**


**Cross References.** Subchapter D is referred to in sections 5433, 5447, 5465 of this title.

**§ 5471. Example.**

The following is an example of a document that combines a living will and health care power of attorney:

DURABLE HEALTH CARE POWER OF ATTORNEY
AND HEALTH CARE TREATMENT INSTRUCTIONS
(LIVING WILL)
PART I
INTRODUCTORY REMARKS ON
HEALTH CARE DECISION MAKING

You have the right to decide the type of health care you want.

Should you become unable to understand, make or communicate decisions about medical care, your wishes for medical treatment are most likely to be followed if you express those wishes in advance by:

(1) naming a health care agent to decide treatment for you; and

(2) giving health care treatment instructions to your health care agent or health care provider.

An advance health care directive is a written set of instructions expressing your wishes for medical treatment.

NOTICE ABOUT ANATOMICAL DONATION

This document may also contain directions regarding whether you wish to donate an organ, tissue or eyes. Under Pennsylvania law, donating a part of the body for transplantation or research is a voluntary act. You do not have to donate an organ, tissue, eye or other part of the body. However, it is important that you make your wishes about anatomical donation known, just as it is important to make your choices about end-of-life care known.

Surgeons have made great strides in the field of organ donation and can now transplant hands, facial tissue and limbs. A hand, facial tissue and a limb are examples of what is known as a vascularized composite allograft. Under Pennsylvania law, explicit and specific consent to donate hands, facial tissue, limbs or other vascularized composite allografts must be given. You may use this document to make clear your wish to donate or not to donate hands, facial tissue or limbs.

Under Pennsylvania law, the organ donor designation on the driver's license authorizes the individual to donate what we traditionally think of as organs (heart, lung, liver, kidney) and tissue and does not authorize the individual to donate hands, facial tissue, limbs or other vascularized composite allografts.

Detailed information about anatomical donation, including the procedure used to recover organs, tissues and eyes, can be found on the Department of Transportation's Internet website. Information about the donation of hands, facial tissue and limbs can also be found on the Department of Transportation's Internet website.

You may wish to consult with your physician or your attorney to determine whether the procedure for making an anatomical donation is compatible with fulfilling your specific choices for end-of-life care. In addition, you may want to consult with clergy regarding whether you want to donate an organ, a hand, facial tissue or limb or other part of the body. It is important to understand that donating a hand, limb or

facial tissue may have an impact on funeral arrangements and that an open casket may not be possible.

An advance health care directive may contain a health care power of attorney, where you name a person called a "health care agent" to decide treatment for you, and a living will, where you tell your health care agent and health care providers your choices regarding the initiation, continuation, withholding or withdrawal of life-sustaining treatment and other specific directions regarding end-of-life care and your views regarding organ and tissue donation.

You may limit your health care agent's involvement in deciding your medical treatment so that your health care agent will speak for you only when you are unable to speak for yourself or you may give your health care agent the power to speak for you immediately. This combined form gives your health care agent the power to speak for you only when you are unable to speak for yourself. A living will cannot be followed unless your attending physician determines that you lack the ability to understand, make or communicate health care decisions for yourself and you are either permanently unconscious or you have an end-stage medical condition, which is a condition that will result in death despite the introduction or continuation of medical treatment. You, and not your health care agent, remain responsible for the cost of your medical care.

If you do not write down your wishes about your health care in advance, and if later you become unable to understand, make or communicate these decisions, those wishes may not be honored because they may remain unknown to others.

A health care provider who refuses to honor your wishes about health care must tell you of its refusal and help to transfer you to a health care provider who will honor your wishes.

You should give a copy of your advance health care directive (a living will, health care power of attorney or a document containing both) to your health care agent, your physicians, family members and others whom you expect would likely attend to your needs if you become unable to understand, make or communicate decisions about medical care. If your health care wishes change, tell your physician and write a new advance health care directive to replace your old one. If your wishes about donating an organ, tissue or eyes change, tell your physician and write a new advance health care directive to replace your old one. If you do not wish to donate a hand, facial tissue or limb, it is important to make that clear in your advance health care directive or health care power of attorney, or both. It is important in selecting a health care agent that you choose a person you trust who is likely to be available in a medical situation where you cannot make decisions for yourself. You should inform that person that you have appointed him or her as your health care agent and discuss your beliefs and values with him or her so that your health care agent will understand your health care objectives, including whether you want to limit or withhold life-sustaining measures in the event that you become permanently unconscious or have an end-stage medical condition. You should also tell your health care agent whether you want to donate organs, tissue, eyes or other parts of the body and whether you want to make a donation of your hands, facial tissue or limbs. It is important to understand that if you decide to donate a hand, limb or facial tissue it may impact funeral arrangements and that an open casket may not be possible.

You may wish to consult with knowledgeable, trusted individuals such as family members, your physician or clergy when considering an expression of your values and health care wishes. You are free to create your own advance health care directive to convey your wishes regarding medical treatment. The following form is an example of an advance health care

directive that combines a health care power of attorney with a living will.

NOTES ABOUT THE USE OF THIS FORM

If you decide to use this form or create your own advance health care directive, you should consult with your physician and your attorney to make sure that your wishes are clearly expressed and comply with the law.

If you decide to use this form but disagree with any of its statements, you may cross out those statements.

You may add comments to this form or use your own form to help your physician or health care agent decide your medical care.

This form is designed to give your health care agent broad powers to make health care decisions for you whenever you cannot make them for yourself. It is also designed to express a desire to limit or authorize care if you have an end-stage medical condition or are permanently unconscious. If you do not desire to give your health care agent broad powers, or you do not wish to limit your care if you have an end-stage medical condition or are permanently unconscious, you may wish to use a different form or create your own. YOU SHOULD ALSO USE A DIFFERENT FORM IF YOU WISH TO EXPRESS YOUR PREFERENCES IN MORE DETAIL THAN THIS FORM ALLOWS OR IF YOU WISH FOR YOUR HEALTH CARE AGENT TO BE ABLE TO SPEAK FOR YOU IMMEDIATELY. In these situations, it is particularly important that you consult with your attorney and physician to make sure that your wishes are clearly expressed, including whether you want to limit or withhold life-sustaining measures in the event that you become permanently unconscious or have an end-stage medical condition and whether you wish to donate a part of the body for transplantation or research. You should also clearly express whether or not you wish to donate hands, facial tissue or limbs.

This form allows you to tell your health care agent your goals if you have an end-stage medical condition or other extreme and irreversible medical condition, such as advanced Alzheimer's disease. Do you want medical care applied aggressively in these situations or would you consider such aggressive medical care burdensome and undesirable?

You may choose whether you want your health care agent to be bound by your instructions or whether you want your health care agent to be able to decide at the time what course of treatment the health care agent thinks most fully reflects your wishes and values.

If you are a woman and diagnosed as being pregnant at the time a health care decision would otherwise be made pursuant to this form, the laws of this Commonwealth prohibit implementation of that decision if it directs that life-sustaining treatment, including nutrition and hydration, be withheld or withdrawn from you, unless your attending physician and an obstetrician who have examined you certify in your medical record that the life-sustaining treatment:

(1) will not maintain you in such a way as to permit the continuing development and live birth of the unborn child;

(2) will be physically harmful to you; or

(3) will cause pain to you that cannot be alleviated by medication.

A physician is not required to perform a pregnancy test on you unless the physician has reason to believe that you may be pregnant.

Pennsylvania law protects your health care agent and health care providers from any legal liability for following in good faith your wishes as expressed in the form or by your health care agent's direction. It does not otherwise change professional standards or excuse negligence in the way your wishes are carried out. If you have any questions about the law, consult an attorney for guidance.

This form and explanation is not intended to take the place of specific legal or medical advice for which you should rely upon your own attorney and physician.

## PART II

## DURABLE HEALTH CARE POWER OF ATTORNEY

I,....., of..... County, Pennsylvania, appoint the person named below to be my health care agent to make health and personal care decisions for me.

Effective immediately and continuously until my death or revocation by a writing signed by me or someone authorized to make health care treatment decisions for me, I authorize all health care providers or other covered entities to disclose to my health care agent, upon my agent's request, any information, oral or written, regarding my physical or mental health, including, but not limited to, medical and hospital records and what is otherwise private, privileged, protected or personal health information, such as health information as defined and described in the Health Insurance Portability and Accountability Act of 1996 (Public Law 104-191, 110 Stat. 1936), the regulations promulgated thereunder and any other State or local laws and rules. Information disclosed by a health care provider or other covered entity may be redisclosed and may no longer be subject to the privacy rules provided by 45 C.F.R. Pt. 164.

The remainder of this document will take effect when and only when I lack the ability to understand, make or communicate a choice regarding a health or personal care decision as verified by my attending physician. My health care agent may not delegate the authority to make decisions.

MY HEALTH CARE AGENT HAS ALL OF THE FOLLOWING POWERS SUBJECT TO THE HEALTH CARE TREATMENT INSTRUCTIONS THAT FOLLOW IN PART III (CROSS OUT ANY POWERS YOU DO NOT WANT TO GIVE YOUR HEALTH CARE AGENT):

1. To authorize, withhold or withdraw medical care and surgical procedures.

2. To authorize, withhold or withdraw nutrition (food) or hydration (water) medically supplied by tube through my nose, stomach, intestines, arteries or veins.

3. To authorize my admission to or discharge from a medical, nursing, residential or similar facility and to make agreements for my care and health insurance for my care, including hospice and/or palliative care.

4. To hire and fire medical, social service and other support personnel responsible for my care.

5. To take any legal action necessary to do what I have directed.

6. To request that a physician responsible for my care issue a do-not-resuscitate (DNR) order, including an out-of-hospital DNR order, and sign any required documents and consents.

7. To authorize or refuse to authorize donation of what we traditionally think of as organs (for example, heart, lung, liver, kidney), tissue, eyes or other parts of the body.

8. To authorize or refuse to authorize donation of hands, facial tissue, limbs or other vascularized composite allografts.

APPOINTMENT OF HEALTH CARE AGENT

I appoint the following health care agent:

Health Care Agent:.....
(Name and relationship)

Address:.....
.....

Telephone Number: Home..... Work.....

E-mail:.....

IF YOU DO NOT NAME A HEALTH CARE AGENT, HEALTH CARE PROVIDERS WILL ASK YOUR FAMILY OR AN ADULT WHO KNOWS YOUR PREFERENCES AND VALUES FOR HELP IN DETERMINING YOUR WISHES FOR TREATMENT. NOTE THAT YOU MAY NOT APPOINT YOUR DOCTOR OR OTHER HEALTH CARE

PROVIDER AS YOUR HEALTH CARE AGENT UNLESS RELATED TO YOU BY BLOOD, MARRIAGE OR ADOPTION.

If my health care agent is not readily available or if my health care agent is my spouse and an action for divorce is filed by either of us after the date of this document, I appoint the person or persons named below in the order named. (It is helpful, but not required, to name alternative health care agents.)

First Alternative Health Care Agent:.....
(Name and relationship)

Address:.....
.....

Telephone Number: Home..... Work.....

E-mail:.....

Second Alternative Health Care Agent:.....
(Name and relationship)

Address:.....
.....

Telephone Number: Home..... Work.....

E-mail:.....

GUIDANCE FOR HEALTH CARE AGENT (OPTIONAL) GOALS

If I have an end-stage medical condition or other extreme irreversible medical condition, my goals in making medical decisions are as follows (insert your personal priorities such as comfort, care, preservation of mental function, etc.):.....
.....
.....
.....

SEVERE BRAIN DAMAGE OR BRAIN DISEASE

If I should suffer from severe and irreversible brain damage or brain disease with no realistic hope of significant recovery, I would consider such a condition intolerable and the application of aggressive medical care to be burdensome. I therefore request that my health care agent respond to any intervening (other and separate) life-threatening conditions in the same manner as directed for an end-stage medical condition or state of permanent unconsciousness as I have indicated below.

Initials.....I agree

Initials.....I disagree

## PART III
## HEALTH CARE TREATMENT INSTRUCTIONS IN THE EVENT OF END-STAGE MEDICAL CONDITION OR PERMANENT UNCONSCIOUSNESS (LIVING WILL)

The following health care treatment instructions exercise my right to make my own health care decisions. These instructions are intended to provide clear and convincing evidence of my wishes to be followed when I lack the capacity to understand, make or communicate my treatment decisions:

IF I HAVE AN END-STAGE MEDICAL CONDITION (WHICH WILL RESULT IN MY DEATH, DESPITE THE INTRODUCTION OR CONTINUATION OF MEDICAL TREATMENT) OR AM PERMANENTLY UNCONSCIOUS SUCH AS AN IRREVERSIBLE COMA OR AN IRREVERSIBLE VEGETATIVE STATE AND THERE IS NO REALISTIC HOPE OF SIGNIFICANT RECOVERY, ALL OF THE FOLLOWING APPLY (CROSS OUT ANY TREATMENT INSTRUCTIONS WITH WHICH YOU DO NOT AGREE):

1. I direct that I be given health care treatment to relieve pain or provide comfort even if such treatment might shorten my life, suppress my appetite or my breathing, or be habit forming.

2. I direct that all life prolonging procedures be withheld or withdrawn. You may want to consult with your physician and attorney in order to determine whether your designated choices regarding end-of-life care are compatible with anatomical donation. In order to donate an organ your body may need to be maintained on artificial support after you have

been declared dead to facilitate anatomical donation. Detailed information about the procedure for being declared brain dead or dead by lack of cardiac function and information about organ donation can be found on the Department of Transportation's publicly accessible Internet website.

3. I specifically do not want any of the following as life prolonging procedures: (If you wish to receive any of these treatments, write "I do want" after the treatment)

heart-lung resuscitation (CPR).....
mechanical ventilator (breathing machine).....
dialysis (kidney machine).....
surgery.....
chemotherapy.....
radiation treatment.....
antibiotics.....

Please indicate whether you want nutrition (food) or hydration (water) medically supplied by a tube into your nose, stomach, intestine, arteries, or veins if you have an end-stage medical condition or are permanently unconscious and there is no realistic hope of significant recovery. (Initial only one statement.)

TUBE FEEDINGS

.....I want tube feedings to be given

OR

NO TUBE FEEDINGS

.....I do not want tube feedings to be given.

4. If I have authorized donation of an organ (such as a heart, liver or lung) or a vascularized composite allograft in the next section of this document, I authorize the use of artificial support, including a ventilator, for a limited period of time after I am declared dead to facilitate the donation.

5. I specifically do not want to be on artificial support after I am declared dead.....

HEALTH CARE AGENT'S USE OF INSTRUCTIONS

(INITIAL ONE OPTION ONLY).

.....My health care agent must follow these instructions.

OR

.....These instructions are only guidance. My health care agent shall have final say and may override any of my instructions. (Indicate any exceptions).....
.....

If I did not appoint a health care agent, these instructions shall be followed.

LEGAL PROTECTION

Pennsylvania law protects my health care agent and health care providers from any legal liability for their good faith actions in following my wishes as expressed in this form or in complying with my health care agent's direction. On behalf of myself, my executors and heirs, I further hold my health care agent and my health care providers harmless and indemnify them against any claim for their good faith actions in recognizing my health care agent's authority or in following my treatment instructions.

SIGNATURE.....

INFORMATION ABOUT ANATOMICAL DONATION

Donating an organ or other part of the body is a voluntary act. Under Pennsylvania law, you do not have to donate an organ or any other part of your body. It is important to know the effect of organ donation on your decisions about end-of-life care so that your wishes about end-of-life care will be fulfilled. If someone wishes to become an organ donor, the person may be kept on artificial support after the person has been declared dead to facilitate anatomical donation. Detailed information about the procedure for recovering organs and other parts of the body and detailed information about brain death

and cardiac death may be found on the Department of Transportation's publicly accessible Internet website.

Under Pennsylvania law, the organ donor designation on the driver's license authorizes the individual to donate what we traditionally think of as organs (for example, heart, lung, liver, kidney) and tissue and does not authorize the individual to donate hands, facial tissue, limbs or other vascularized composite allografts.

Under Pennsylvania law, explicit and specific consent to donate hands, facial tissue, limbs and other vascularized composite allografts is needed. Donation of these parts of the body is voluntary. Information about the procedure to transplant hands, facial tissue and limbs can be found on the Department of Transportation's publicly accessible Internet website. It is important to know that donating a hand, limb or facial tissue may impact funeral arrangements and that an open casket may not be possible.

ORGAN DONATION

.....I consent to making an anatomical gift. This gift does not include hands, facial tissue, limbs or other vascularized composite allografts. I understand that if I want to donate a hand, facial tissue, limb or other vascularized composite allograft, there is another place in this document for me to do so. I also understand the hospital may provide artificial support, which may include a ventilator, after I am declared dead in order to facilitate donation. I consent to making a gift of the following parts of my body for transplantation or research (please insert any limitations you desire on donation of specific organs or tissues or eyes or any limitation on the use of a donated part of the body):

.....

.....

.....

SIGNATURE.....DATE.....

GIFT OF HANDS, FACIAL TISSUE, LIMBS AND OTHER VASCULARIZED COMPOSITE ALLOGRAFTS

.....I consent to making a gift of my hands, facial tissue, limbs or other vascularized composite allografts. I also understand that I have the option of requesting reconstruction of my body in preparation for burial and that anonymity of identity may not be able to be protected in the case of donation of hands, facial tissue or limbs. I also understand that burial arrangements may be affected and that an open casket may not be possible. I also understand that the hospital may provide artificial support, which may include a ventilator, after I am declared dead in order to facilitate donation.

Please insert any limitations you desire on donation of hands, facial tissue, limbs or other vascularized composite allografts and whether you request reconstructive surgery before burial:

.....

.....

.....

SIGNATURE.....DATE.....

.....I do not consent to donating my organs, tissues or any other part of my body, including hands, facial tissue, limbs or other vascularized composite allografts. This provision serves as a refusal to donate any part of my body. This provision also serves as a revocation of any prior decision I have made to donate organs, tissues or other parts of my body, including hands, facial tissue, limbs or other vascularized composite allograft made in a prior document, including a driver's license, will, power of attorney, health care power of attorney or other document.

SIGNATURE.....DATE.....

Having carefully read this document, I have signed it this.....day of....., 20..., revoking all previous

health care powers of attorney and health care treatment instructions.

.....

(SIGN FULL NAME HERE FOR HEALTH CARE POWER OF ATTORNEY AND HEALTH CARE TREATMENT INSTRUCTIONS)

WITNESS:.....

WITNESS:.....

Two witnesses at least 18 years of age are required by Pennsylvania law and should witness your signature in each other's presence. A person who signs this document on behalf of and at the direction of a principal may not be a witness. (It is preferable if the witnesses are not your heirs, nor your creditors, nor employed by any of your health care providers.)

NOTARIZATION (OPTIONAL)

(Notarization of document is not required by Pennsylvania law, but if the document is both witnessed and notarized, it is more likely to be honored by the laws of some other states.)

On this.....day of ....., 20...., before me personally appeared the aforesaid declarant and principal, to me known to be the person described in and who executed the foregoing instrument and acknowledged that he/she executed the same as his/her free act and deed.

IN WITNESS WHEREOF, I have hereunto set my hand and affixed my official seal in the County of....., State of..... the day and year first above written.

..... .....

Notary Public My commission expires

(Oct. 23, 2018, P.L.594, No.90)

**2018 Amendment.** Section 11(3) of Act 90 provided that the amendment of section 5471 shall take effect upon publication of the notice under section 8629.

**§ 5808. Combining mental health instruments.**

**(a) General rule.--**A declaration and mental health power of attorney may be combined into one mental health document.

**(b) Form.--**A combined declaration and mental health power of attorney may be in the following form or any other written form which contains the information required under Subchapters B (relating to mental health declarations) and C (relating to mental health powers of attorney):

Combined Mental Health Care Declaration
and Power of Attorney Form

Part I. Introduction.

I, , having capacity to make mental health decisions, willfully and voluntarily make this declaration and power of attorney regarding my mental health care.

I understand that mental health care includes any care, treatment, service or procedure to maintain, diagnose, treat or provide for mental health, including any medication program and therapeutic treatment. Electroconvulsive therapy may be administered only if I have specifically consented to it in this document. I will be the subject of laboratory trials or research only if specifically provided for in this document. Mental health care does not include psychosurgery or termination of parental rights.

I understand that my incapacity will be determined by examination by a psychiatrist and one of the following: another psychiatrist, psychologist, family physician, attending physician or mental health treatment professional. Whenever possible, one of the decision makers will be one of my treating professionals.

Part II. Mental Health Declaration.

A. When this declaration becomes effective.

This declaration becomes effective at the following designated time:

( ) When I am deemed incapable of making mental health care decisions.

( ) When the following condition is met:
(List condition)

B. Treatment preferences.

1. Choice of treatment facility.

( ) In the event that I require commitment to a psychiatric treatment facility, I would prefer to be admitted to the following facility:
(Insert name and address of facility)

( ) In the event that I require commitment to a psychiatric treatment facility, I do not wish to be committed to the following facility:
(Insert name and address of facility)

I understand that my physician may have to place me in a facility that is not my preference.

2. Preferences regarding medications for psychiatric treatment.

( ) I consent to the medications that my treating physician recommends.

( ) I consent to the medications that my treating physician recommends with the following exception, preference or limitation:

(List medication and reason for exception, preference or limitation)

The exception, preference or limitation applies to generic, brand name and trade name equivalents. I understand that dosage instructions are not binding on my physician.

( ) I do not consent to the use of any medications.

( ) I have designated an agent under the power of attorney portion of this document to make decisions related to medication.

3. Preferences regarding electroconvulsive therapy (ECT).

( ) I consent to the administration of electroconvulsive therapy.

( ) I do not consent to the administration of electroconvulsive therapy.
( ) I have designated an agent under the power of attorney portion of this document to make decisions related to electroconvulsive therapy.

4. Preferences for experimental studies or drug trials.

( ) I consent to participation in experimental studies if my treating physician believes that the potential benefits to me outweigh the possible risks to me.
( ) I have designated an agent under the power of attorney portion of this document to make decisions related to experimental studies.
( ) I do not consent to participation in experimental studies.
( ) I consent to participation in drug trials if my treating physician believes that the potential benefits to me outweigh the possible risks to me.
( ) I have designated an agent under the power of attorney portion of this document to make decisions related to drug trials.
( ) I do not consent to participation in any drug trials.

5. Additional instructions or information.

Examples of other instructions or information that may be included:

Activities that help or worsen symptoms.
Type of intervention preferred in the event of a crisis.
Mental and physical health history.
Dietary requirements.
Religious preferences.
Temporary custody of children.
Family notification.
Limitations on the release or disclosure of mental health records.
Other matters of importance.

C. Revocation.

This declaration may be revoked in whole or in part at any time, either orally or in writing, as long as I have not been found to be incapable of making mental health decisions. My revocation will be effective upon communication to my attending physician or other mental health care provider, either by me or a witness to my revocation, of the intent to revoke. If I choose to revoke a particular instruction contained in this declaration in the manner specified, I understand that the other instructions contained in this declaration will remain effective until:

(1) I revoke this declaration in its entirety;
(2) I make a new combined mental health declaration and power of attorney; or
(3) two years after the date this document was executed.

D. Termination.

I understand that this declaration will automatically terminate two years from the date of execution unless I am deemed incapable of making mental health care decisions at the time that this declaration would expire.

(Specify date)

E. Preference as to a court-appointed guardian.

I understand that I may nominate a guardian of my person for consideration by the court if incapacity proceedings are commenced under 20 Pa.C.S. § 5511. I understand that the court will appoint a guardian in accordance with my most recent nomination except for good cause or disqualification. In the event a court decides to appoint a guardian, I desire the following person to be appointed:

(Insert name, address, telephone number of the designated person)

( ) The appointment of a guardian of my person will not give the guardian the power to revoke, suspend or terminate this declaration.
( ) Upon appointment of a guardian, I authorize the guardian to

revoke, suspend or terminate this declaration.
Part III. Mental Health Power of Attorney.
I, , having the capacity to make mental health decisions, authorize my designated health care agent to make certain decisions on my behalf regarding my mental health care. If I have not expressed a choice in this document or in the accompanying declaration, I authorize my agent to make the decision that my agent determines is the decision I would make if I were competent to do so.
A. Designation of agent.
I hereby designate and appoint the following person as my agent to make mental health care decisions for me as authorized in this document. This authorization applies only to mental health decisions that are not addressed in the accompanying signed declaration.
(Insert name of designated person)
Signed:
(My name, address, telephone number)
Witnesses' signatures:
(Insert names, addresses, telephone numbers of witnesses)
Agent's acceptance:
I hereby accept designation as mental health care agent for
(Insert name of declarant)
Agent's signature:
(Insert name, address, telephone number of designated person)
B. Designation of alternative agent.
In the event that my first agent is unavailable or unable to serve as my mental health care agent, I hereby designate and appoint the following individual as my alternative mental health care agent to make mental health care decisions for me as authorized in this document:
(Insert name of designated person)
Signed:
(My name, address, telephone number)
Witnesses' signatures:
(Insert names, addresses, telephone numbers of witnesses)
Alternative agent's acceptance:
I hereby accept designation as alternative mental health care agent for (Insert name of declarant)
Alternative agent's signature:
(Insert name, address, telephone number of alternative agent)
C. When this power of attorney become effective.
This power of attorney will become effective at the following designated time:
( ) When I am deemed incapable of making mental health care decisions.
( ) When the following condition is met:
(List condition)
D. Authority granted to my mental health care agent.
I hereby grant to my agent full power and authority to make mental health care decisions for me consistent with the instructions and limitations set forth in this document. If I have not expressed a choice in this power of attorney or in the accompanying declaration, I authorize my agent to make the decision that my agent determines is the decision I would make if I were competent to do so.
(1) Preferences regarding medications for psychiatric treatment.
( ) My agent is authorized to consent to the use of any medications after consultation with my treating psychiatrist and any other persons my agent considers appropriate.
( ) My agent is not authorized to consent to the use of any medications.
(2) Preferences regarding electroconvulsive therapy (ECT).
( ) My agent is authorized to consent to the administration of electroconvulsive therapy.
( ) My agent is not authorized to consent to the administration of electroconvulsive therapy.
(3) Preferences for experimental studies or drug trials

(3) Preferences for experimental studies or drug trials:
( ) My agent is authorized to consent to my participation in experimental studies if, after consultation with my treating physician and any other individuals my agent deems appropriate, my agent believes that the potential benefits to me outweigh the possible risks to me.
( ) My agent is not authorized to consent to my participation in experimental studies.
( ) My agent is authorized to consent to my participation in drug trials if, after consultation with my treating physician and any other individuals my agent deems appropriate, my agent believes that the potential benefits to me outweigh the possible risks to me.
( ) My agent is not authorized to consent to my participation in drug trials.

E. Revocation.

This power of attorney may be revoked in whole or in part at any time, either orally or in writing, as long as I have not been found to be incapable of making mental health decisions. My revocation will be effective upon communication to my attending physician or other mental health care provider, either by me or a witness to my revocation, of the intent to revoke. If I choose to revoke a particular instruction contained in this power of attorney in the manner specified, I understand that the other instructions contained in this power of attorney will remain effective until:

(1) I revoke this power of attorney in its entirety;

(2) I make a new combined mental health care declaration and power of attorney; or

(3) two years from the date this document was executed. I understand that this power of attorney will automatically terminate two years from the date of execution unless I am deemed incapable of making mental health care decisions at the time that the power of attorney would expire.

I am making this combined mental health care declaration and power of attorney on the (insert day) day of (insert month), (insert year).

My signature:

(My name, address, telephone number)

Witnesses' signatures:

(Names, addresses, telephone numbers of witnesses).

If the principal making this combined mental health care declaration and power of attorney is unable to sign this document, another individual may sign on behalf of and at the direction of the principal.

Signature of person signing on my behalf:

(Name, address, telephone number)