

Who is the Pennsylvania Health Care Decision Maker?

(Who's on First?)

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 Not intended to take the place of legal or medical advice for a specific patient situation for which appropriate Professional guidance should be sought.

Competent Patient	Health Care Agent	Health Care Representative	Guardian Of the Person	Incompetent Patient
Always in charge – can override the decision of Health Care Agent or purported Health Care Representative	In charge <u>if</u> patient has Health Care Power of Attorney and patient has become incapacitated or if patient has “sprung” the Health Care Power of Attorney if allowed by Health Care Power of Attorney document §5454(a)	In charge <u>if</u> (1) patient is an adult (2) patient is incompetent (3) there is no Health Care Power of Attorney or Agent is unable or unwilling to act (4) Guardian of Person to make health care decisions not appointed §5461(a)	In charge if appointed by Orphans' Court Division. Subject to powers and limitation in Order of Appointment §5461(a)(3)	A patient can override Living Will at any time and in any manner regardless of physical or mental condition §5444(a). A patient can countermand decision of Health Care Agent to withhold or withdraw life sustaining treatment regardless of physical or mental condition §5457(b)

What are the Powers of Pennsylvania Health Care Decision Makers?*

Power	Competent Patient	Health Agent	Health Care Representative	Guardian of the Person	Incompetent Patient
Power to sign a Health Care Power of Attorney or Living Will	Yes -- an adult person of "sound mind" can execute these documents §5442(a) §5452(a)	No	No	No	No
Power to sign POLST or DNR	Yes	Yes, unless limited by Health Care Power of Attorney §5456(a)	Yes, but <u>MAY</u> <u>DECLINE HEALTH CARE NECESSARY TO PRESERVE LIFE ONLY IF END STAGE MEDICAL CONDITION OR PERMANENT UNCONSCIOUSNESS</u> §5462(c)	Yes -- subject to limitations in Order of Court. <u>MAY</u> <u>DECLINE HEALTH CARE NECESSARY TO PRESERVE LIFE ONLY IF END STAGE MEDICAL CONDITION OR PERMANENT UNCONSCIOUSNESS</u> §5462(c) and <u>In re D.L.H.*</u> Proposal by JSGC would clarify powers and process. <u>If</u> <u>disagreement</u> , go to Court.	No.
Power to revoke a Living Will or Health Care Power of Attorney	Yes. §5444(a); §5459(a)	No	No	Power to revoke or amend Health Care Power of Attorney but not Living Will (§5460(a))	Yes -- a patient can revoke a Living Will or countermand Health Care Agent's decision to withhold or withdraw life sustaining treatment regardless of physical or mental condition. §5444(a). §5457(b)

Power	Competent Patient	Health Agent	Health Care Representative	Guardian of the Person	Incompetent Patient
Power to revoke POLST or DNR	Yes	Yes if signed by Health Care Agent -- If signed by patient prior to incompetency, it is an "instruction" which may be entitled to substantial weight in health care decision-making as described in §5456(c). But note that instruction applies to patient's <u>then current condition</u> .	Yes if signed by Health Care Representative -- If signed by patient prior to incompetency, it is an "instruction" which may be entitled to substantial weight in health care decision-making as described in §5456(c). But note that instruction applies to patient's <u>then current condition</u> .	Yes if signed by Guardian or Health Care Representative prior to appointment of Guardian of the Person. -- If signed by patient prior to incompetency, it is an "instruction" which may be entitled to substantial weight in health care decision-making as described in §5456(c). But note that instruction applies to patient's <u>then current condition</u> .	Yes, theoretically by parity of reasoning with the revocation of a Living Will or a countermand of a Health Care Agent's order to withhold or withdraw life-sustaining care if POLST or DNR order directs the withholding or withdrawal of life sustaining treatment. Was there actually a "revocation"? Evaluate using best medical judgment
Power to decline health care necessary to preserve life	Yes	Yes if empowered by Health Care Power of Attorney	Yes if patient is in End Stage Medical Condition or Permanently Unconsciousness §5462(c). But not otherwise.	Yes if patient in End Stage medical condition or Permanently Unconscious §5462(c) and <i>In re DLH**</i> but not otherwise. Powers and procedure of guardian will be clarified if Joint State Government Commission recommendation is adopted	No

**Concerns have been expressed that for a Guardian to withhold or withdraw health care necessary to preserve life, a Court Order is necessary even if the patient is in an End-Stage Medical Condition or is Permanently Unconscious. The author believes this is an overly restrictive reading of *In re DLH*, 2 A.3d 505 (Pa. 2010) which would be fundamentally inconsistent with our Supreme Court's decision of *In re Fiori*, 673 A.2d 905 (Pa. 1996). *Fiori* held that a close family member could withdraw life sustaining treatment for a patient in a confirmed permanent vegetative state without a Court Order where there

was no disagreement among the parties in interest; including the physicians, the family members, the Guardian of the Person and the medical facility. The current legislative recommendation of the Joint State Government Commission would clarify and reaffirm that rule, generally equating the powers of a Guardian of the Person with those of a Health Care Representative. Where there is disagreement amongst the parties in interest, the facility should consider seeking a Court Order.

***All Health Care Decisions by anyone acting for a patient should made as set forth in Section 5456(c) which explicitly applies to Health Care Agents and Health Care Representatives, but should also be consistently utilized by a Guardian of the Person making health care decisions for a patient.**

“ Health care decisions--

- (1) The health care agent shall gather information on the principal's prognosis and acceptable medical alternatives regarding diagnosis, treatments and supportive care.
- (2) In the case of procedures for which informed consent is required under section 504 of the act of March 20, 2002 (P.L. 154, No. 13), known as the Medical Care Availability and Reduction of Error (McCare) Act, the information shall include the information required to be disclosed under that act.
- (3) In the case of health care decisions regarding end of life of a patient with an end-stage medical condition, the information shall distinguish between curative alternatives, palliative alternatives and alternatives which will merely serve to prolong the process of dying. The information shall also distinguish between the principal's end-stage medical condition and any other concurrent disease, illness or physical, mental, cognitive or intellectual condition that predated the principal's end-stage medical condition.
- (4) After consultation with health care providers and consideration of the information obtained in accordance with paragraphs (1), (2) and (3), the health care agent shall make health care decisions in accordance with the health care agent's understanding and interpretation of the instructions given by the principal at a time when the principal had the capacity to understand, make and communicate health care decisions. Instructions include an advance health care directive made by the principal and any clear written or verbal directions that cover the situation presented.
- (5) (i) In the absence of instruction, the health care agent shall make health care decisions that conform to the health care agent's assessment of the principal's preferences and values, including religious and moral beliefs.
(ii) If the health care agent does not know enough about the principal's instructions, preferences and values to decide accordingly, the health care agent shall take into account what the agent knows of the principal's instructions, preferences and values, including religious and moral beliefs, and the health care agent's assessment of the principal's best interests, taking into consideration the following goals and considerations:
 - (A) The preservation of life.
 - (B) The relief from suffering.
 - (C) The preservation or restoration of functioning, taking into account any concurrent disease, illness or physical, mental, cognitive or intellectual condition that may have predated the principal's end-stage medical condition.
 - (iii) (A) In the absence of a specific, written authorization or direction by a principal to withhold or withdraw nutrition and hydration administered by gastric tube or intravenously or by other artificial or invasive means, a health care agent shall presume that the principal would not want nutrition and hydration withheld or withdrawn.
 - (B) The presumption may be overcome by previously clearly expressed wishes of the principal to the contrary. In the absence of such clearly expressed wishes, the presumption may be overcome if the health care agent considers the values and preferences of the principal and assesses the factors set forth in subparagraphs (i) and (ii) and determines it is clear that the principal would not wish for artificial nutrition and hydration to be initiated or continued.
- (6) The Department of Health shall ensure as part of the licensure process that health care providers under its jurisdiction have policies and procedures in place to implement this subsection.”

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I cannot manage to die

Pitt health law pioneer Nathan Hershey explains why he wishes to die and how the law will not allow it

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*This article was written by **Nathan Hershey** with the help of his friend and memoir assistant, **Alicia NiTracy**.*

I would prefer to bring my life to an end at a time of my choosing, but it appears that I am unable to do so without help. I do not want to do it in a way that will bring possible penalty to anyone who would choose to cooperate with me in accomplishing this goal, in response to an expression of my desire to end my life.

Due to both the progression of my Alzheimer's and the permanent effects of a stroke, my capacity to plan and accomplish is severely inhibited. I rely on the help of my daughters to organize my economic and living situations as well as the hiring of daily helpers I need to maintain a relatively safe, active and comfortable life. I rely on these helpers so I can communicate with people I still know, by reading and sending emails and by making phone calls.

I need this help around the clock, to know when and how to reach the dining room in my memory-care assisted-living building, to shower safely, to organize my transportation and support for cultural and political events, to locate possessions I rely on such as my shaver and shaving cream beside my bathroom sink and the cups in my kitchen, to take my medication and to continue writing — including this essay.

This feeling of dependence is an experience I dodged in my youth, during my service in the military and throughout my career as a professor of health law. My intelligence and autonomy have been of utmost importance to me for almost all my life. I had a fairly good memory and an independent personality during my earlier life. To exist in such extreme dependence today is agonizing for me.

Recently, I apparently had a very enjoyable day at a party and a performance. I awakened the next morning with no recollection of experiencing any pleasure the day before and no knowledge of what had occurred. When I woke, the confusion, frustration and dependence of the day felt as if they had gone on forever, and would continue forever. I am no longer able to hold onto a sense of fulfillment.

I thought about end-of-life issues for many years prior to the onset of my Alzheimer's and the occurrence of my stroke. Decades before my condition became evident, I held the belief that the choice of if and when to have one's life end should be left to the individual as an exercise of freedom. I told my daughters about my conviction in this matter long before it became an issue for me.

Accordingly, with the help of my daughter, who holds a power of attorney for me, my medical directive has been constructed to allow for comfort measures only. This was put into place well before anyone could question my memory or brain function.

Looking ahead to concluding my life also involves looking back on my life as a whole, taking stock of my experiences.

I enjoyed a well-supported childhood with two loving parents, a full academic experience at both New York University and Harvard Law School, service in the U.S. Army, a successful career in health law, 50 years as a professor at the University of Pittsburgh's Graduate School of Public Health and many other professional achievements. I met a beautiful woman named Carol to whom I was married for 50 years, had two wonderful children and many friends and athletic adventures along the way.

As I assess my life, I feel fulfilled. I am prepared to conclude my life now.

This essay is the result of many gathered notes and drafts over the course of several months, and it draws on ideas I've discussed with my memoir assistant for more than four years. I am certain that my decision that I am ready to pass on is thoroughly considered, permanent and final.

Although my cognitive health is poor and in progressive decline, my physical health is relatively stable for a man of 84 years. Currently, only three U.S. states permit aid in dying: Oregon, Washington and Vermont. Three of their requirements are cognitive competence, a likelihood of

dying in the next six months anyway and residency in that state. Residency is relatively easy to establish. However, the other requirements are impossible for me.

A hospice nurse evaluated my physical health within the last few weeks and determined that I am unlikely to die in the next six months. (I do not remember that evaluation.)

The cognitive health requirement is that the individual seeking aid in dying must be 100 percent undoubtedly sound of mind in order to get his or her wishes met, attempting to ensure the highest possible legitimacy of consent. Even if my physical health declines to the extent that I become likely to die in the following six months, due to my brain injuries and disease, I will never pass the cognitive requirements to qualify for aid in dying in any state.

Live too long, lose your right to make a decision that will be honored.

If I terminated my life by my own actions, I fear that those close to me might be accused of assisting me in doing so. They have assured me that they do not care if others do not approve of my position on end-of-life decision-making, and they are confident that if they do not aid me in dying, they can't be proven to have done so and therefore will not be punished by the law. However, the obstacle still remains that I am not able, without help, to plan and implement an effective and comfortable method to end my life.

I don't have the answers. I do have a certainty that I face an ultimate dilemma. I am not capable of planning or implementing my own death, but I believe I am capable of knowing that I want to die. The very fact that I need assistance in order to terminate my life is the same requirement that disqualifies me from receiving that help. I wonder for how many people this is a common experience. I wonder what can be done.

Nathan Hershey is emeritus professor of health law at the University of Pittsburgh (hershey@pitt.edu). He joined Pitt as a research associate in 1956 and played an integral role in creating the field of health law, which regulates what is now the nation's largest industry.

Health law expert wrote essay on dying on own terms

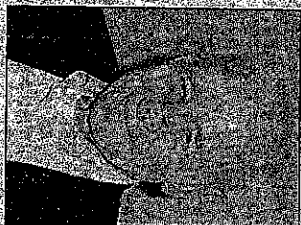
By Bill Schnackner
Pittsburgh Post-Gazette

Nathan Hershey, a pioneering figure in health law who for over five decades at the University of Pittsburgh was known as a passionate and opinionated scholar, died April 15 in an Austin, Texas, hospital of complications from a fall.

A professor emeritus in Pitt's Graduate School of Public Health, he was 83 days shy of his 87th birthday, said his daughter, Suzanne, who lives in that city. His fall two days earlier in a memory care facility came amid his struggle with Alzheimer's disease, a struggle he went public with, including a 2014 essay in the Pittsburgh Post-Gazette.

In that piece, he expressed a desire to die on his own terms but lamented that current law does not allow it. His words were seen by some as one more act of courage by an academic who colleagues said was an unrelenting advocate for justice and equity.

My intelligence and autonomy have been of utmost importance to me for almost all my life," he said in the article written with help of an essay assistant, Aleta N. Tracy. "To exist in such



Nathan Hershey on his 80th birthday.

extreme dependence today is agonizing for me.

Mr. Hershey was a fixture in the classroom and a prominent figure in campus governance through his long tenure on the University Senate, a representative body of faculty, staff, administrators and students. He served the maximum three terms as its president from 1988 to 2001.

He loved history, in particular American history, said his daughter. He also enjoyed athletics from tennis to baseball and was an avid runner, explaining the light gray tennis shoes he often wore.

Nat, as he was often called, was less than imposing at 5 feet, 8 inches tall, but intellectually he was a force, self-

down to offer an opinion, in a distinctively nasal voice.

For sure, he focused on the discipline — expanding access to education and to health care, women's health and reproductive rights, workplace equity and the academic performance of student athletes.

Many of his students were health professionals with baggers, which so irritated him in 1998 he raised it with the faculty assembly.

You start to get edgy when you get to the third page in a two-hour class. It catches you off guard," he said in a Post-Gazette article that year. "Maybe I'm the only one dumb enough to raise this."

Even on campus matters where they disagreed, said Pitt Chancellor Emeritus Mark Nordenberg, it was clear Mr. Hershey had the school's interests at heart.

He was a person who had strong ideas and he presented them quite directly, but inside he was just a wonderful guy with a big heart," Mr. Nordenberg said.

He recalled how emails from Mr. Hershey would arrive with the words just below the man's name and title: "I am against people who push over people around."

Persistence made him effective in dealing with the administration, whether it was working on an improved search integrity policy or an accelerated faculty grievance process, said emeritus associate dental professor John Baker, a former University Senate president.

"He had a very wit," Mr. Baker said. "He could be quite snide, but once you got to know him, he had a heart of gold."

Students over the decades recalled his impact.

"It's amazing what I learned from him and how often I think of him as I work through my days at the hospital," said one of those students, Christopher Gessner, president, Children's Hospital of Pittsburgh of UPMC.

"Such a great man," Mr. Hershey was born and raised in the Bronx, N.Y. He enrolled in New York University, receiving an undergraduate history degree in 1950 and a law degree from Harvard three years later.

After service in the Army stationed at Fort Knox, Ky., Mr. Hershey worked for a law firm in New York City before coming to Pitt in 1956, initially as a research associate.

He worked on early efforts to provide computerized ac-

cess to law. Pittsburgh is where he met his wife of 50 years, Carol, who died in 2008.

A health law professor in the Department of Health Policy and Management, he authored many books, chapters and articles, recalled Donald Burke, dean of the Graduate School of Public Health and associate vice chancellor for global health at Pitt.

In a memo Monday notifying faculty of Mr. Hershey's death, the dean recalled his colleague as "an irresistible champion for justice and equity" who had an integral role in creating the field of health law, which regulates what is now the nation's largest industry.

Even at 76 years old, Nat knew how to get your attention.

With his office just down the hall from mine, Nat would frequently stop in to give me advice about running the school, usually unbidden, but always on the mark," the dean added.

Mr. Hershey had been a Squirrel Hill resident until August before moving into Lochust Grove in West Mifflin, and more recently Austin.

The disease that consumed his later years was

the antithesis of the life he led.

Having his thoughts about Alzheimer's put into an essay was a validation, said his daughter, Suzanne, whose younger sister, Madeleine, of Swissvale, died in 2015. Suzanne said her father talked about the dilemma created by the disease often.

"As soon as he would start telling me I'm ready to pass on, I would say, 'Hey, dad. Do you know you're writing an article about that?' He would say, 'Is it any good? I'd say it's coming along.'"

Mr. Hershey directed that his body be donated for scientific purposes, his daughter said.

In keeping with his preference, no memorial service is planned, but his daughter suggested marking his upcoming birthday by doing something her father would have enjoyed — taking a run or walk in the park, shooting hoops or eating bagels.

To read Mr. Hershey's essay about dying on his own terms, go to post-gazette.com.

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1. Decision-making capacity

- a. Medical providers avoid use of the term competence (legally determined), but are appropriate to determine decision-making capacity
- b. Assessment is complex, and capacity can vary from day to day
- c. Elements:
 - i. Understanding - does the individual understand what medical conditions they have
 - ii. Appreciation - do they understand the significance of those conditions
 - iii. Reasoning - are they able to engage in a discussion process of risk/benefits, pros/cons and consider alternatives
 - iv. Choice - after all of the above, are they able to make a specific choice
- d. Cognition is an important part of decision-making capacity
 - i. Most people with moderate cognitive impairment will lack full decision-making capacity . . . But some people with normal cognitive function will still lack full decision-making capacity
 - ii. Thus cognition is a marker but not the sole indicator of decision-making capacity

2. Cognitive screening tests

- a. Folstein Mini-Mental status exam (MMSE)
 - i. Moving out of favor in geriatric medical field
 - ii. Copyrighted
 - iii. Insensitive – by the time the test shows abnormalities, most individuals have limited decision-making capacity
- b. Minicog – 3 minute screening test
 - i. <http://mini-cog.com/> - has copy of test, instructions for use, and scoring
 - ii. Scoring suggestions:
 - 1. 4-5 is usually consistent with retained decision-making capacity
 - 2. Less than 4, should raise question of decision-making capacity. Consider more comprehensive testing with MOCA or SLUMS, or referral to medical provider
 - 3. Less than 3 indicates a significant likelihood that the individual lacks decision-making capacity, and requires further evaluation. Involving a medical provider may be indicated.

3. Cognitive tests

- a. MOCA (Montreal Cognitive Assessment)
 - i. <http://www.mocatest.org/>
 - 1. Requires (free) registration to use
 - 2. Is available on a tablet
 - 3. Instructions for use and scoring available online
 - ii. Types
 - 1. Full test, English version 7.1 - most commonly used
 - 2. MOCA basic – for those illiterate or < 5 years education

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Tools for Assessment of Decision-Making Capacity

3. MOCA blind – for those with visual impairment
4. Also available in multiple languages
- iii. Scoring suggestions (on full test)
 1. 30/30 - Maximum points
 2. 26 or greater - Normal
 3. 22 or less - Consider further evaluation
 4. 19 or less - Strongly question if retains full medical decision-making capacity
- b. SLUMS (St. Louis University Mental Status Exam)
 - i. <http://aging.slu.edu/index.php?page=saint-louis-university-mental-status-slums-exam>
 - ii. Scoring - at bottom of test

Letter from Attorney to Client to Give to Client's Physician re Advance Directives

Draft

Date _____

Dear Physician:

Your patient _____ was recently seen by me for review and completion of certain legal documents for Advance Care Planning. Based upon my discussions with your patient and your patient's permission to correspond with you, I request that you please attach the following documents to the patient's medical record, and, if possible, have them scanned electronically into the patient's record:

_____ Advance Directive for Health Care and "Living Will"

_____ Health Care Power of Attorney

In the above documents, which may have been combined as one document, your patient has expressed, in the Living Will, the following specific wishes (*Examples: full medical interventions, DNR, no renal dialysis, no blood transfusions, etc.*). I ask that you confirm these wishes with your patient and then document them in the medical record:

1. _____

2. _____

3. _____

In addition, your patient has appointed the following individuals, in the order named, as Health Care Agents);

1. _____

2. _____

3. _____

Additional Optional Language

Your patient has expressed interest in and/or may qualify for completion of a POLST (Pennsylvania Orders for Live Sustaining Treatment) document which translates your patient's wishes for medical care into practical medical orders based upon your meeting/conversation with your patient.

Thus, please discuss the POLST with your patient and, if appropriate, sign the document and attach/scan it into the patient's medical record. The patient will keep the original of the document.

If you do not have a POLST in your office, one can be obtained at:

<http://www.upmc.com/services/aginginstitute/partnerships-and-collaborations/pages/polst.aspx> and should be printed on pink card stock for easy visibility.

Attorney Signature