STATEMENTS OF POLICY

Title 55—PUBLIC WELFARE

DEPARTMENT OF PUBLIC WELFARE

[ 55 PA. CODE CH. 6000 ]

Procedures for Surrogate Health Care Decision Making

[41 Pa.B. 352]
[Saturday, January 15, 2011]

Scope

This statement of policy applies to the following: administrative entity administrators or directors; county mental health and mental retardation administrators; supports coordination organization directors; providers of community mental retardation residential services; State Center directors; and directors of non-State intermediate care facilities for the mentally retarded.

Purpose

The purpose of this statement of policy is to clarify surrogate health care decision making procedures applicable to individuals with mental retardation who are 18 years of age or older in light of the act of November 29, 2006 (P. L. 1484, No. 169) (Act 169), which added 20 Pa.C.S. Chapter 54 (relating to advance directive health care), and other applicable laws. The Department of Public Welfare (Department) recognizes that it does not have statutory authority to interpret Act 169 and the Department does not assume any liability that may arise from the application of these guidelines with respect to private providers. This statement of policy, therefore, is not binding on these entities and does not offer protection against claims that may arise with respect to those entities.

Agencies are encouraged to consult their legal counsel for advice on the implementation of the statutes discussed in this statement of policy.

Background

When situations arise when a health care decision is necessary and an adult individual is not able to make that decision, then a decision shall be made on that individual's behalf. Bulletin 00-98-08, "Procedures for Substitute Health Care Decision Making," issued on November 30, 1998, detailed the applicable standards for surrogate decision making for individuals with mental retardation over 18 years of age. Act 169 amended the law concerning advance health care directives and authorized a "health care representative" (HCR) to make health care decisions for
individuals who are not competent and do not have valid and applicable advance health care
directives or court-appointed guardians of the person.

This statement of policy updates the Department's interpretation of the laws and procedures for
surrogate health care decision making for individuals receiving mental retardation services
through the Department under Act 169 and other applicable law.

Discussion

Act 169

State law and general standards of practice establish health care standards to which all
individuals are entitled without discrimination. Individuals with mental retardation have the right
to receive the same health and life-sustaining treatment as offered to individuals without
disabilities.

Generally, health care can be provided only with the consent of the patient. There are, however,
exceptions in emergencies or if the patient is incompetent to make health care decisions. If a
patient is incompetent, a surrogate health care decision maker is authorized by law to make
health care decisions on behalf of the patient. Historically, there has been some uncertainty about
who can serve as a surrogate health care decision maker and the extent of the surrogate health
care decision maker's authority, particularly in doctors' offices, clinics and hospitals.

The autonomy of persons who have the capacity to make particular health care decisions as they
arise should be respected. In the event that a health care decision becomes necessary, a
reasonable effort should be made to explain the proposed course of action, any alternate options
and the risks and benefits for each to the individual prior to instituting a course of action.
However, situations may arise when a health care decision is necessary and the individual,
whether incompetent as defined by Act 169, or adjudicated incapacitated, does not have the
capacity to make that decision. In these cases, a decision shall then be made on that individual's
behalf by a surrogate health care decision maker, as identified in several statutes.

2713 (relating to neglect of care-dependent person); 20 Pa.C.S. Chapter 55 (relating to
incapacitated persons); the Medical Care Availability and Reduction of Error Though Act 169
covers many aspects of health (MCARE) Act (MCARE Act) (40 P. care, several other statutes
also govern health care decision making and were not repealed by Act 169. Accordingly, they
remain in effect. These statutes include the following: 18 Pa.C.S. § 1303.101—1303.910); and
section 417(c) of the Mental Health and Mental Retardation Act of 1966 (MH/MR S. §§ Act)
(50 P. 4417(c)), regarding powers S. § and duties of directors.

Mental Health and Mental Retardation Act of 1966

For multiple reasons, section 417(c) of the MH/MR Act survives Act 169:

Section 5421(b) of 20 Pa.C.S. (relating to applicability) declares that "this chapter shall not
impair or supersede any existing . . . responsibilities not addressed in this chapter." In addition,
Act 169 does not address the situation that section 417(c) of the MH/MR Act does—the identification of a surrogate health care decision maker for a resident of an mental health and mental retardation facility who has no other surrogate health care decision maker, not even an HCR.

5461(f) (relating to decisions by health care representative) on a health care provider's being an HCR is not applicable to the facility director under section 417(c) of the MH/MR Act because the facility director is made a guardian under section 417(c) of the MH/MR Act, not an HCR. While both guardians and HCRs are surrogate health care decision makers, the constraints specifically applicable to HCRs are applicable to them only. Act 169 does not affect the rules for the identification of guardians. There are policy justifications for the The distinction. In ordinary nursing homes, the need for a facility director as an HCR is less because there will usually be 2. prohibition in 20 Pa.C.S. § others available and the facility may have had only days or weeks of contact with the patient; therefore, a facility director would not likely be a good HCR. In contrast, at an intermediate care facility for the mentally retarded (ICF/MR) or group home, some residents lack any involved family, thereby triggering the need for default surrogate health care decision makers. Facility staff in ICF/MRs and group homes have often known the residents for years or even decades, thereby becoming aware of the residents' preferences, unlike the circumstance in the ordinary nursing home.

Section 417(c) of the MH/MR Act and Act 169 need to be read in pari materia. The plain purpose of both statutory provisions is to permit surrogate health care decision making for incompetent individuals without the need to obtain a court order. If Act 169 were construed to repeal section 417(c) of the MH/MR Act, court orders would be required when there was not an HCR, thereby defeating a principal 3. purpose of Act 169 itself.

In addition, although section 417(c) of the MH/MR Act explicitly references only "elective surgery," this section should be read as applicable to health-care decisions generally. There are several reasons for this:

Section 417(c) of the MH/MR Act was enacted at the dawn of the doctrine of informed consent, when only elective surgery was thought to require explicit informed consent. Consent to emergency surgery was (and still is) implied in law. Consent to routine medical procedures such as immunizations and x-rays was thought to be 1. implied by the mere fact of the patient's cooperation. See Fay Rozovsky, Consent to Treatment, 1.10.1 (3rd ed., 2000). See also Paul Appelbaum, et al., Informed Consent (1987). Even today in this Commonwealth, only a limited number of procedures require "informed consent," see section 504 of the MCARE Act (40 P. 1928(c) (relating to rule of strict and liberal construction), and because the obvious purpose of section 417(c) of the MH/MR Act is to provide for a surrogate decision maker for medical decisions when decision makers are needed; and to do so without petitioning a 1303.504), regarding court, its scope must be read in light of its purpose. informed consent. Competent patients, or in the case of incompetent patients, their surrogate health care decision makers, are often expected in practice to "sign for" a wide range of procedures, whether informed consent is required by law or not. Because statutes are to be construed liberally to effectuate their S. purposes (with certain exceptions not applicable here), see 1 Pa.C.S. § §
Under the legal doctrine that "the greater power includes the lesser," see, for example, Griffin v. SEPTA, 757 A.2d 448 (Pa. Commw. 2000), the power to consent to "elective surgery," for example, amputation of a leg with a malignant tumor, necessarily includes the power to consent to diagnostic procedures to determine the appropriateness of an amputation. Similarly, the facility director's authority under section 417(c) of the MH/MR Act should be construed to include authority to make decisions regarding palliative and life-sustaining care for persons in an end-stage (terminal) condition.

2713 requires that necessary care and treatment be provided without consent. For care outside the mental retardation facility, such as in a doctor's office or hospital, the primary care physician and the specialist performing the procedure can serve as the two physicians (except in the rare circumstance when a primary care physician is a payroll employee of the mental retardation facility) as Section 417(c) of the MH/MR Act required under section 417(c) of the MH/MR Act. explicitly limits the facility director's authority to decision making after receiving "the advice of two physicians not employed by the facility." This requirement, however, will rarely create a practical problem. For necessary care and treatment provided in the mental retardation facility itself, consent from a surrogate is not needed because 18 Pa.C.S. §

Guideline

The guideline is in Annex A.

Effective Date

This statement of policy is effective immediately upon publication in the Pennsylvania Bulletin.

Obsolete Bulletin

This bulletin replaces and supersedes Bulletin 00-98-08, "Procedures for Substitute Health Care Decision Making."

Contact Person

The contact person for this statement of policy is Jill Morrow-Gorton, M.D., Medical Director, Office of Developmental Programs, (717) 783-5661, imorrowgor@state.pa.us.

MICHAEL P. NARDONE,
Acting Secretary

(Editor's Note) Title 55 of the: Pa. 6000.101—6000.103, 6000.111—6000.118, 6000.1021, 6000.1031 and 6000.1032 to read as set forth in Code is amended by adding a statement of policy in §§ Annex A.)

Fiscal Note: 14-BUL-94. No fiscal impact; (8) recommends adoption.
Annex A

TITLE PUBLIC WELFARE 55.

PART MENTAL RETARDATION MANUAL VIII.

Subpart STATEMENTS OF POLICY A.

CHAPTER STATEMENTS OF POLICY 6000.

PROCEDURES FOR SURROGATE HEALTH CARE Subchapter R.
DECISION MAKING

GENERAL PROVISIONS

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HEALTH CARE DECISION MAKING

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GENERAL PROVISIONS

§ 6000.1001. Scope.

Administrative entity administrators and directors, county MH/MR administrators, supports coordination organization directors and providers of MR services may consider this subchapter with respect to the decisions of surrogate health care decision makers identified under law of the Commonwealth.

§ 6000.1002. Purpose.

The purpose of this subchapter is to clarify surrogate health care decision making procedures applicable to individuals with MR who are 18 years of age or older in light of Act 169 and other applicable law.

§ 6000.1003. Definitions.

The following words and terms, when used in this subchapter, have the following meanings, unless the context clearly indicates otherwise.


Act 28 facility 2713 (relating to neglect—A nursing home, personal care home, domiciliary care of care-dependent person). home, community residential facility, State-operated intermediate care facility for the mentally retarded, privately operated intermediate care facility for the mentally retarded, adult daily living center, home health agency or home health service provider whether licensed or not. See 18 Pa.C.S. §

Advance health care directive 5422 (relating to definitions). An advance health care directive is a signed and witnessed document which directs health care in the event that the individual (the principal) is incompetent and has an end-stage medical condition or is permanently unconscious. It also may designate a person to carry out the individual's wishes regarding health care at the end of life. defined in 20 Pa.C.S. §

CPR—Cardiopulmonary Resuscitation—The term as defined in 20 Pa.C.S. 5422. §

Competent 5422. Under Act 169, the attending physician determines competency. §

DNR Order—Do not resuscitate order—An order in the individual's medical record that CPR should not be provided to the individual.

End stage medical condition—The term as defined in 20 Pa.C.S. §
Facility director—

For those facilities that are MR facilities as defined in the MH/MR Act, the facility director is the administrative head of a (i) facility.

6400.43 In facilities licensed under Chapter 6400 (relating to chief executive officer). (relating to community homes for individuals with mental retardation), the term (ii) means the chief executive officer under §

6500.42 In facilities licensed under Chapter 6500 (relating to chief executive officer). (relating to family living homes), the term means the chief executive officer (iii) under §

In intermediate care facilities for persons with mental retardation, the term means the administrator appointed under 42 CFR 483.410(a)(3) (relating to condition of participation: governing body and (iv) management).

5310.11 In facilities licensed under Chapter 5310 (relating to governing body). (relating to community residential rehabilitation services for the mentally ill), the term means the director selected under (v) §

5320.22 In facilities licensed under Chapter 5320 (relating to governing body). (relating to requirements for long-term structured residence licensure), the term means the program director selected under (vi) §

Health care—The term as defined in 5422. 20 Pa.C.S. §

Health care agent—The term as 5422. defined in 20 Pa.C.S. §

Health care decision—The term as 5422. defined in 20 Pa.C.S. §

Health care power of attorney—A health care power of attorney is the actual document declaring an individual to make health care decisions for the principal. The person designated in a health care power of attorney is sometimes referred to as the "health care agent." 5422. The term as defined in 20 Pa.C.S. §

Health care provider—The term as 5422. defined in 20 Pa.C.S. §

Health care representative—In addition, Act 169 specifies the following limitation on designation of the health care representative: Unless related by blood, marriage or adoption, a health care representative may not be the principal's attending physician or other health care provider, not an owner, operator or employee of a health care provider in which the principal receives care. Pa.C.S. §

Incompetent—The term as defined in 5422. 20 Pa.C.S. §

Living will—The term as defined in 5422. 20 Pa.C.S. §

MH—Mental health.

MR—Mental retardation.

Mental health advance directive—A document that directs MH services and supports that an individual might want to receive during a crisis if the individual is unable to make decisions because of the individual's mental illness. This is a separate document from an advance health care directive. See 20 Pa.C.S. Chapter 58 (relating to mental health care).

Permanently unconscious—The term as 5422. defined in 20 Pa.C.S. §

Person—The 1991 (relating to definitions). term as defined in 1 Pa.C.S. §

Principal5422. The principal is at least 18 years of age, has graduated from high school, has married or is an —The term as defined in 20 Pa.C.S. emancipated minor. §

Surrogate health care decision maker—A person that makes health care decisions for another individual.

HEALTH CARE DECISION MAKING

Competent § 6000.1011. individuals.

The health care or end of life decisions of an individual who is competent should be (a) honored.

Competent individuals may also execute advance health care directives in accordance with 20 Pa.C.S. Chapter 54 (relating to health (b) care).

Competent individuals should be encouraged to make advance health care directives which will become operative if they lose competency unless revoked in accordance with (c) 20 Pa.C.S. Chapter 54.

Advance health care directives should be reviewed and updated in writing (d) periodically.

Individuals who are not competent and need emergency § 6000.1012. treatment.

Consent is implied in law for emergencies and there is no need to seek a surrogate health care decision maker before providing emergency medical treatment. See the Medical Care Availability and Reduction of Error (MCARE) Act (40 P. S. §§ 1303.101—1303.1115); In re Dorone, 534 A.2d 452 (Pa. 1987).
Individuals who are not competent and who do not have end-stage medical conditions or are not permanently § 6000.1013. unconscious.

If an individual is not competent to make a particular nonemergent health care decision, another person must make that decision on the individual's (a) behalf.

Under Act 169, when a guardian, health care agent or health care representative will be making the decision, the attending physician determines whether an individual has an end stage medical condition or is permanently (b) unconscious.

When a surrogate health care decision maker is needed to make a nonemergent health care decision for an individual who neither has an end-stage medical condition nor is permanently unconscious, the health care decision maker should be chosen in the (c) following order:

1. Health care agent. If the individual, while competent, has executed a valid advance health care directive that designates a health care agent and the health care agent is available and willing to make the decision, the health care agent should make the health care decision for the individual. See 20 Pa.C.S. Chapter 54, Subchapter C (relating to health care agents and representatives).

2. Guardian of the individual's person.

If, under Pennsylvania's guardianship statute (20 Pa.C.S. Chapter 55 (relating to incapacitated persons)), a court has already appointed a guardian to make health care decisions on the individual's behalf, the guardian should make those (i) decisions for the individual.

If a person who executed a valid health care power of attorney is later adjudicated an incapacitated person and a guardian of the person is appointed by the court to make health care decisions, the health care agent named in the health care power of attorney is accountable to both the guardian and the (ii) individual.

5460(a) (relating to relation of health care agent to court-appointed guardian and other The guardian has the same power to revoke or amend the appointment of a agents). health care agent as the individual would have if he were not incapacitated, but may not revoke or amend the instructions in an advance health care directive absent judicial authorization. See 20 Pa.C.S. (iii) §

3. Health care representative.

In the absence of a health care agent designated under a valid advance health care directive or a court-appointed guardian of the person with authority to make health decisions, an available and willing health care representative should (i) make the health care decision.

In descending order of priority, the following persons can act as health care (ii) representatives for individuals:
A person chosen by the individual (in a signed writing or by informing the individual's attending physician) while the individual was of sound (A) mind.

The individual's spouse (unless a divorce action is (B) pending).

The (C) individual's adult child.

The (D) individual's parent.

The (E) individual's adult brother or sister.

The (F) individual's adult grandchild.

An adult who has knowledge of the individual's preferences and values. See 20 Pa.C.S. (G) Chapter 54, Sub- chapter C.

(4) 

Facility director.

In the absence of any other appointed decision maker or willing next of kin, the facility director becomes the health care decision maker under the MH/MR (i) Act.

Under the MH/MR Act, the director of a facility may by and with the advice of two physicians not employed by the facility, determine when elective surgery should be performed upon any mentally disabled person admitted or committed to the facility when the person does not have a living parent, spouse, issue, next of kin or legal guardian as fully and to the same effect as if the director had been appointed guardian and had applied to and received the approval of an (ii) appropriate court therefor.

Section (iii) 417(c) of the MH/MR Act (50 P. 4417(c)) specifies that the facility director may authorize elective surgery, but the Department has consistently interpreted that section to recognize that the facility director's S. § authority also encompasses health care decisions generally.

The facility director may authorize elective surgery and other treatment only with the advice of two physicians not employed by the (iv) facility.

When the facility director becomes the surrogate health care decision maker for an individual who does not have an end-stage medical condition or is not permanently unconscious, the director should first review the individual's support plan and relevant medical history and records to help identify the individual's medical status historically and immediately prior to making a (v) surrogate health care decision.

The facility director should be informed of the decision to be made and gather information based on the direct knowledge of those familiar with the (vi) individual.
In this manner, the facility director will have sufficient information to make the decision that the individual would make if able to do (vii) so.

Even when another surrogate health care decision maker is identified, the facility director should continue to monitor the situation to ensure that decisions are made with the best interest of the individual as the paramount (viii) concern.

In the event of a short-term absence of the facility director, the director may assign (ix) a designee to perform these functions.

The assigned designee may only be a person authorized to perform the facility director's functions in the director's (x) absence.

The facility director may not authorize a DNR order for a person who is not competent and does not have an end stage medical (xi) condition.

**Individuals who are not competent and who have either end-stage medical conditions or are permanently § 6000.1014. unconscious.**

Under Act 169, when a guardian, health care agent or health care representative will be making the decision, the attending physician determines whether an individual has an end stage medical condition or is permanently (a) unconscious.

In contrast, the MH/MR Act, which applies to health care decisions by facility directors, requires the advice of two physicians for recommended treatment of health care conditions, including end stage medical (b) conditions.

When a care decision maker is needed to make a nonemergent health (c) surrogate health care decision for an individual who has an end-stage medical condition or is permanently unconscious and who has not executed a valid living will that governs the decision, the surrogate health care decision maker should be chosen in the following order:

1. **Health care agent.** If the individual, while competent, has executed a valid advance health care directive that designates a health care agent and the health care agent is available and willing to make the decision, the health care agent should make health care decisions for the individual.

2. **Guardian of the individual's person.**

If, under Pennsylvania's guardianship statute, a court has already appointed a guardian of the person to make health care decisions on the individual's behalf, the guardian should make the decisions for the (i) individual.

If a person who executed a valid health care power of attorney is later adjudicated an incapacitated person and a guardian of the person is appointed by the court to make medical
decisions, the health care agent named in the health care power of attorney is accountable to both the guardian and the (ii) individual.

The guardian has the same power to revoke or amend the appointment of a health care agent as the individual would have if he were not incapacitated, but may not revoke or amend the instructions in an advance health care directive absent (iii) judicial authorization.

(3) Health care representative.

In the absence of a health care agent designated under a valid advance health care directive or a court-appointed guardian of the person with authority to make health care decisions, an available and willing health care representative (i) should make the health care decision.

In descending order of priority, the following individuals can act as health care representatives for individuals:

A person chosen by the individual (in a signed writing or by informing the individual's attending physician) while the individual was of sound (A) mind.

The individual's spouse (unless a divorce action is (B) pending).

The (C) individual's adult child.

The (D) individual's parent.

The (E) individual's adult brother or sister.

The (F) individual's adult grandchild.

An adult who has knowledge of the individual's preferences and (G) values.

(4) Facility director.

In the absence of any other appointed decision maker or willing next of kin, the facility director in his discretion becomes the surrogate health care decision (i) maker under section 417(c) of the MH/MR Act.

Section 417(c) of the MH/MR Act specifies that the facility director may authorize elective surgery, but the Department has consistently interpreted that section to recognize that the facility director's authority also encompasses health care (ii) decisions generally.

The facility director may authorize elective surgery and other treatment only with the advice of two physicians not employed by the (iii) facility.

When the facility director becomes the surrogate health care decision maker for an individual who has an end-stage medical condition or is permanently unconscious, the director shall first
review the individual's support plan and relevant medical history and records to help identify the individual's medical status historically and immediately prior to making a surrogate health care (iv) decision.

The facility director must be informed of the decision to be made and gather information based on the direct knowledge of those familiar with the (v) individual.

In this manner, the facility director will have sufficient information to make the decision that the individual would make if able to do (vi) so.

For a decision to withdraw treatment or life-sustaining care for a person who is not competent who has an end-stage medical condition or is permanently unconscious, the Department recommends a facility director seek judicial authorization prior to the withdrawal of treatment or life-sustaining care due to a risk of conflict (vii) of interest claims.

For a DNR order for a person who is not competent who has an end-stage medical condition or is permanently unconscious, the Department recommends a facility director seek judicial authorization prior to requesting the issuance of a DNR order due to a risk of conflict of interest claims (viii).

Pending the judicial authorization under subparagraphs (vii) and (viii), the Department recommends a facility director direct that treatment or life-sustaining care be continued for a person who is not competent who has an end-stage medical (ix) condition or is permanently unconscious.

Even when another surrogate health care decision maker is identified, the facility director should continue to monitor the situation to ensure that decisions are made with the best interest of the individual as the paramount (x) concern.

In the event of a short-term absence of the facility director, the director may assign (xi) a designee to perform these functions.

The assigned designee may only be a person authorized to perform the facility director's functions in the director's (xii) absence.

In the rare circumstance that the individual with an end-stage medical condition or who is permanently unconscious does not have a living will, health care agent, court-appointed guardian, available and willing health care representative or facility director, then a court should appoint a guardian with authority to act. Appropriate medical care should be provided pending the appointment of a (d) guardian.

In reaching decisions about appropriate care, the following may be (e) helpful:

Holding a team meeting including the health care provider, the family/health care representative, the mental retardation service provider and any other interested parties to clarify the issues and each party's understanding of the (1) situation.
Involving the palliative care team, the patient advocate, or both, at a hospital to act as an objective party and help communicate issues and assist each party in understanding the situation.

Using hospital ethics committees to review situations.

Having a second medical or surgical opinion, which can sometimes clarify the prognosis or possible treatments for a particular condition.

As a last resort, pursuing resolution through the courts.

**Health care power of § 6000.1015. attorney.**

Unless otherwise specified in the health care power of attorney, a health care power of attorney becomes operative when the following occurs:

- A copy is provided to the attending physician.
- 5422 and 5454(a) (relating to definitions; and when health care power of attorney The attending physician has determined that the principal is incompetent). See 20 Pa.C.S. §§

Unless otherwise specified in the health care power of attorney, a health care power of attorney becomes inoperative when, in the determination of the attending physician, the principal is competent.

**Limitations on authority of the surrogate health care § 6000.1016. decision maker.**

A surrogate health care decision maker may not execute an advance health care directive or name a health care agent on behalf of an incompetent individual.

Under 20 Pa.C.S. Chapter 54 (relating to health care) and applicable case law (see *In re D.L.H.*, 2 A.2d. 505 (Pa. 2010)), neither a health care representative nor a guardian nor a facility director has authority to refuse life-preserving care for a person who has a life-threatening medical condition, but is neither in an end-stage medical condition nor permanently unconscious. 5462(c)(1) (relating to duties of attending physician and health care provider) Title 20 Pa.C.S. § provides:

"Health care necessary to preserve life shall be provided to an individual who has neither an end-stage medical condition nor is permanently unconscious, except if the individual is competent and objects to such care or a health care agent objects on behalf of the principal if authorized to do so by the health care power of attorney or living will."
2713(e) A residential facility must provide necessary treatment, care, goods or services to an individual except where otherwise permitted under 18 Pa.C.S. §

The caretaker's, individual's, or facility's lawful compliance with a care-dependent person's living will as provided in 20 Pa.C.S. Chapter §

The caretaker's, individual's, or facility's lawful compliance with a care-dependent person's written, signed, and witnessed instructions, executed when the care-dependent person is competent as to the treatment he wishes to receive.

The caretaker's, individual's or facility's lawful compliance with the direction of one of the following:

An agent acting under a lawful durable power of attorney under 20 Pa.C.S. Chapter 56 (relating to powers of attorney), within the scope of that power.

A health care agent acting under a health care power of attorney under 20 Pa.C.S. Chapter 54, Sub- chapter C (relating to health care agents and representatives), within the scope of that power.

The caretaker's, individual's, or facility's lawful compliance with a DNR order written and signed by the care-dependent person's attending physician. Generally, a DNR order is appropriate in the presence of an end-stage medical condition.

5422 (relating to definitions) as determined and documented in the person's medical record by the person's attending physician, health care representative, provided the care dependent person has an end-stage medical condition or is permanently unconscious as these terms are defined in 20 Pa.C.S. § the direction of a care-dependent person's health care representative under 20 Pa.C.S. §

Guidance for individuals without family or an advocate.

For individuals that may not have living family members or anyone that is currently advocating for them, the county or administrative entity, supports coordination organization, or the provider agency working with the individual should help the individual identify someone who knows the individual and would be willing to act as the individual's health care representative.

The health care representative may be a friend, a family friend, someone in the individual's church or neighborhood, or someone that has worked with the individual in the past, but is no longer actively providing their services.

Intermediate Care Facility for the Mentally Retarded (ICF/MR) facility director as a guardian.
5461(f) (relating to decisions by health care representative) on a health care provider's being a health care representative is not applicable to a facility. The prohibition in 20 Pa. Code director under section 417(c) of the MH/MR Act (50 Pa. Code § 4417(c)), regarding powers and duties of directors, because a facility director is made a guardian under S. § that section, not a health care representative.

RECORDS

Access to § 6000.1021. records.

Under the Health Insurance Portability and Accountability Act (HIPAA), guardians, agents or representatives as medical surrogates have the same access to medical records that the principal does. See 45 CFR 164.502(g) and 164.510(b)(3) (relating to uses and disclosures of protected health information: general rules; and uses and disclosures requiring an opportunity for the individual to agree or to object).

STATUTES

Applicable § 6000.1031. statutes.

Several other statutes also govern health care decision making, and were not repealed by Act 169. Accordingly, they remain in effect. These statutes include the following:

2713 Title 18 Pa.C.S. (relating to neglect of care-dependent person). (1) §

Title 20 Pa.C.S. Chapter 55 (relating to incapacitated persons). (2) §

The Medical Care Availability and Reduction of Error (MCARE) Act (40 P. S. 1303.101—1303.115). (3) §§

Section 417(c) of the MH/MR Act (50 P. 4417(c)), regarding powers and duties of directors. (4) §

Applicability of section 417(c) of the MH/MR Act to § 6000.1032. health-care decisions.

Notwithstanding that section 417(c) of the MH/MR Act (50 P. 4417(c)), regarding powers and duties of directors, explicitly references only "elective surgery," that section should be read as applicable to health care decisions generally. §

A facility director's authority under section 417(c) of the MH/MR Act should be construed to include authority to make decisions regarding palliative care for persons in an end-stage (terminal) condition.
2713 (relating to neglect of care-dependent person) requires that necessary care and For care provided in the MR facility itself, treatment be provided without it. No surrogate consent is needed because 18 Pa.C.S. (c) §

For care outside the mental retardation facility, such as a doctor's office or hospital, the primary care physician (PCP) and the specialist performing the procedure can serve as the two physicians (except in the rare circumstance where the PCP is a payroll employee of the MR facility) required under section 417(c) of the MH/MR Act.

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