



## CHAPTER 4: HEALTH CARE DECISION-MAKING

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Individuals with and without disabilities are required to make decisions about medical treatment every day. This chapter will address when people with intellectual disabilities can make health care decisions. This chapter will also address substitute decision-making options that can be used when a person cannot make his or her own health care decisions, including when each option can be used and the scope of authority for various substitute decision-makers. Since access to medical records can be important in making health care decisions, this chapter also briefly addresses who can access the records of an individual with a disability.

## **I. MAKING YOUR OWN HEALTH CARE DECISIONS**

Adults generally have the right to make their own decisions. When a person has an intellectual disability, he or she still has authority to make his or her own decisions, including health care decisions, if he or she has "capacity" (also called "competence") to do so.

Many individuals with intellectual disabilities have capacity to make health care decisions that require only "simple consent" (rather than "informed consent"). Decisions for which simple consent is adequate are those that do not pose a risk of harm greater than that normally encountered in daily life, such as whether to participate in routine physical exams, tests, and treatment.

Health care decisions that might have greater risks and consequences than those generally encountered in daily life, however, can only be made by

individuals who have capacity to give "informed consent." These types of decisions can include whether to take part in invasive testing, surgery, or treatment for chronic or complex illnesses. Capacity or competence to give informed consent requires that the individual: (1) have an ability to understand the decision, the alternative options, and the risks of benefits; (2) have the ability to use the information in a logical and rational way to reach a decision; and (3) be able to communicate the decision verbally or through other means.

Some individuals with intellectual or other developmental disabilities have the capacity to make health care decisions, including those that require informed consent. Some individuals with intellectual or other developmental disabilities have capacity to make some medical decisions but not others, depending on the complexity of the issue. Even when individuals do not have capacity to make health care decisions, it is vital to involve them as fully as possible in the decision-making process.

Finally, it is important to remember that a person who has the capacity to consent to health care also has the capacity to refuse health care. A person's decision to refuse health care which most people would authorize does not suggest that a person lacks capacity to make decisions. All people who have capacity to consent to health care have the corollary right to refuse treatment.

## **II. SUBSTITUTE DECISION-MAKING IN HEALTH CARE**

While individuals with intellectual or other developmental disabilities often can make some types of health care decisions, there may be situations in which they will be unable to do so. Moreover, most individuals who do not now have disabilities may reach a point in their lives when they are no longer able to make their health care decisions. Under Pennsylvania law, various devices are available to allow substitute decision-makers to act for individuals who lack capacity to make some or all of their health care decisions.

#### **A. Guardianship**

"Guardians of the person" can be appointed by a court to make some or all decisions for persons who are determined to lack capacity. "Plenary" guardians of the person have authority to make medical decisions for the persons in their care. "Limited" guardians of the person have only those powers specified by the court, although such powers can include the authority to make some or all medical decisions for the persons in their care. "Guardians of the estate" deal solely with financial matters and have no authority to make medical decisions.

The chapter on guardianship describes more fully when guardians can be appointed, the duties of guardians, and alternatives to guardianship. Two alternatives to guardianship -- advance health care directives and health care representatives -- are further detailed in this chapter.

Although guardians of the person may have authority to make medical decisions, they do not have the authority to withhold or refuse life-preserving treatment for individuals who do not have end-stage medical conditions or are not permanently unconscious.

Note: The phrases "end-stage medical condition" and "permanently unconscious" are used repeatedly in this chapter. Pennsylvania law defines an "end-stage medical condition" as an incurable and irreversible medical condition in an advanced state, caused by injury, disease, or physical illness that will, to a reasonable degree of certainty, result in death. It does not include permanent and irreversible physical, mental, or intellectual conditions where treatment can provide a benefit that does not merely prolong the process of dying, such as cerebral palsy or quadriplegia. Pennsylvania law defines "permanently unconscious" to mean total and irreversible loss of consciousness and capacity for interaction with the environment, such as a permanent vegetative stage or permanent coma.

## **B. Advance Health Care Directives**

### **1. Advance Health Care Directives, Health Care POAs, and Living Wills**

An "**advance health care directive**" is a health care power of attorney (POA), a living will, or a combination of those two documents.

- A "**living will**" is a document that expresses the wishes and

instructions of an individual, known as the "principal," when the individual becomes incompetent and has an end-stage medical condition or is permanently unconscious. Unlike a health care POA, discussed below, it is not necessary to appoint a "health care agent" in a living will to make decisions, though it is often wise to do so. A living will usually just sets forth specific types of end-of-life care (such as mechanical ventilation, dialysis, and supplying water and nutrition through tubes) and states whether the individual desires or does not desire such care at that stage. If, however, the instructions are more ambiguous (such as stating that the person desires a particular treatment only if necessary to alleviate pain), then it may be best to designate a health care agent to make those decisions.

- A **“health care POA”** is a document in which an individual, known as the "principal," designates one or more persons, known as "health care agents," to make health care decisions for the individual if she or he is determined to be incompetent to make those decisions. Unlike a living will, a health care POA can apply to all health care decisions that arise after a person becomes incompetent -- not simply to those decisions that arise at the end of life. For example, if a person is in a car accident resulting in a serious brain injury, but not in an end-stage medical condition or permanent unconsciousness, a health care agent acting under a health care POA will be able to make necessary health care decisions for her. If she only has a living will, a guardian may be needed to make her health care decisions.

Health care advance directives are important for everyone, regardless of disability. They allow individuals, while they have capacity to do so, to put in writing their wishes about the types of treatment they want and factors that should be considered in making treatment decisions in the event that they become unable to make those decisions for themselves. Health care advance directives thus assure that individuals' health care treatment wishes will be respected. These directives also have the benefit of relieving families and friends of the pressure of determining what the individuals would want in specific situations since the individuals have given them guidance.

As used in this section, the term "advance health care directive" will mean both living wills and health care POAs unless otherwise noted.

## **2. Ability to Make Advance Health Care Directives**

Any individual who is of "sound mind" can make an advance health care directive as long as he or she meets one of the following criteria: (1) he or she is 18 years of age or older; (2) he or she has graduated from high school; (3) he or she has married; or (4) he or she is an emancipated minor.

The law does not explicitly define "sound mind," but, in essence, it means that the individual is able to make an informed decision about the matters in the advance health care directive. Again, it is important to remember that a diagnosis of an intellectual or other developmental disability does not mean that a person cannot make an advance health care directive.

Moreover, to the extent that an individual with such a disability can make an advance health care directive, he or she should be encouraged to do so to assure that their health care wishes are followed in the event that they become unable to make health care decisions in the future. Family, friends, advocates, case managers and other involved persons may be able to encourage and, where necessary, assist individuals with disabilities to create advance health care directives.

### **3. Creating Advance Health Care Directives**

An advance health care directive must be made in writing. The document must be signed and dated by the individual who makes it (the principal). If an individual cannot write his signature, he can make a mark. If the individual is unable to sign or mark the document, another person can sign the document on his or her behalf if the individual specifically directs him or her to do so. Neither a health care provider who provides services to the individual nor the provider's agents, however, can sign the health care directive on behalf of the individual.

To be valid, a health care advance directive must be signed by at least two witnesses who are at least 18 years old. A witness cannot be the same person who has signed the document on behalf of an individual who is unable to sign the document.

The form of an advance health care directive can vary, although it is required that a health care POA identify the principal and the health care

agent and declare that the principal authorizes the health care agent to make decisions on behalf of the principal. Although lawyers can draft advance health care directives, it is not necessary to hire a lawyer to do so. Pennsylvania law includes a statutory form for an advance health care directive that combines a health care POA and living will. This form can be completed and modified as needed to create a valid advance health care directive.

If family, friends, or the individual's physician is not aware that a person has created a health care advance directive, it may be meaningless. It is important that the individual make others aware of the document and where it can be found so that, in the event the individual becomes suddenly incapacitated, his or her wishes as expressed in the document will be followed. Accordingly, at a minimum, an individual should give copies to his or her primary physician and to any health care agent who is named in the document. Family and friends should also be aware that the document exists and where it can be located.

#### **4. Health Care Advance Directives' Effective Dates**

A living will becomes operative when: (1) a copy is provided to the individual's attending physician; and (2) the attending physician determines that the individual is both incompetent to make decisions and has an end-stage medical condition or is permanently unconscious.

A health care POA becomes operative when: (1) a copy is provided to the individual's attending physician; and (2) the attending physician determines that the individual is incompetent, regardless of whether the person has an end-stage medical condition or is permanently unconscious.

For purposes of determining whether a living will or health care POA is effective, "incompetent" means that the individual, despite receiving appropriate medical information, communication supports, and technical assistance, is unable to do any one of the following: (1) understand the potential benefits, risks, and alternatives involved in a particular health care decision; (2) make that decision on his or her own behalf; or (3) communicate that health care decision to any other person.

## **5. Termination and Revocation of Health Care Advance Directives**

Unless the living will or health care POA has a termination date or has been revoked by the individual, it will remain in effect regardless of how long ago it was made.

An individual can revoke a living will at any time and in any manner regardless of his or her physical or mental condition. The decision to revoke must be communicated to the attending physician by the individual or someone who witnessed the individual's decision to revoke the living will.

In contrast, a health care POA can be revoked only when the individual is of sound mind and the revocation either must be in writing or communicated by the individual to the attending physician, health care provider, or health care agent. Although an individual must be of sound mind to revoke a health care POA, an individual who is incompetent has the authority to overrule a health care decision made by his or her agent that would withhold or withdraw life-sustaining treatment (treatment that merely prolongs dying for a person with an end-stage medical condition or that merely prolongs an unconscious state for a person who is permanently unconscious). The individual can overrule such a decision simply by personally informing his or her attending physician. An individual who is incompetent cannot overrule a health care decision made by his or her agent to provide life-sustaining treatment, however, as long as the agent's decision is consistent with the POA.

## **6. Selection of Health Care Agents**

As described above, a health care agent is a person who is designated by the individual to make decisions in accordance with his or her health care advance directive in the event that he or she becomes incompetent to make those decisions. Health care agents must be identified in health care POAs, but they are optional in living wills.

One of the key parts of creating an advance health care directive, particularly a health care POA, is the selection of a health care agent who will make decisions when the individual becomes incompetent. It is

important for individuals to ask potential health care agents whether they are willing to serve in that capacity and, most importantly, whether they are comfortable following the individuals' wishes for health care treatment. Individuals should explore with potential health care agents their views about treatment to assure that, if the time comes when the individual can no longer make his own health care decisions, the person chosen as a health care agent will comply with the individual's stated wishes for treatment.

The individual's physicians, health care providers, and employees of the individual's health care providers cannot serve as health care agents. The only exception to this rule is if the physician, provider, or employee is related to the individual by blood, marriage, or adoption.

More than one person can be appointed as the individual's health care agent. Unless stated otherwise in the advance health care directive, multiple agents will be required to act jointly (that is, they must make decisions together). A health care advance directive also can (and probably should) identify one or more individual who will act as "successor" health care agents in the event that the health care agent is not available or refuses to act.

## **7. Health Care Agents' Authority**

Unless otherwise provided in the health care advance directive, a health care agent has authority to make any health care decision and to exercise any right and power regarding the individual's care, custody, and health

care treatment the individual could have made and exercised when competent to do so. The health care agent's authority also can extend beyond the individual's death, allowing him or her to make anatomical gifts, dispose of the individual's remains, and consent to autopsies.

The health care agent's decisions, however, must comply with the individual's instructions in the health care advance directive. In the absence of specific instructions, the health care agent must consider the individual's preferences and values, including his or her moral or religious beliefs. If the health care agent does not know enough about those preferences and values, he or she should take into account what is known about the individual's preferences and values and consider the individual's best interests, taking into consideration the goals of preserving life, relieving suffering, and preserving or restoring functioning. In making these decisions, the health care agent should gather information on the individual's prognosis and acceptable medical alternatives regarding diagnosis, treatment, and supporting care.

## **8. Relationship Between Health Care Agents and Guardians**

A guardian may be appointed for a person who becomes incapacitated even if he or she has a validly executed health care advance directive. An individual can nominate someone in his or her health care advance directive who should be appointed as a guardian, if necessary, and the court will honor that request absent good cause or disqualification.

If the guardian is different than the health care agent, the health care agent is accountable to the guardian as well as the individual who made the advance directive. The guardian has the same power to revoke or amend the appointment of a health care agent, but does not have the authority to revoke the advance directive or to amend its terms or instructions without judicial authorization.

### **C. Health Care Representatives**

Individuals who have not made health care advance directives -- including those who never had capacity to execute such documents -- may have some health care decisions made for them by "health care representatives" without the necessity for guardianship or court approval.

#### **1. Health Care Representatives' Authority & Duty**

A health care representative can make health care decisions for an individual if all of the following circumstances are met: (1) the individual's attending physician has determined the individual to be incompetent to make a health care decision; (2) the individual is at least 18 years old or has graduated from high school or is married or is an emancipated minor; (3) the individual does not have a guardian who is authorized to make health care decisions; and (4) the individual either does not have a health care POA or he or she does have a health care POA but the appointed health care agent is not willing to act and there is no alternative health care agent previously designated by the individual.

There is a debate as to the types of health care decisions that a health care representative has authority to make. Although the Pennsylvania law creating health care representatives, known as Act 169, can be read to allow health care representatives to make decisions only for individuals with end-stage medical conditions or who are permanently unconscious, many hospitals and physicians, as well as others, interpret the law more broadly to allow health care representatives to make any health care decisions for individuals who meet the criteria set out in the preceding paragraph.

It may be a good idea for the family and friends of an individual with an intellectual or other developmental disability who has not made and cannot make a health care advance directive to discuss with the individual and his or her doctor the use of a health care representative to make decisions.

This will allow friends and family to explore whether and to what extent they will be permitted to make health care decisions for the individual, if necessary, without going to court to obtain legal guardianship.

## **2. Selecting a Health Care Representative**

An individual who is of sound mind can identify the person or persons who he or she wants to serve as his or her health care representative. To make such a designation, the individual either must write and sign a document that designates the health care representative or personally tell his or her attending physician or health care provider.

If the individual has not designated a health care representative, the law provides that the following individuals can act as the health care representative in the following order of priority:

- the individual's spouse (unless a divorce action is pending) and adult
- children of the individual who are not the spouse's children;
- the individual's adult child;
- the individual's parent;
- the individual's adult sibling;
- the individual's adult grandchild;
- an adult who has knowledge of the individual's preferences and values, including religious and moral beliefs.

The individual's attending physician, his or her health care provider, and any service provider's employees cannot serve as the individual's health care representative unless they are related by blood, marriage, or adoption to the individual.

An attending physician or health care provider can require a person claiming the right to act as a health care representative to provide a written

declaration made under penalty of perjury. This declaration should set forth facts and circumstances that are sufficient to establish that the person has authority to act as the health care representative.

### **3. Countermanding a Health Care Representative's Decision**

Regardless of the individual's physical or mental capacity, he or she has authority at any time to countermand (that is, to overrule) a decision by a health care representative that would withhold or withdraw life-sustaining treatment (that is, treatment that will merely prolong dying for a person with an end-stage medical condition or that will merely prolong an unconscious state for a person who is permanently unconscious). The individual can overrule such a decision to deny life-sustaining treatment simply by personally informing his or her attending physician. An individual who is incompetent cannot overrule a health care decision made by his or her health care representative to provide life-sustaining treatment, however.

#### **D. MH/ID Providers**

For individuals who do not have living relatives or legal guardians, Section 4417(c) of the Pennsylvania Mental Health and Intellectual Disability Act provides that mental health and intellectual disability facility directors (including, for example, group home operators) have the authority to consent to "elective surgery" when two physicians who are not employed by the facility determine that it is necessary. The Pennsylvania Department of Human Services has historically construed this law to permit providers to

make health care decisions beyond "elective surgery" for individuals in their care who do not have living relatives or legal guardians.

This law, however, is limited. It does not permit the facility director to consent to psychiatric treatment, to AIDS/HIV testing, or to medical treatment that the individual is refusing. It does not permit facility directors to authorize Do Not Resuscitate Orders or refuse life-preserving treatment for someone who is not at the end-of-life. Moreover, facility directors cannot make end-of-life decisions for persons with end-stage medical conditions or who are permanently unconscious because they would be acting as health care representatives, and Pennsylvania law prohibits health care providers from acting as health care representatives.

NOTE: The Department of Human Services has taken the position that facility directors can make end-of-life decisions for persons with end-stage medical conditions or who are permanently unconscious in the absence of a health care agent, court-appointed guardian, or health care representative. It suggests, however, that the facility director seek judicial authorization prior to authorizing withdrawal of treatment or life-sustaining care or Do Not Resuscitate Orders for such individuals.

#### **E. Life-Ending Decision-Making**

Some issues regarding substitute health care decision-making that would effectively hasten or cause a person's death have been addressed above.

Since this is such an important area, however, some further discussion is warranted.

## **1. Life-Sustaining Decisions for Persons at the End-of-Life**

Generally, physicians or health care agents acting pursuant to living wills, health care agents acting pursuant to health care POAs, and health care representatives have authority to make decisions about life-sustaining treatment for persons with end-stage medical conditions or who are permanently unconscious. Life-sustaining treatment is treatment that will simply prolong the process of dying or maintain an individual in a state of permanent unconsciousness.

As noted in Sections II.B.5 and II.C.3 above, however, individuals who have end-stage medical conditions -- regardless of their physical or mental conditions -- can stop the implementation of decisions that would withhold or withdraw life-sustaining treatment to keep them alive by countermanding (that is, overruling) those decisions. This applies to decisions that are otherwise authorized in the individuals' living wills and health care POAs. It also applies to decisions made by health care representatives.

(Technically, individuals who are permanently unconscious also have the right to countermand those types of decisions, but as a practical matter cannot exercise it.) In contrast, individuals with end-stage medical conditions who have court-appointed guardians with authority to make

medical decisions probably cannot overrule those guardians' decisions to refuse life-sustaining treatment without going to court.

## **2. Life-Preserving Decisions for Persons Who Are Not at the End-of-Life**

Unlike "life-sustaining treatment," "life-preserving treatment" refers to treatment or interventions necessary to save the life of an individual who does not have an end-stage medical condition or who is not permanently unconscious. The general rule is that life-preserving treatment must be provided to individuals.

There are two exceptions to this general rule. First, an individual who is competent can always refuse treatment, including life-preserving treatment. Second, a health care agent appointed under a health care POA can refuse or terminate life-preserving treatment if the individual expressly gave him or her authority to object to such treatment in the health care POA since the individual -- when competent -- effectively made the decision to refuse such treatment himself or herself.

Life-preserving treatment cannot be refused in any other circumstances. Accordingly:

- health care agents cannot refuse life-preserving treatment for individuals whose health care POAs do not explicitly authorize such decisions;

- health care representatives cannot refuse life-preserving treatment; and
- court-appointed guardians -- even those authorized to make medical decisions -- cannot refuse life-preserving treatment for people in their care.

### **3. Out-of-Hospital DNR Orders**

A Do Not Resuscitate (DNR) order is an instruction by an individual that he or she does not want to receive cardiopulmonary resuscitation (CPR). Existing procedures for emergency medical services often require personnel to administer CPR when an individual has been found in cardiac or respiratory arrest, even if the person has an advance health care directive that indicates that he or she does not want CPR administered.

Pennsylvania law allows individuals who do not want emergency CPR administered under these circumstances to secure written DNR orders and to wear bracelets or necklaces supplied by the Pennsylvania Department of Health that reflect their DNR wishes. When emergency medical services providers know that an individual has a DNR order (by examining the order itself or by seeing the DNR bracelet or necklace), they will not administer CPR to the individual. They will, however, provide other medical interventions necessary and appropriate to provide comfort and alleviate pain unless otherwise directed by the individual or the emergency medical service provider's authorized physician.

Individuals can secure these DNR orders, necklaces, or bracelets from their attending physician only if: (1) the attending physician certifies that the individual either has an end-stage medical condition or is both permanently unconscious and has a living will that directs no CPR to be provided; (2) the individual requests the DNR order, necklace, or bracelet; and (3) the individual is 18 years old, has graduated from high school, has married, or is an emancipated minor. An individual's health care agent or health care representative also can request such out-of-hospital DNR orders, bracelets, or necklaces.

An individual, regardless of his mental or physical condition, can revoke an out-of-hospital DNR order whether it was secured on his or her own request or by his or her health care agent or health care representative. It can be revoked verbally, by destroying it, or by not displaying the order, bracelet, or necklace.

#### **4. Pennsylvania Orders for Life-Sustaining Treatment (POLST)**

In addition to advance health care directives, health care representatives, and out-of-hospital Do Not Resuscitate (DNR) orders, Pennsylvania has adopted another way that individuals or their legally appropriate substitute decision-makers can direct their care in end-of-life situations – the Pennsylvania Orders for Life-Sustaining Treatment (POLST) Program. The intent of the POLST Program is to improve the quality of care that

individuals receive at the end of life by turning patient goals and preferences for care into medical orders.

The POLST Program: (1) assists health care professionals to discuss and develop treatment plans that reflect patient wishes; (2) results in the completion of a POLST form; and (3) helps health care professionals, health care facilities, and emergency personnel honor patient wishes regarding life-sustaining treatment in emergency situations. Use of the POLST form is completely voluntary, but it is recommended for individuals who have advanced chronic progressive illness and/or frailty, those who might die in the next year, or anyone of advanced age with a strong desire to further define their preferences of care.

The POLST form is not the same as a DNR order or an advance directive (health care power of attorney (POA) and/or living will), but the use of a POLST form is authorized by the same law that governs DNR orders and advance directives. The POLST form can be used in conjunction with a DNR order and/or an advance directive – it represents and summarizes a patient's wishes in the form of medical orders for end-of-life care. The POLST form is designed to be most effective in emergency situations and can be completed even in the absence of a DNR order or an advance directive.

For an adult with intellectual disabilities, as for an adult without disabilities, a POLST form can be completed based on the individual's own treatment choices as well as those choices expressed by a health care agent, a legal

guardian, or a health care representative on the individual's behalf. As noted in Section II.E.2 above, however, neither a health care representative nor a legal guardian may use the POLST form to decline life-preserving treatment for an individual who does not have an end-stage medical condition or who is not permanently unconscious. Only a competent individual or a health care agent expressly authorized to object to such treatment in the health care POA can decline life-preserving care.

The POLST form, at a minimum, must include the patient name, resuscitation orders, and a signature of a physician, physician assistant, or certified registered nurse practitioner. A physician countersignature is required for physician assistant signed forms within ten days or less as established by facility policy and procedure. The POLST form should be reviewed if: (1) the patient is transferred from one care setting or care level to another; (2) there is a substantial change in the patient's health status; the patient's treatment preferences change; (4) the patient has an emergency room visit and/or inpatient hospitalization; or (5) the patient or his or her substitute decision-maker identifies a reason for a POLST review (e.g., the patient's closeness to death, extraordinary suffering, improved condition, advanced progressive illness, etc.). In general, patients, including patients with intellectual disabilities determined to be incompetent to make their own health care decisions, can revoke a POLST form to the same extent that they can revoke a living will or overrule a health care agent's decision to withhold or withdraw life-sustaining treatment (treatment that will simply prolong the process of dying or maintain an individual in a state of permanent unconsciousness).

The POLST form is specifically designed to assure an individual's treatment choices for end-of-life care are respected whether the choices are for full or limited treatment or comfort measures only. The orders on the POLST form are based on a patient's medical condition and his or her treatment choices. A POLST form may only be completed after a discussion of end-of-life choices between a patient or his or her substitute decision-maker and the patient's attending physician. For more information about the POLST Program in Pennsylvania, visit the Aging Institute of UPMC Senior Services and the University of Pittsburgh website at [www.aging.pitt.edu/professionals/resources-polst.htm](http://www.aging.pitt.edu/professionals/resources-polst.htm).

NOTE: Ideally, the values and choices expressed through an advance directive will not conflict with the medical orders on the POLST form. If there is a conflict between these instruments, the one that is not representative of the patient's values and choices for medically indicated treatments should be amended. The attending physician should carefully elicit patient values from the patient and/or his or her substitute decision-maker and make sure that the POLST is consistent with these values. If it is a crisis situation and the goals of care are not clear, then the higher level of care should be provided until more information about the patient's values and preferred treatment is known.

### **III. ACCESSING MEDICAL RECORDS**

Health care agents appointed under advance health care directives, health care representatives, and court-appointed guardians generally have the

same right to control the individual's records and information as the individual would have. Therefore, these substitute decision-makers can see the individual's medical records and discuss the individual's medical conditions with his or her treating physicians and providers. These substitute decision-makers also have authority to determine whether to release that information to third-parties. The only exception would arise if an individual created an advance health care directive that explicitly restricts the right of his or her health care agent to access or control his or her medical information, though such a restriction would be uncommon.

The ability to make a health care decision for a person who lacks capacity to do so often depends upon the decision-maker's ability to review and discuss with the individual's physicians or other providers health care information about the individual, including his or her diagnoses, prognosis, treatment alternatives, and supportive care. Substitute decision-makers -- whether health care agents, health care representatives, providers, or guardians -- should consider this information in light of the individual's express instructions, preferences, or values when making a decision.

## **Contact Information**

If you need more information or need help, please contact Disability Rights Pennsylvania (DRP) at 800-692-7443 (voice) or 877-375-7139 (TDD). The email address is: [intake@disabilityrightspa.org](mailto:intake@disabilityrightspa.org).

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