



## **HEALTH CARE DECISION-MAKING WITHOUT GUARDIANSHIP – THE ROLE OF HEALTH CARE REPRESENTATIVES**

### **Who can make health care decisions for an adult with a disability?**

If an adult with a disability is competent (as determined by his or her physician) to give the necessary consent to make a health care decision, he or she can and should make the decision. If the person is not competent to give the necessary consent, it should be determined if the person has previously made a valid advance health care directive (which is a living will and/or a health care power of attorney). If there is an advance health care directive, the doctor should make decisions in accordance with that directive. If the person has no advance health care directive, then Pennsylvania law (Act 2006-169, 20 Pa. Cons. Stat. Ann. § 5461) authorizes a “**health care representative**” to make health care decisions for him or her.

### **Who can act as a health care representative for an adult with a disability?**

A person can designate a health care representative if he or she is competent to do so by either putting it in writing and signing it or by telling his or her physician. If the person cannot make such a designation, then the law specifies that the following individuals in the listed order of priority can act as the health care representative: (1) the person’s spouse and his/her adult children if they are not the spouse’s children; (2) the person’s adult child; (3) the person’s parent; (4) the person’s adult sibling; (5) the person’s adult grandchild; and (6) an adult with knowledge of the person’s preferences and values. The person’s physician, health care providers, and employees of his/her health care providers generally cannot serve as the health care representative.

## **Are there any limits on the health care representative's decision-making power?**

Health care representatives cannot refuse or withdraw life-preserving treatment (which is treatment necessary to save the life of a person who does not have an end-stage medical disease or is not permanently unconscious). In addition, although the law is not explicit, a health care representative probably cannot make decisions that court-appointed guardians cannot make either at all or without a specific court order (such as sterilization, experimental procedures, and removal of healthy bodily organs). Finally, a person (despite incapacity) who has an end-stage medical condition can verbally override the decision of a health care representative to refuse or withdraw life-sustaining treatment (which is treatment that will only prolong the process of dying).

## **Does a health care representative need a court order to make decisions?**

No. The purpose of the law is to empower family members and others to make decisions for their loved ones without going to court. A physician or health care provider may only require that a person claiming the right to act as the health care representative provide a written declaration under penalty of perjury to support his/her authority to serve as the health care representative. A sample format for a declaration is attached.

## **Does a person with a disability need a guardian for health care decision-making?**

No. Under Pennsylvania law, if a person has a health care representative then it is not necessary to have a guardian appointed to make health care decisions.

## **HEALTH CARE REPRESENTATIVE DECLARATION**

I/we, **[List All Names of Health Care Representatives]** have authority to serve as the health care representative for **[Name of Person for Whom Health Care Decisions Will Be Made]** with whom I/we have the following relationship:

\_\_\_\_\_ Spouse (and there are no adult children with a person other than the spouse)

\_\_\_\_\_ Spouse and adult child(ren) of person other than the spouse

\_\_\_\_\_ Adult child(ren)

\_\_\_\_\_ Parent(s)

\_\_\_\_\_ Adult sibling(s)

\_\_\_\_\_ Adult grandchild(ren)

\_\_\_\_\_ Other adult who has knowledge of the values and preferences of **[Name of Person for Whom Health Care Decisions Will Be Made]**

I/we certify that there are no persons in a higher class (as designated above) who are available and willing to serve as the health care representative.

I/we certify that there either are no other members of the same class or that any other members of the same class do not wish to act as health care representatives.

**[If more than one person is acting as the health care representative]:** We certify that we understand that health care decisions can be made by a simple majority of the health care representatives and that in the event that the health care representatives are equally divided on a decision then the health care provider will wait until a majority agrees on a decision (though the provider will continue to provide treatment in accordance with accepted standards of medical practice).

I/we hereby state that the facts set forth are true and correct to the best of my/our knowledge, information and belief. I/we understand that the statements made herein are made subject to the penalties of 18 Pa.C.S. § 4904 (relating to unsworn falsification to authorities).

Date: \_\_\_\_\_

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Print Name

**[add Date and Signature Lines if more than one person is signing]**

## 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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