Adults generally have the right to make their own health care decisions, including the right to refuse treatment. If a health care decision requires informed consent (and most, but not all, do), then a health care provider likely will not allow an adult who lacks capacity to make the treatment decision. The law provides several options for health care decision-making for persons who cannot give informed consent:

- **Health Care Advance Directives** – These are documents (living wills and/or health care powers of attorneys) that are created by individuals while they have capacity to guide health care decision-making in the event they lose capacity to make those decisions.

- **Health Care Representatives** – Pennsylvania law allows certain family members or other specified persons to make health care decisions for individuals who lack capacity to make their own decisions, do not have a health care advance directive, and do not have a court-appointed guardian.

- **MH/ID Facility Directors** – Directors of facilities for individuals with mental illness or intellectual disabilities (such as group homes) can make some health care decisions for individuals who do not have family or a guardian if two independent doctors approve the decision.

- **Guardians of the Person** – Guardians who are appointed by a court may have authority to make health care decisions if they are “plenary guardians of the person” or “limited guardians of the person” whose powers expressly include health care.

This Fact Sheet will address who can make decisions to consent to or refuse “life-preserving” and “life-sustaining” treatment for persons who lack capacity to give informed consent. These are decisions that involve treatment for individuals who are dying or at risk of death. Of course, most health care treatment will not fall into either category. Information about decision-making relating to other kinds of health care decisions is discussed in our Manual on Consent, Capacity, and Substitute Decision-Making which can be found here.
I. What Is the Difference Between Life-Preserving and Life-Sustaining Treatment?

Life-sustaining treatment means any medical procedure or intervention that will only prolong the process of dying of someone who has an “end-stage medical condition” or that only will maintain an individual who is “permanently unconscious” in that state. An end-stage medical condition is an incurable and irreversible medical condition in an advanced state caused by injury, disease, or physical illness that will result in death despite medical treatment. “Permanently unconscious” means a total and irreversible loss of consciousness and the capacity for interaction with the environment and includes people deemed to be in an irreversible coma or permanent vegetative state. In brief, life-sustaining treatment is treatment that will not prevent the death of a person who has an end-stage medical condition or will not result in a person who is permanently unconscious regaining consciousness.

Life-preserving treatment is treatment or interventions that are necessary to save the life of an individual who does not have an “end-stage medical condition” or who is not “permanently unconscious.” In other words, if a person may recover if he gets the treatment but will likely die if he does not, the treatment is life-preserving.

II. Who Can Make Decisions Regarding Life-Preserving Treatment?

Individuals who have capacity to give informed consent can always consent to – or refuse – life preserving treatment. Individuals, while they have capacity, can also execute advance health care directives (living wills and/or health care powers of attorney) that will govern decision-making in the event that they become incapacitated. In an advance health care directive, a person can set forth his wishes, including his desire to refuse some types or all types of life-preserving treatment. Health care providers must respect decisions in advance health care directives, including decisions to refuse life-preserving treatment.
Health care providers must provide life-preserving treatment to any individual who lacks capacity, does not have an advance health care directive, and needs such treatment. Guardians, health care representatives, and MH/ID Facility Directors thus DO NOT have authority to refuse or withdraw life-preserving treatment under any circumstances for persons in their care. Accordingly, a person who lacks capacity to give informed consent will always receive life-preserving treatment unless he had an advance health care directive (made when he had capacity) reflecting his wishes not to receive life-preserving treatment.

III. Who Can Make Decisions Regarding Life-Sustaining Treatment?

Individuals who have capacity can consent to or refuse life-sustaining treating. They can also execute advance health care directives to set forth their wishes to receive or not receive life-sustaining treatment.

Guardians of the person whose authority includes health care decisions can consent to the provision of life-sustaining treatment or can refuse or withdraw life-sustaining treatment from persons in their care. However, while not mandated under Pennsylvania law, some county Orphans’ Courts (including the Orphans’ Court in Montgomery County) require that guardians seek approval from the court before refusing or withdrawing life-sustaining treatment.

Health Care Representatives can also either consent to life-sustaining treatment or can refuse or withdraw life-sustaining treatment (without any court order). An individual can override a Health Care Representative’s decision to refuse or withhold life-sustaining treatment – even though he lacks capacity – by simply telling his attending physician that he wants to receive the treatment. In contrast, the individual cannot override a Health Care Representative’s consent to life-sustaining care. In other words, when the decisions of the individual and his Health Care Representative are in conflict the individual’s desire to continue living must be honored but not his decision to hasten his death.

Pennsylvania’s Department of Human Services has advised that Facility Directors should seek judicial authorization before refusing or withdrawing life-sustaining treatment and, until such authorization is given, should continue treatment.

If you need more information or need help, please contact Disability Rights Pennsylvania (DRP) at 800-692-7443 (voice) or 877-375-7139 (TDD). Our email address is: intake@disabilityrightspa.org. DRP’s live intake line is open Monday-Friday from 9:00 a.m. to 3:00 p.m.

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