



# End of Life Planning

## Resources and Guidance

### Legal/Ethical

#### Important Facts

- People in Pennsylvania can communicate their instructions for end of life care to their family, friends, and health care providers by completing a Pennsylvania Advance Directive, also known as an Advance Healthcare Declaration or Living Will. For easier understanding, we will refer to it as the Advance Directive.
- **No one** can make an Advance Directive for another person. The person must complete it themselves.
- The Advance Directive has two parts: a part to select specific treatments (referred to as the Living Will) and a part to designate another person to make medical treatment decisions for the person (referred to as the Durable Power of Attorney for Healthcare). The document needs to be a signed and witnessed. The person can complete one or both parts of the document as they choose.

#### Advance Directive – Living Will

- An **Advance Directive** is a document prepared *by an individual* that specifies what treatment they would want and what treatment they would refuse *in the event* they lost the capacity to make such decisions.
- An **Advance Directive** does not require anyone else to communicate an individual's wishes to their doctor because it is a stand-alone document and when complete contains the individual's choices for or against treatment.
- An **Advance Directive** includes preferences about:
  - Cardiopulmonary Resuscitation (CPR)
  - Tube feeding
  - Kidney dialysis

- Ventilators or respirators
- An **Advance Directive** must be prepared by an individual who is at least 18 years of age or a high school graduate or married.
- An **Advance Directive** *must* be signed and dated.
- An **Advance Directive** needs to be witnessed by two people who are over the age of 18; it cannot be witnessed by a healthcare worker who is providing services to the individual.
- An **Advance Directive** can be changed or revoked at any time.
- An **Advance Directive** only takes effect when an individual is terminally ill or permanently unconscious and unable to communicate their wishes.

### **Durable Power of Attorney for Healthcare (DPAHC)**

- This is the second part of the Advance Directive. An individual can document who they want to make medical decisions for them in the event that they are not able to do so.
- The *key* to understanding this concept is the word “*durable*”. In this context it means the person designated as a substitute decision maker has the potential to do that on a continued basis.
- The decision maker also potentially may be making wide ranging decisions on an individual’s behalf. Decisions can include authorizing medical, therapeutic and surgical procedures. Great care is needed when appointing a **Durable Power of Attorney for Healthcare** because of the wide range potential of decisions.
- You do not need an attorney to be part of the process.
- The ideal is to have both parts of the Advance Directive completed by the person. The Advance Directive-Living Will part communicates the treatment decisions made by the person and the Advance Directive-Durable Power of Attorney for Healthcare part identifies a person to advocate and ensure that the individual’s decisions are followed.

### **Guardianship**

- Parents **do not** automatically remain the legal guardian for their adult child with I/DD.

- **Guardianship** involves the removal of a person's individual rights.
- **Guardianship** is a highly intrusive form of advocacy and should only be used as a last resort when all other alternatives have been examined.
- There are different types of **guardianship** which can limit the guardian's role.
- For more information go to <http://www.guardianship.org/>

