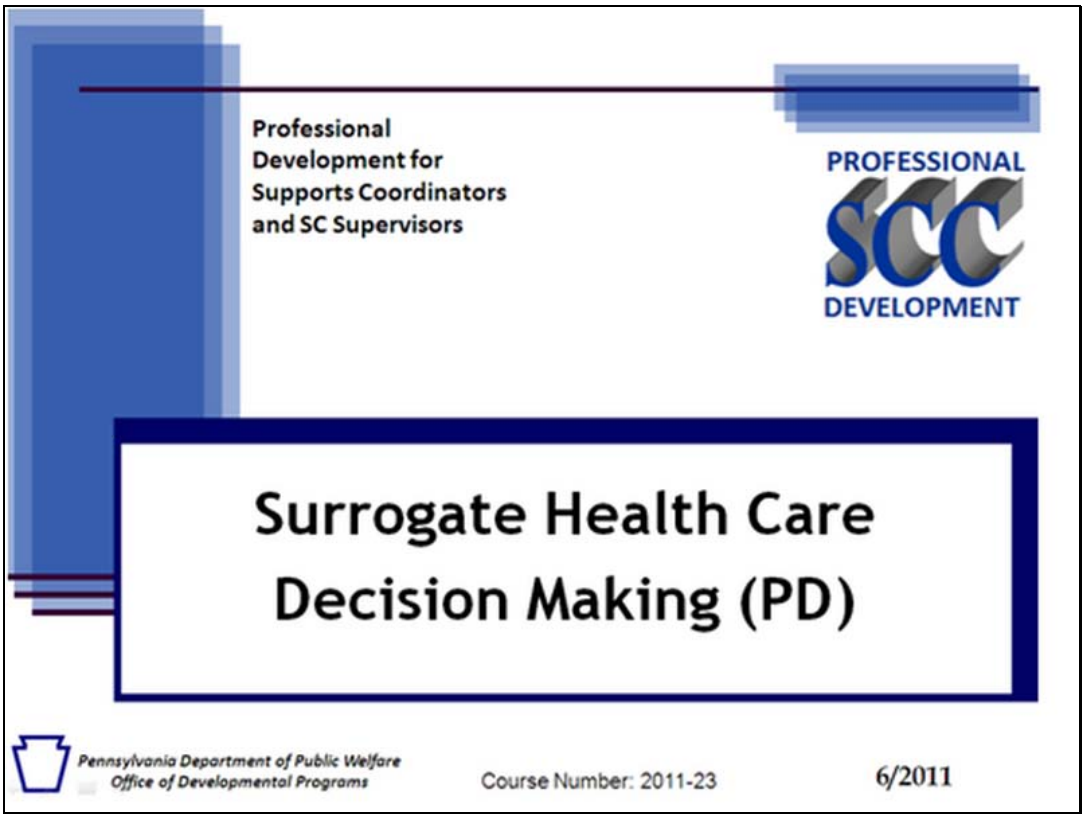

Professional
Development for
Supports Coordinators
and SC Supervisors
PROFESSIONAL
SCC
DEVELOPMENT
Surrogate Health Care
Decision Making (PD)
Pennsylvania Department of Public Welfare
Office of Developmental Programs
Course Number: 2011-23
6/2011

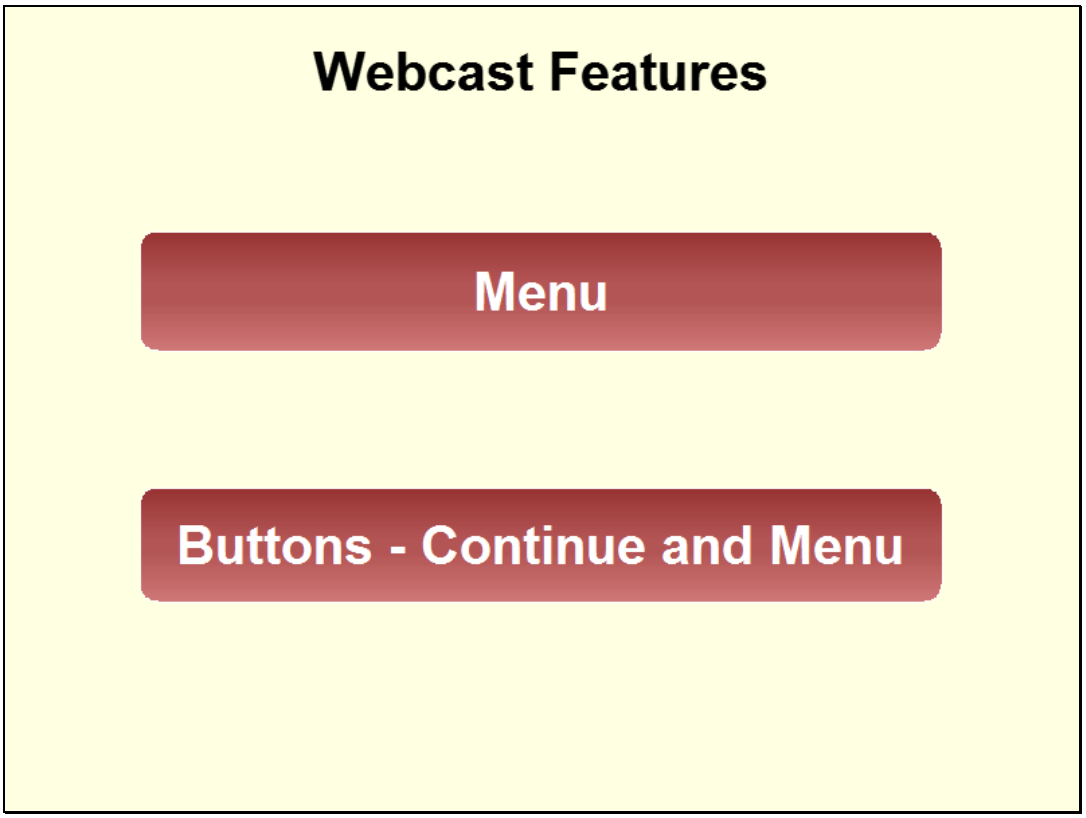
Surrogate Health Care Decision Making

Department of Public Welfare

Welcome to this webcast about Surrogate Health Care Decision Making.

My name is Jill Morrow, and I am the Medical Director for the Pennsylvania Office of Developmental Programs. I will be your presenter for this webcast.

If you have not viewed this webcast before, please select yes to continue to view this webcast in its entirety. If you select “No,” you will be taken to a menu where you can select which area of the webcast to view. It is only recommended to select “No” if you have already viewed this webcast and would like to watch a particular section again.



As mentioned on the previous slide, there is a menu you can use to navigate through the webcast if there are particular areas that you would like to watch again.

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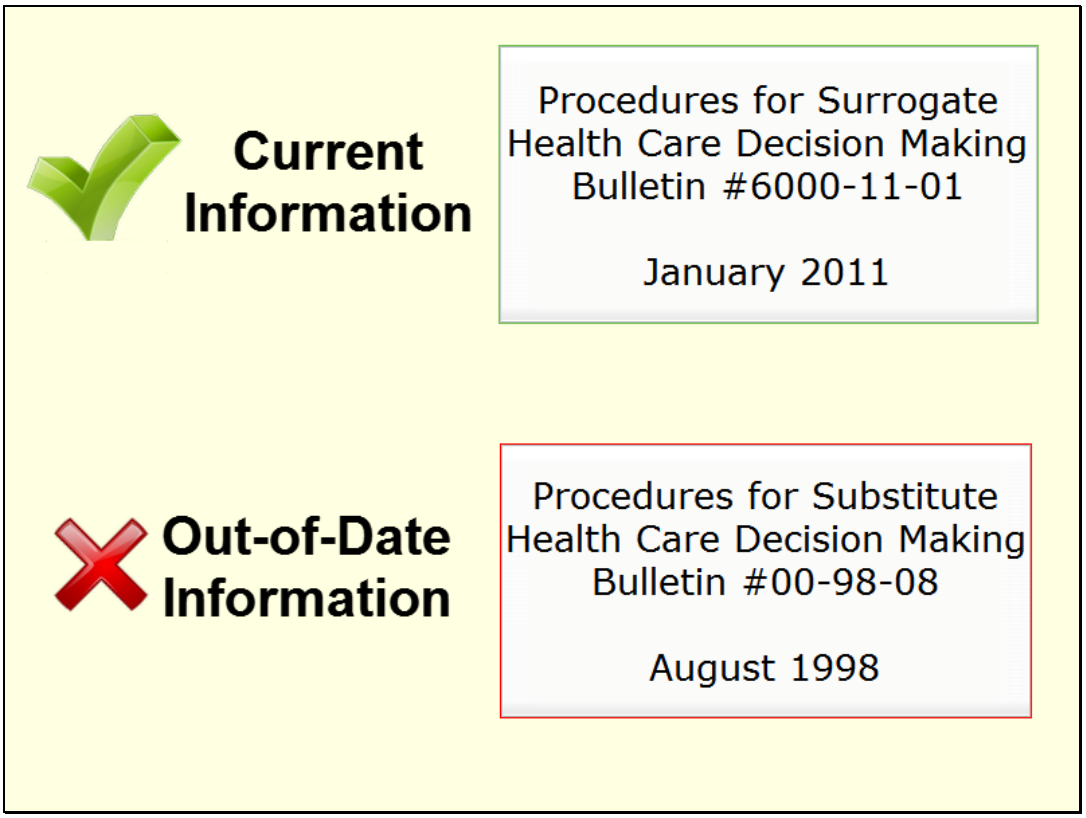


This webcast will discuss ODP's statement of policy regarding "Procedures for Surrogate Health Care Decision Making" found in bulletin number 6000-11-01 with attachments which were released in January of 2011. This bulletin replaces the previous bulletin 00-98-08, "Procedures for Substitute Health Care Decision Making" issued November 30, 1998. The statutes referred to in this presentation have broader reaching effects, but this presentation will concentrate on their relationship to surrogate health care decision making for people with intellectual disabilities.

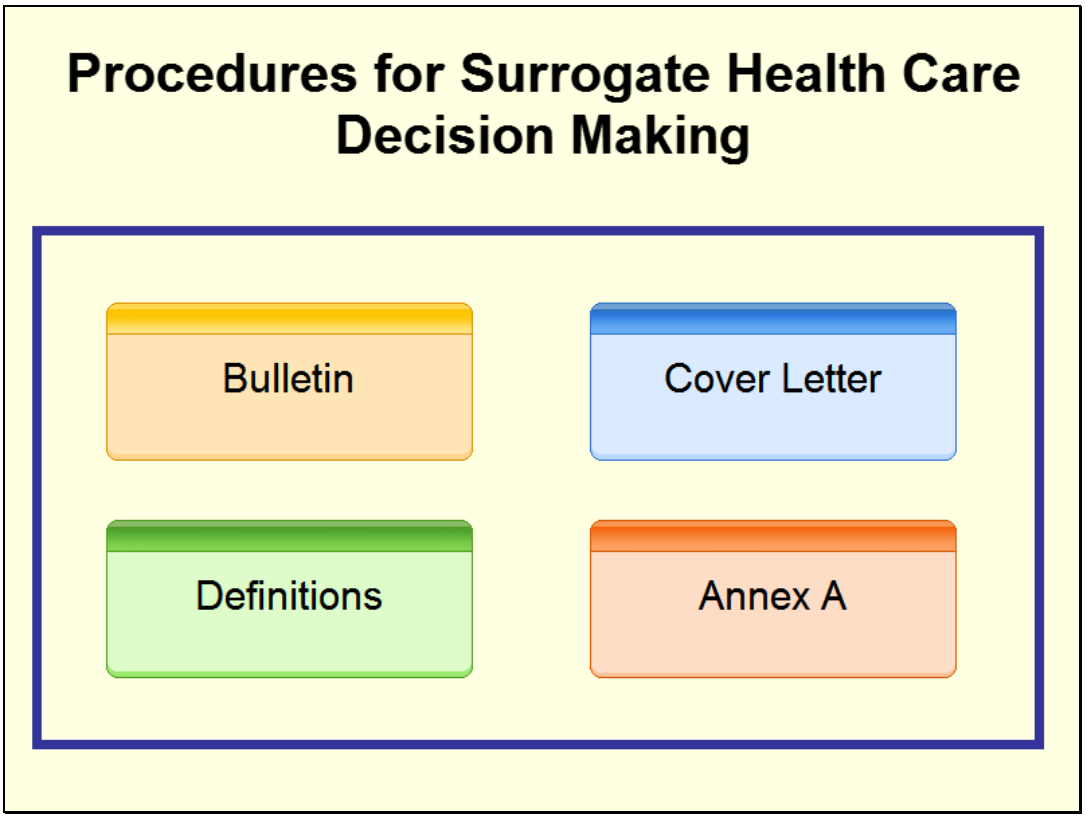
This statement of policy updates the Department's interpretation of the laws and procedures for surrogate health care decision-making for individuals receiving mental retardation services through the Department under Act 169 and other applicable law.

Why is there a new statement of policy about surrogate health care decision making?

Act 169, which updates Pennsylvania's statute on health care decision making, was signed into law on November 30, 2006. Act 169 provides a framework for advance health care directives like living wills and health care power of attorney and health care decision-making for individuals unable to make medical health care decisions for themselves. This new law changes who can participate in health care decision making. Act 169 changes the role of physicians in the health care decision making process.

Act 169 does not revoke the MH/MR Act of 1966, therefore the powers and duties of facility directors regarding their role as health care decision makers continue. For more information about the legal interpretation related to this, please refer to the bulletin.

There is also new case law regarding continuation of treatment for life-threatening conditions for someone not in an end-stage medical condition.



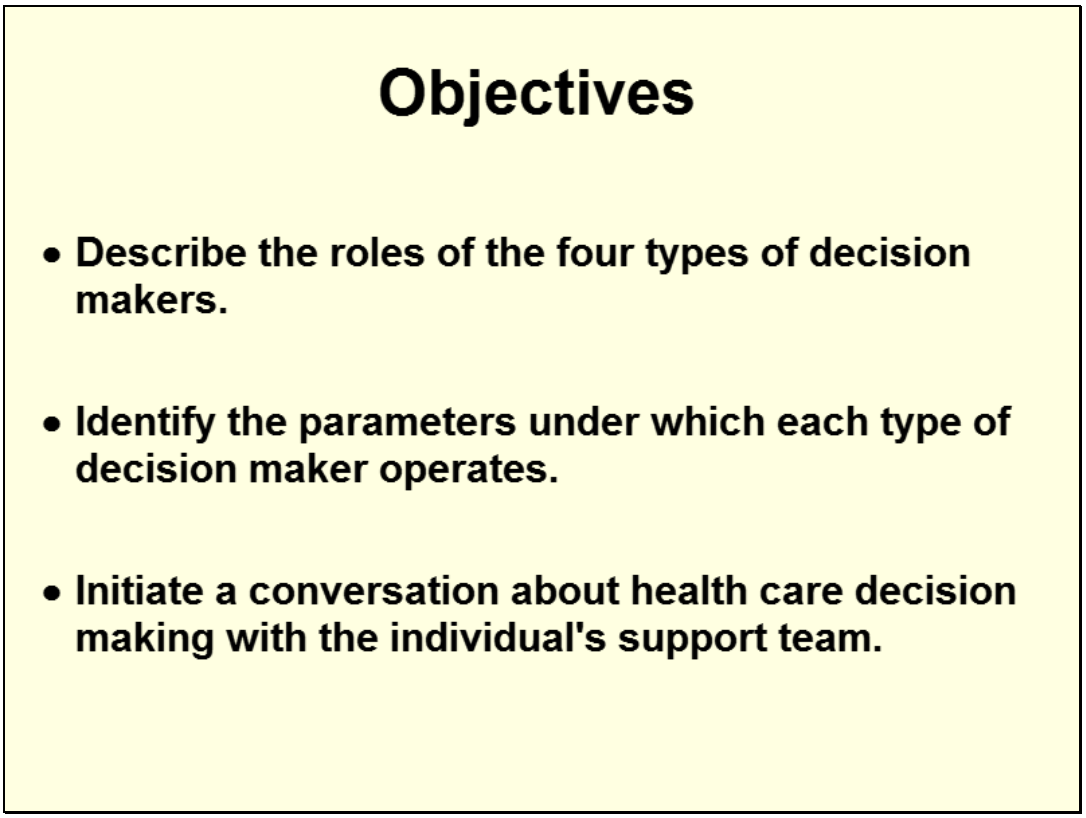
This “Procedures for Surrogate Health Care Decision Making” Bulletin consists of four parts, the bulletin itself and three attachments.

The bulletin contains information about statutes and case law relevant to surrogate health care decision making.

The first attachment is the cover letter to the bulletin.

Another attachment entitled Definitions contains the relevant definitions.

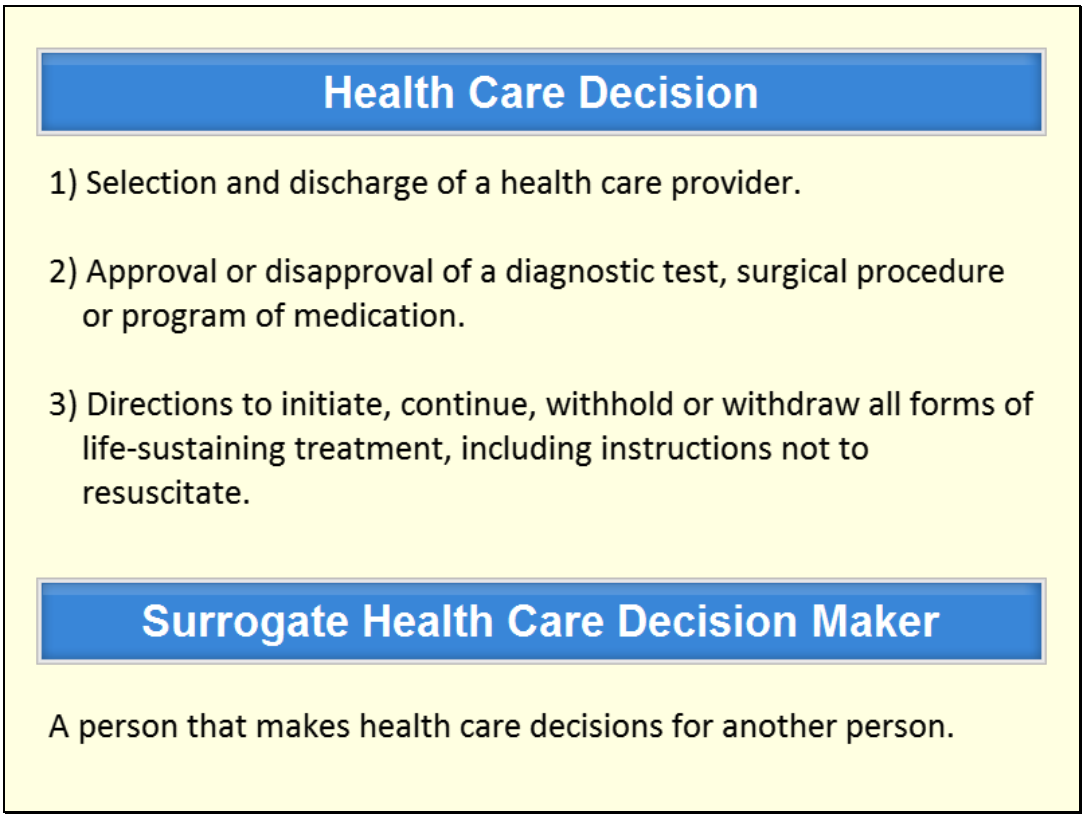
The final attachment is Annex A which contains the guidelines clarifying surrogate health care decision making procedures for adults with intellectual disabilities.



Here are the objectives for the webcast: describe the roles of the four types of decision makers, identify the parameters under which each type of decision maker operates and initiate a conversation about health care decision making with the individual's support team.

The Department of Public Welfare 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 webcast should not replace the reading of the “Procedures for Surrogate Health Care Decision Making” bulletin and its attachments.



There are two terms that have already been mentioned that are worth defining. The terms are health care decision and surrogate health care decision maker.

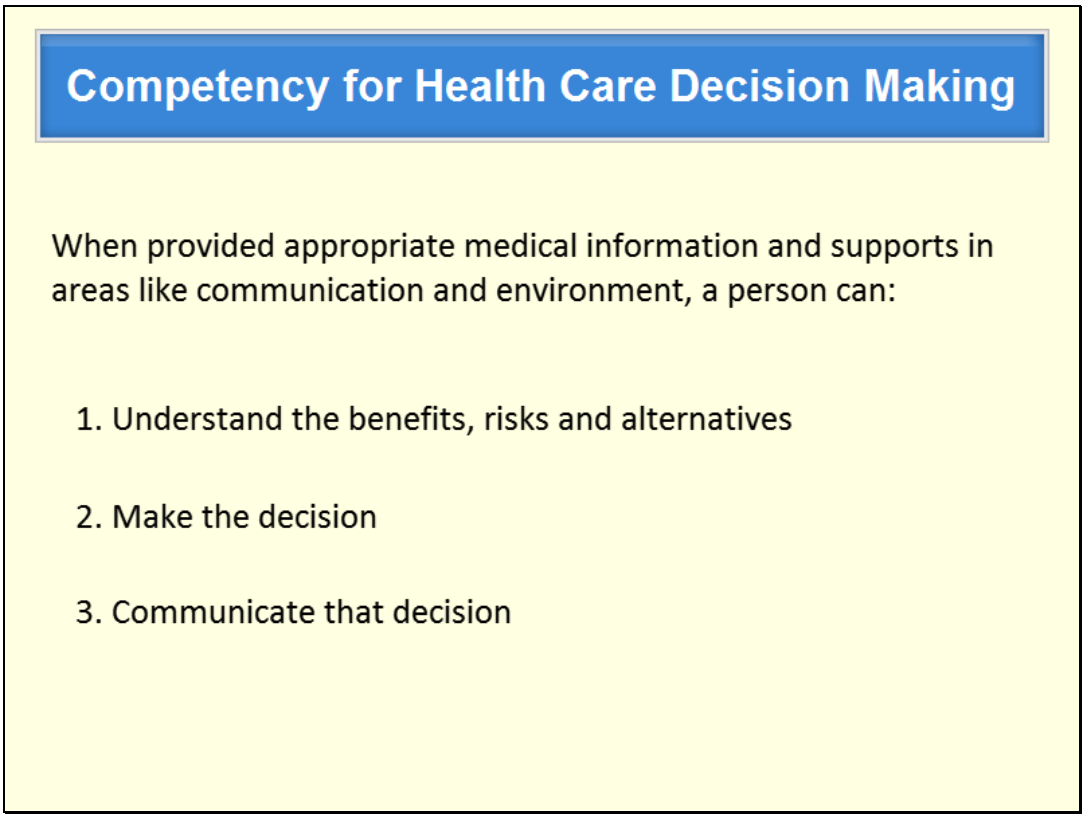
A health care decision is a decision regarding a person's health care, including, but not limited to:

1) The selection and discharge of a health care provider,

2) Approval or disapproval of a diagnostic test, surgical procedure or program of medication and

3) Directions to initiate, continue, withhold or withdraw all forms of life-sustaining treatment, including instructions not to resuscitate.

A surrogate health care decision maker is a person that makes health care decisions for another person.



When competency is referred to in this webcast and in the bulletin, it refers to the competency to make particular health care decisions. It is important to keep in mind that legal competency is a different concept with a different definition and it is determined differently.

In regards to health care decision making, when provided appropriate medical information, communication supports and technical assistance, individuals are considered competent when a health care provider documents that they can do all of the following:

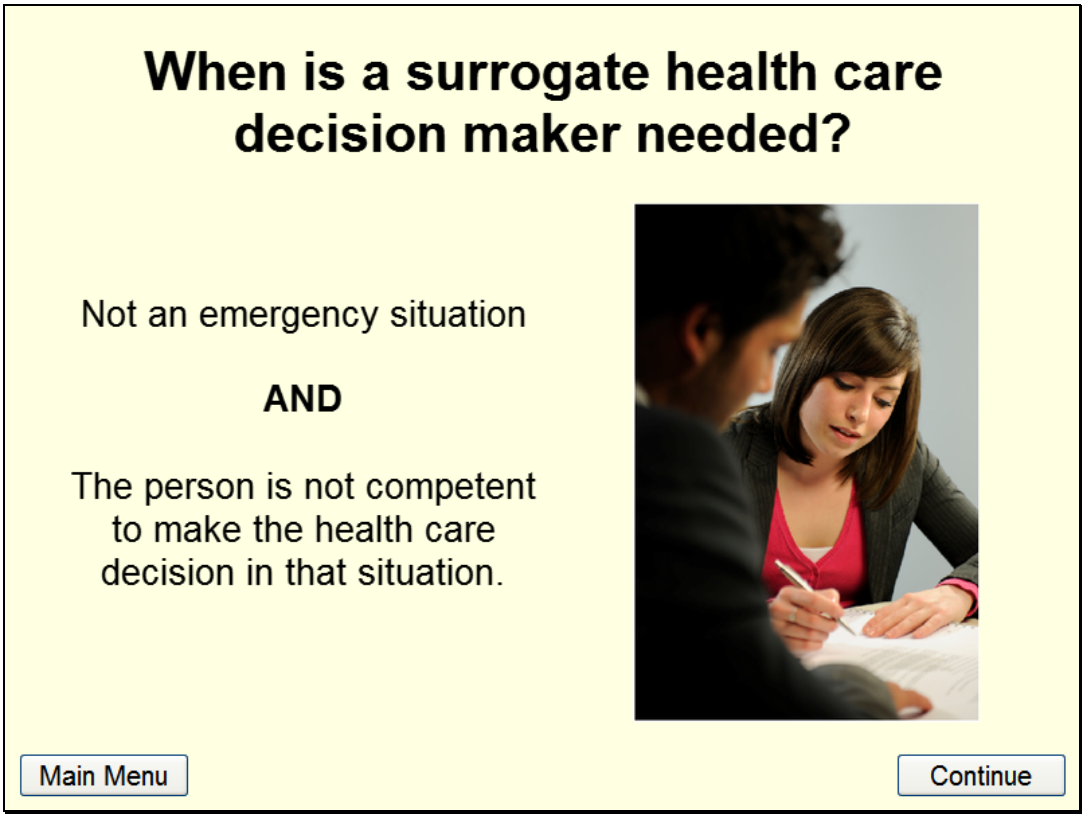
1) Understand the potential material benefits, risks and alternatives involved in a specific proposed health care decision,

2) Make that health care decision and

3) Communicate that health care decision to any other person.

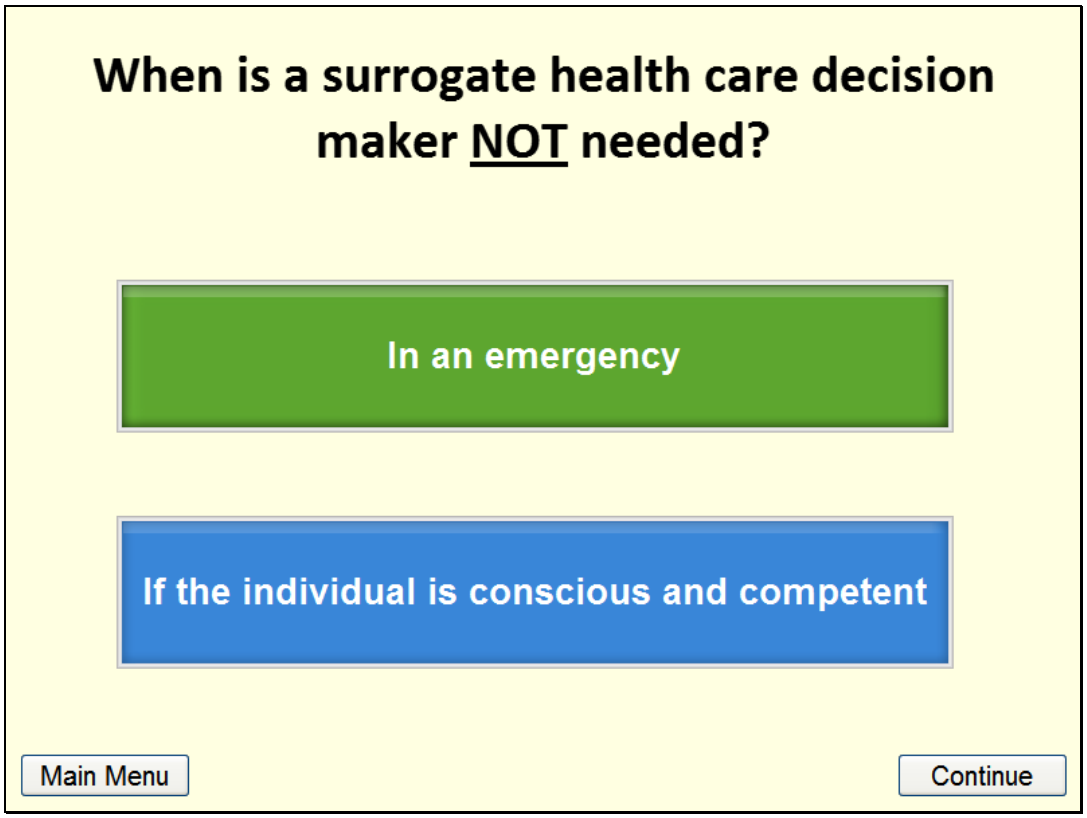
The term competent allows for individuals to be found competent to make some health care decisions, but incompetent to make others.

So, competency in regards to health care decision making is determined by the health care provider for that decision at that point in time.



If an individual is not competent to make a particular non-emergent health care decision, another person must make that decision on the individual's behalf. The person who is making the decision is the surrogate health care decision maker.

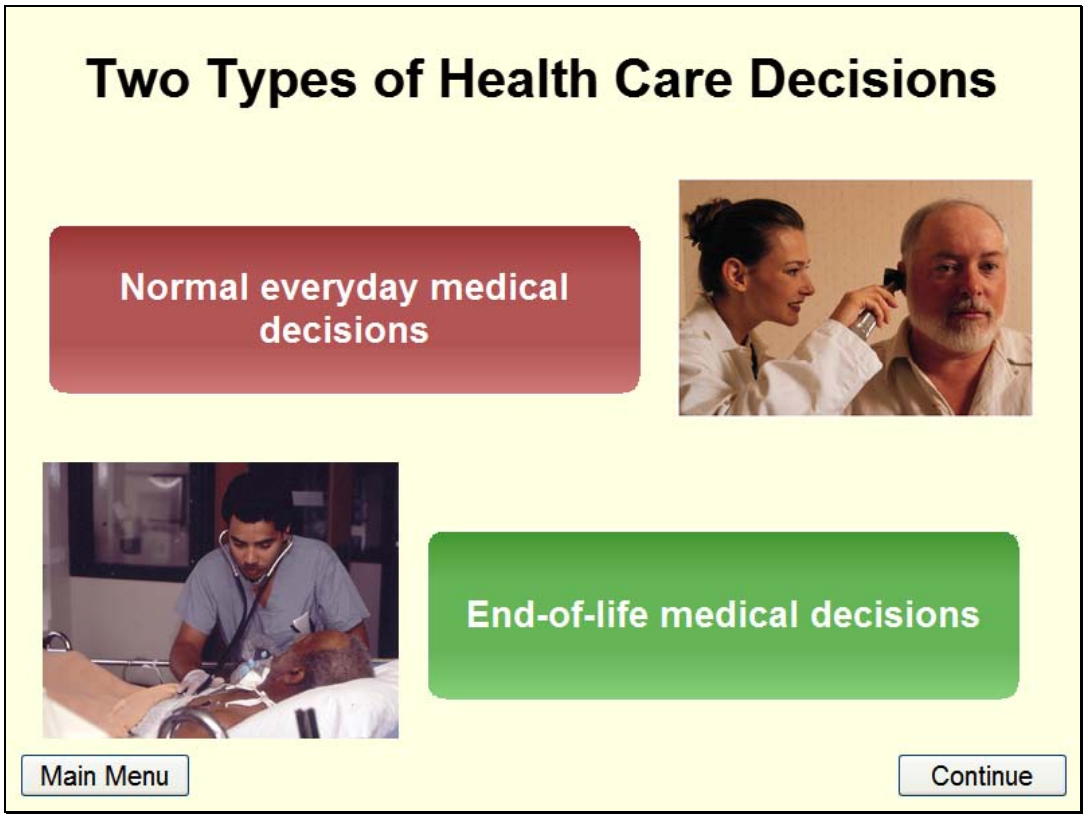
So to have a health care decision maker, the situation must not be an emergency and the individual must not be competent to make that decision. Both of these must be present.



Before we begin talking about when a surrogate health care decision maker is needed, let's first talk about when a surrogate health care decision maker is not needed.

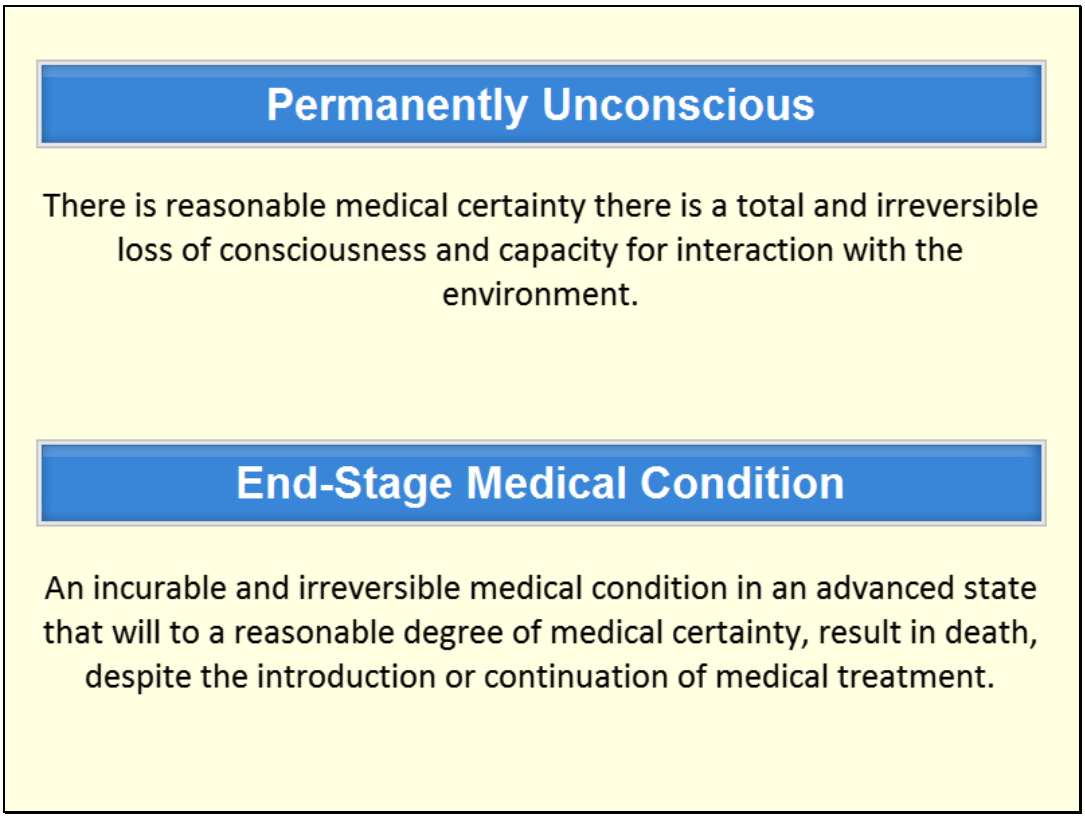
Under Pennsylvania law in the case of an emergency, a surrogate health care decision maker is not needed. The law assumes that the person would desire treatment. Therefore, consent is implied for emergencies and there is no need to seek a surrogate health care decision maker before providing emergency medical treatment.

If the individual is conscious and competent, then the individual can make his or her own health care decisions.



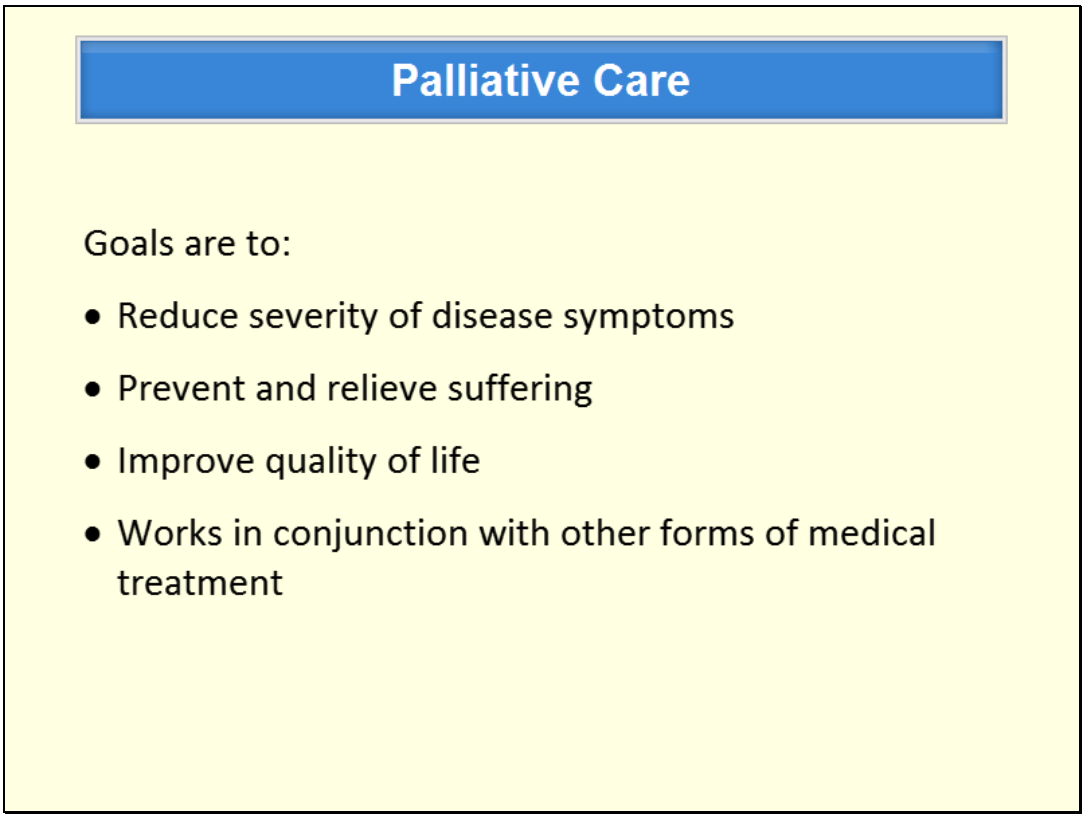
There are two types of health care situations in which decision making is needed. The first is the case of normal everyday medical conditions like the need for gall bladder surgery. In this case, the condition is clearly treatable, but a decision and consent are needed to do the surgery.

The other situation is one in which the person has a condition that regardless of treatment will result in death. This is called an end-of-life condition. We are going to talk more about the two types of end-of-life conditions, permanent unconsciousness and end-stage medical condition.



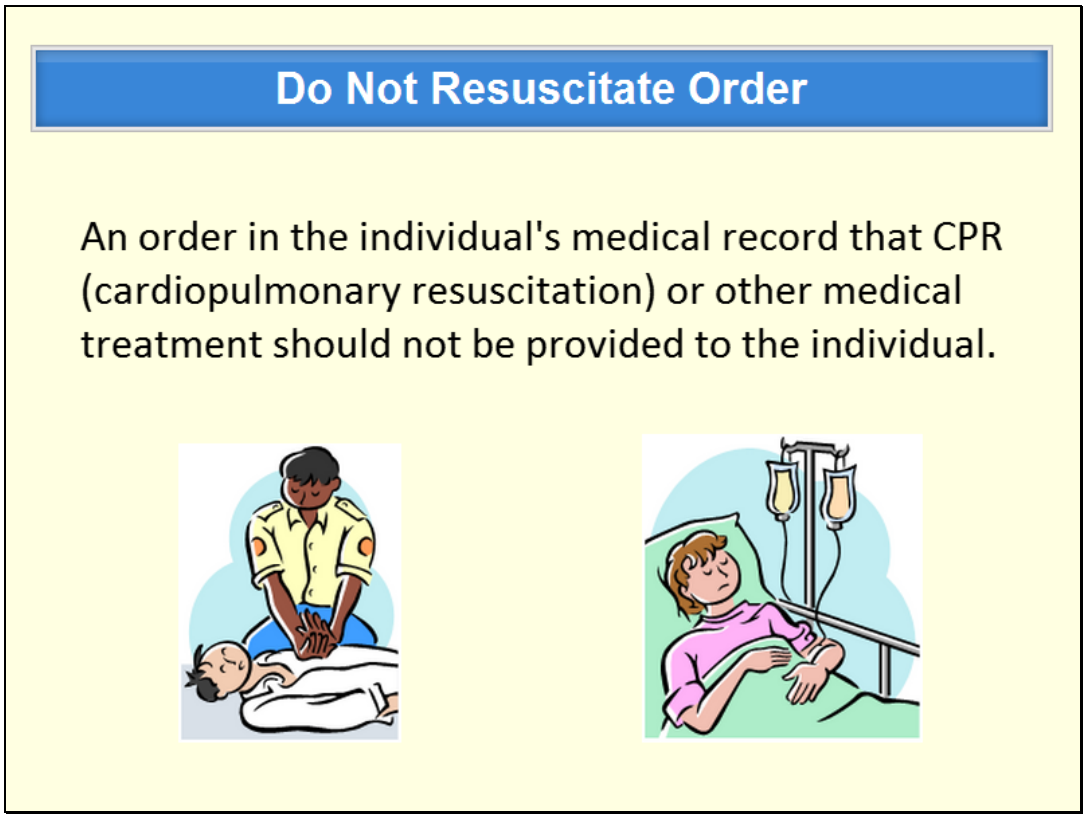
A person is considered permanently unconscious when with reasonable medical certainty there is a total and irreversible loss of consciousness and capacity for interaction with the environment. Being permanently unconscious is a medical condition that is diagnosed in accordance with currently accepted medical standards. You may also know permanently unconscious as an irreversible vegetative state or irreversible coma.

Another term which appears frequently in the bulletin and Act 169 is end-stage medical condition. 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, in the opinion of the attending physician to a reasonable degree of medical certainty, result in death, despite the introduction or continuation of medical treatment. Unless specifically stated in an advance health care directive, having a diagnosis of an end-stage medical condition does not mean the person should not receive treatment if they would benefit from the treatment. This can also include palliative care designed to minimize symptoms of the condition.



Palliative care is a form of medical care or treatment that concentrates on reducing the severity of disease symptoms, rather than solely striving to halt, delay, or reverse progression of the disease itself or provide a cure.

The goal of palliative care is to prevent and relieve suffering and to improve quality of life for people facing serious, complex illness. Unlike hospice, palliative care is not dependent on prognosis and can be offered in conjunction with curative and all other appropriate forms of medical treatment.



One of the considerations of end of life care is whether or not CPR should be performed in attempt to keep the person alive. In a health care situation where CPR should not be performed, this is documented with a Do Not Resuscitate or DNR order in the person's medical record.

A DNR order means that the person will not receive CPR and other medical treatment if the person would stop breathing or his or her heart would stop.

Generally, a DNR order is appropriate only when a person has an end-stage medical condition or is permanently unconscious, but the decision to authorize the DNR order is up to the person or his or her surrogate health care decision maker.

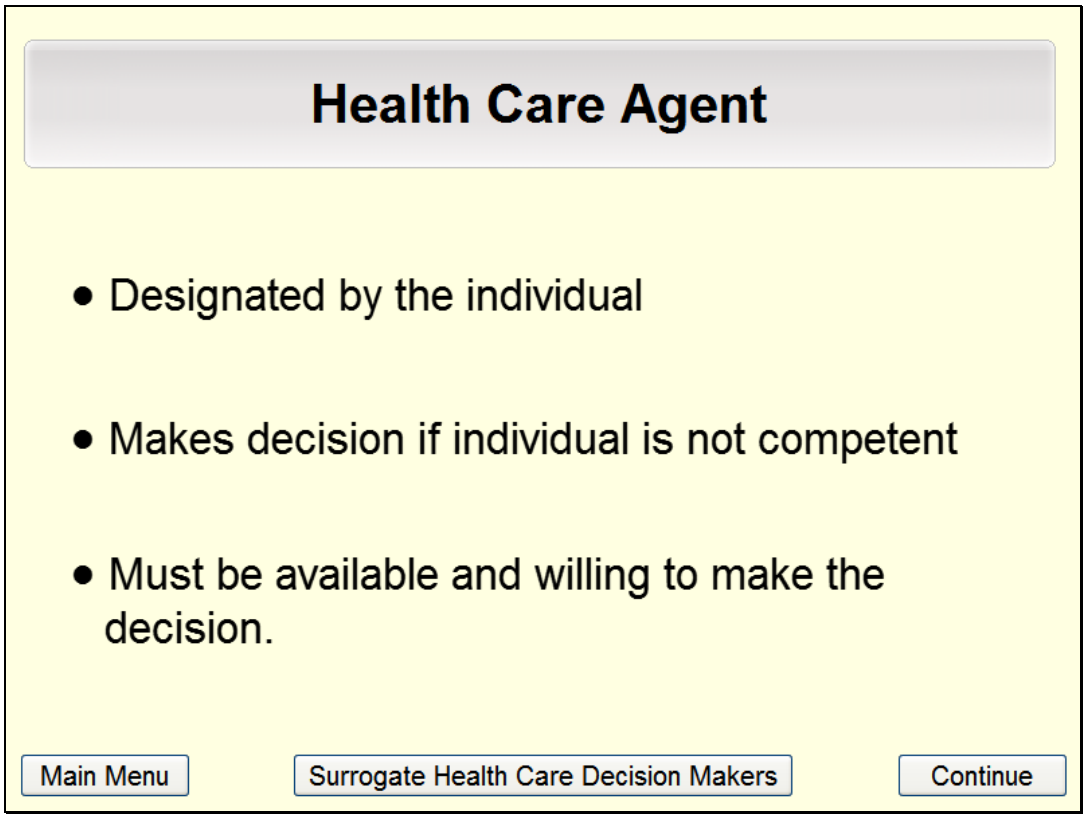
Now that we've talked about the types of decisions that can be made, let's talk about who can make the decisions. If the individual is able to make his or her own health care decision, he or she would do so. If not, then a surrogate health care decision maker is needed.

There are four types of surrogate health care decision makers. The following persons, provided they are willing and able, can act as decision makers in the order of priority shown here.

First would be a health care agent, then a guardian, followed by a health care representative.

If none of these decision makers are available and willing, then the facility director or Chief Executive Officer of the agency would become the health care decision maker under 417 (c) of the MH/MR Act of 1966.

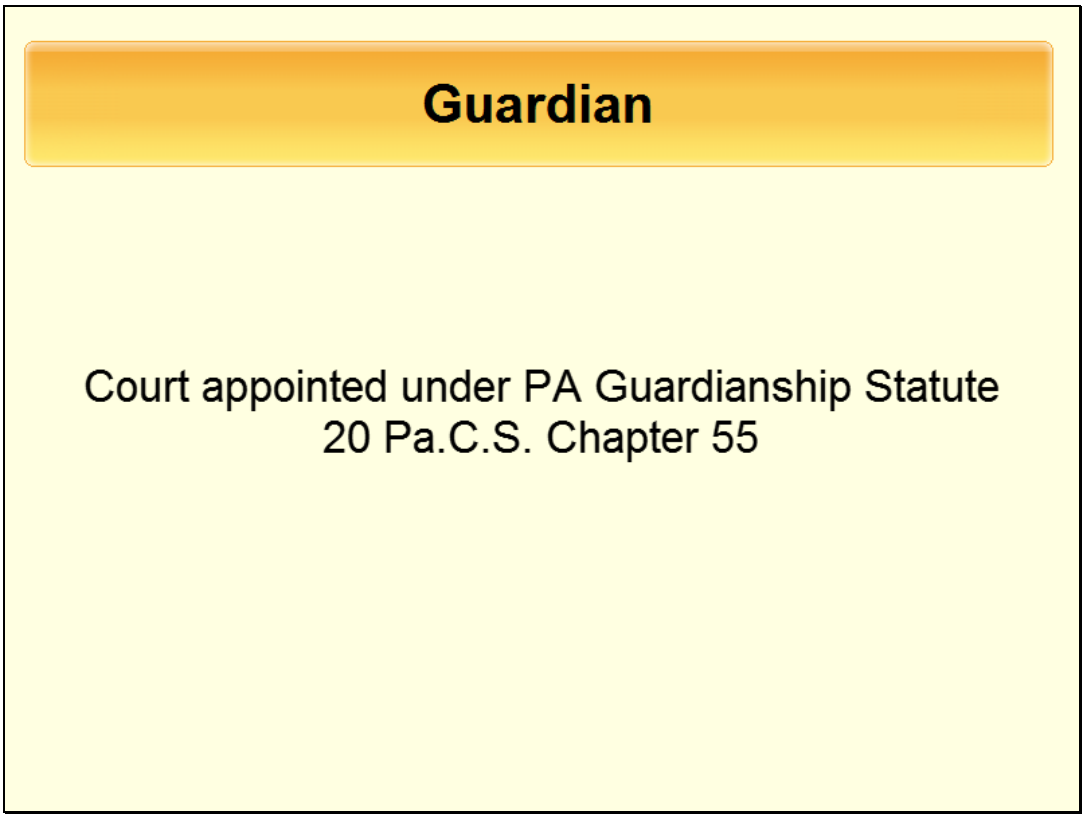
Let's talk more about each of these decision makers.



A health care agent is a person chosen by the individual to make health care decisions for him or her. A person does not need to be able to make the health care decisions him or herself, but must be competent to choose a health care agent. The choice of a health care agent is documented in either a health care power of attorney or a living will. These two types of documents singularly or in combination can be referred to as an advance health care directive.

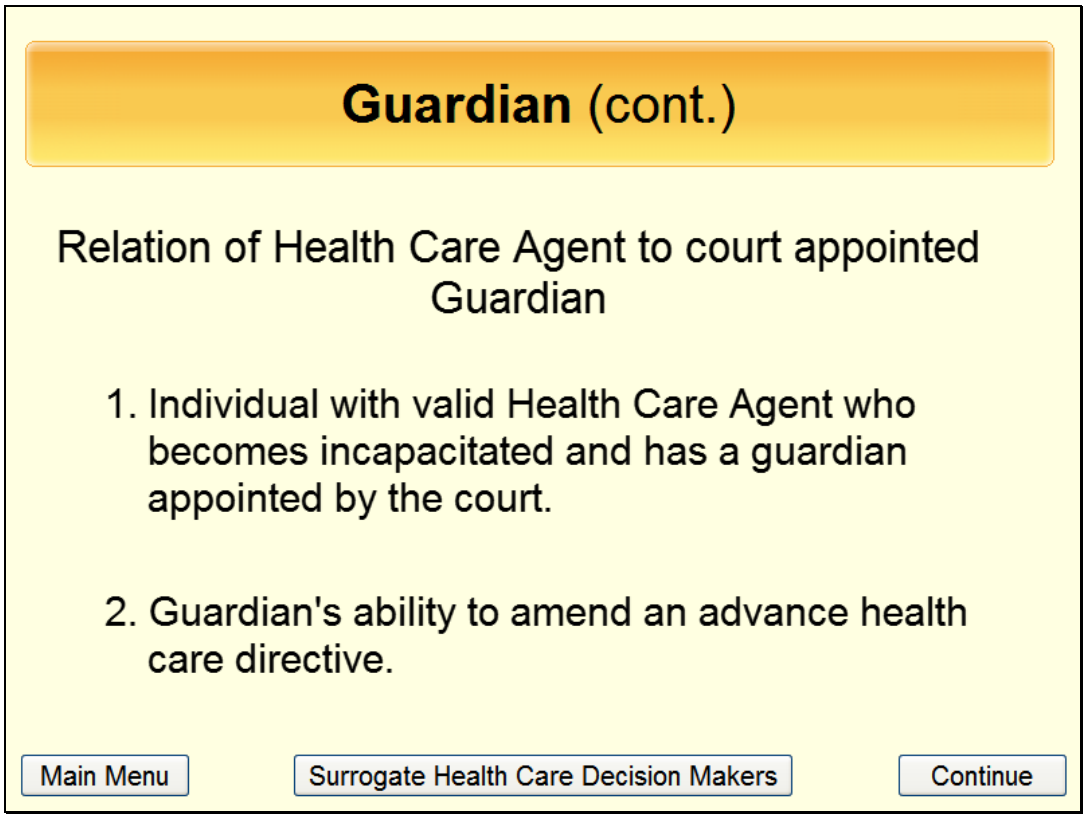
An advance health care directive is a signed and witnessed document written by an individual for him or herself. For individuals who are able to direct their own health care, the purpose of an advance health care directive is to not only designate a person to carry out their wishes, but also direct health care in the event that they become incompetent and have an end-stage medical condition or permanent unconsciousness.

The health care agent chosen by the individual must be available, willing and able to make the decision. If there is not a health care agent, then the next decision maker would be a guardian.



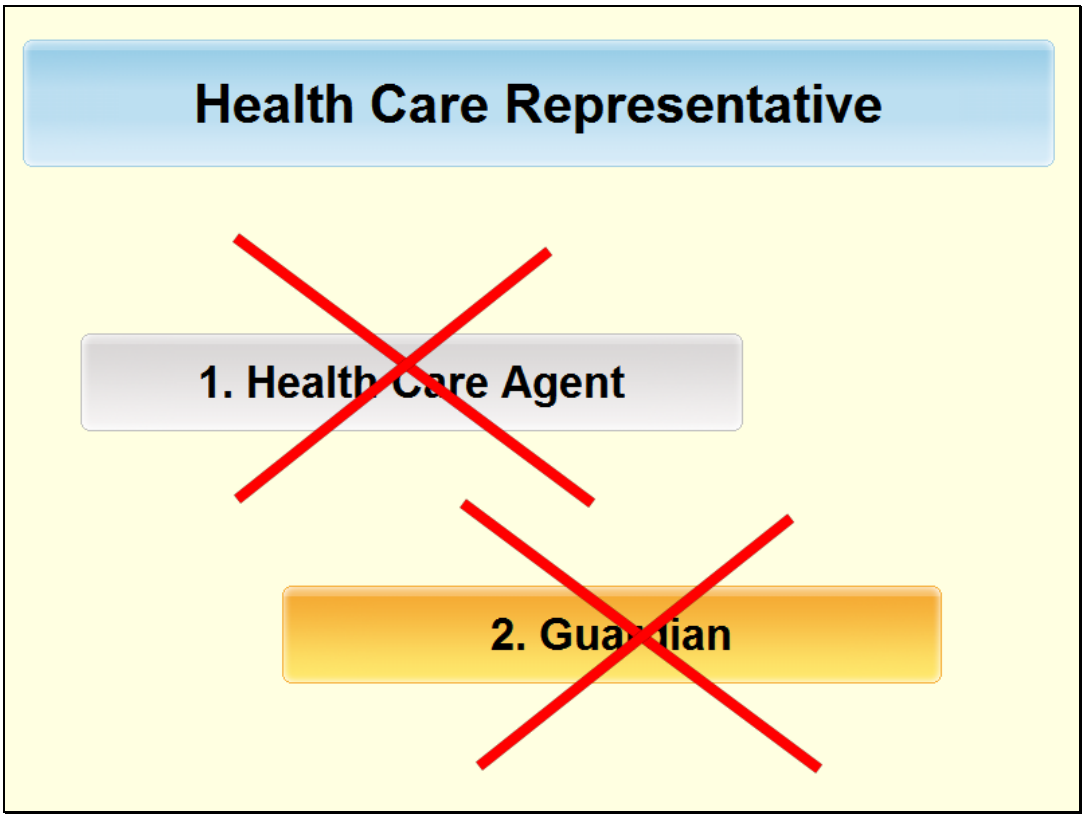
A guardian is appointed by the court under Pennsylvania's guardianship statute. If a court has appointed a guardian, then that person should make health care decisions for the individual. Each guardianship order can be different with different effect and authority of the guardian. Therefore, it is important to know the specifics of the guardianship order for each individual. As a court appointed guardian, that individual is bound by the principles in the Pennsylvania's guardianship statute when making decisions.

There are two situations when an individual may have both a health care agent and a guardian. Next we'll talk about how to approach these situations.

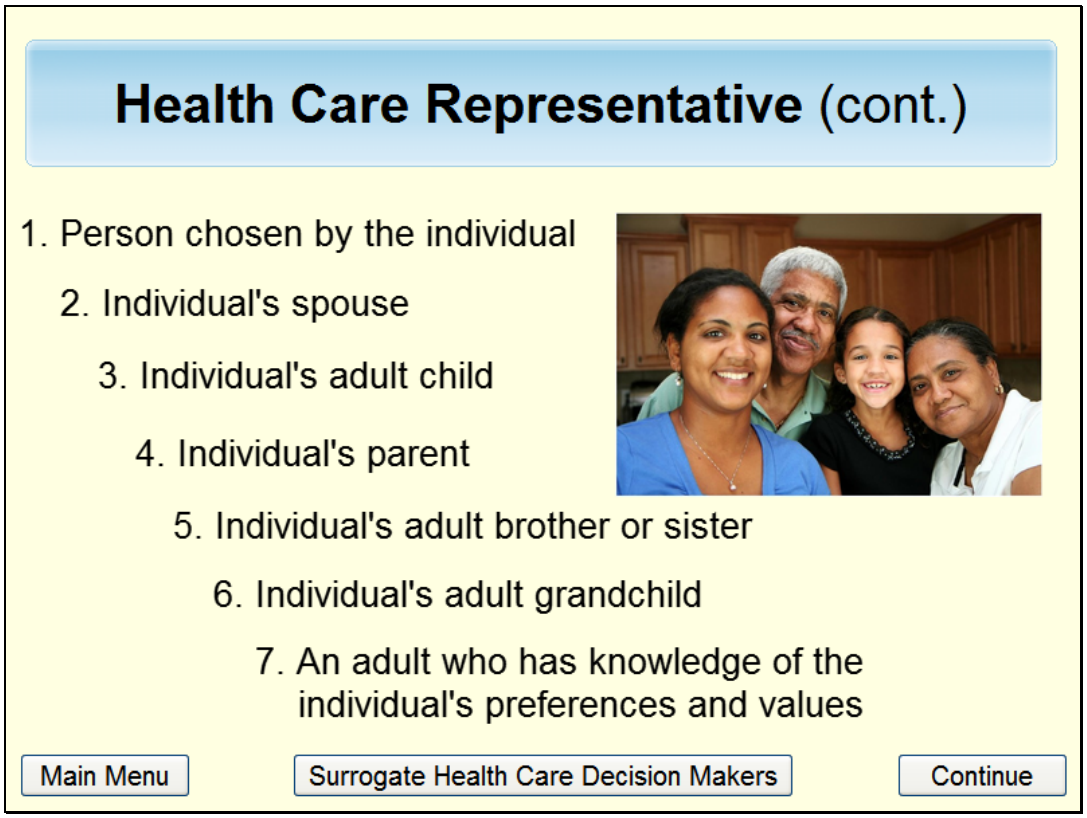


If a person executed a valid health care power of attorney and is later adjudicated an incapacitated person and a guardian of the person is appointed by the court to make health care decisions, the health care agent named in the health care power of attorney is accountable to both the guardian and the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

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



If there is not 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 make the health care decision.

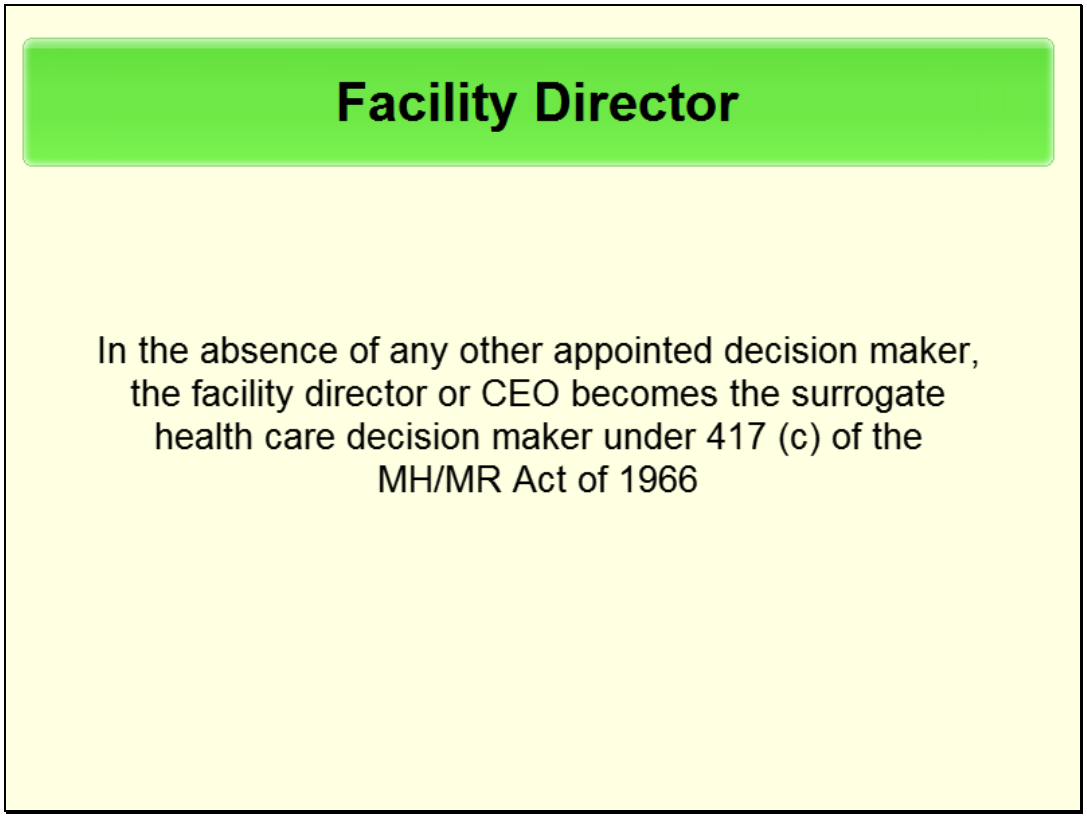


The following persons in order of priority can act as health care representatives for individuals providing they are available, willing and able.

These include:

- A person chosen by the individual while the individual was of sound mind. This could be done in a signed written document or by informing the individual's attending physician.
- If no such person is named, then the next person to act as a health care representative would be the individual's spouse unless a divorce action is pending.
- The next choice would be next of kin in the order of the individual's adult child, parent, adult brother or sister or an adult grandchild.
- In the absence of any of these, an adult who has knowledge of the individual's preferences and values could act as the health care representative.

Act 169 prohibits employees of health care providers from becoming health care representatives unless they are related to the person. In addition, generally it is not appropriate for supports coordinators to act as health care representatives for the individuals they support.



In the absence of an appointed decision maker or health care representative, the facility director or Chief Executive Officer, which we will call the CEO, becomes the surrogate health care decision maker under 417 (c) of the MH/MR Act of 1966. In this case, the MH/MR Act of 1966 makes the facility director or CEO the individual's guardian as if the director had been appointed guardian by the court.

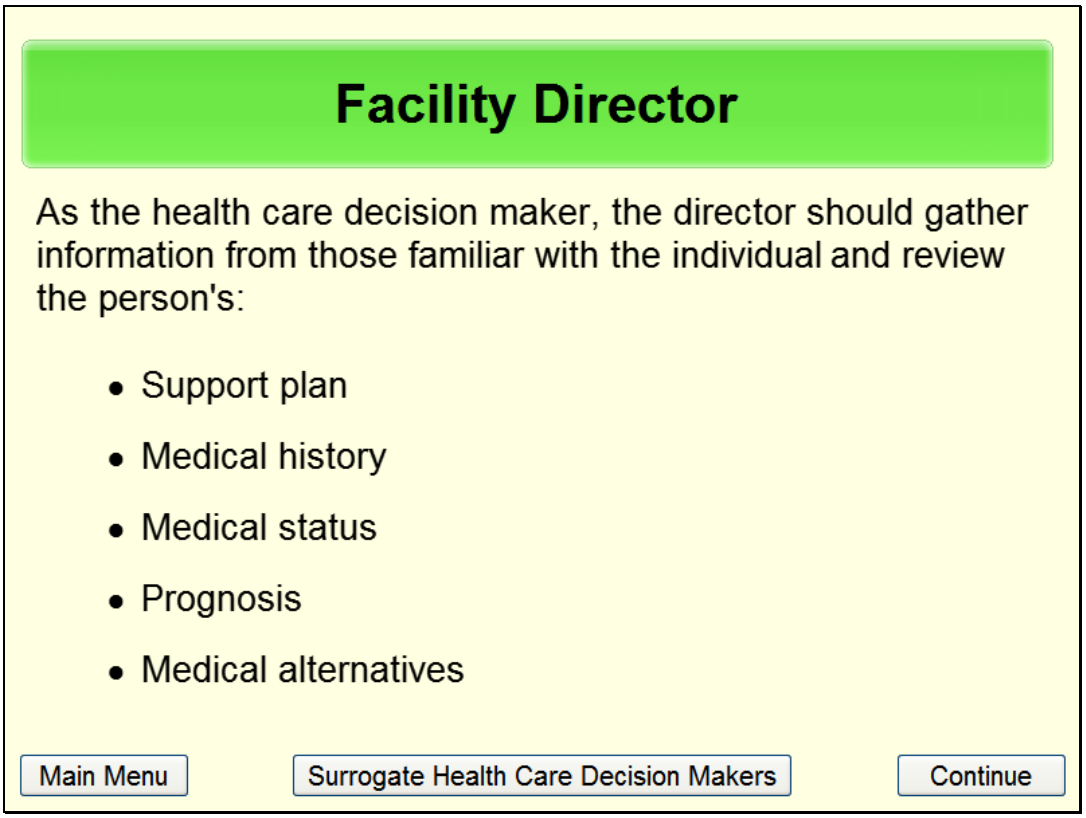
Facility Director (cont.)

With the advice of *two* physicians not employed by the facility, the facility director or CEO, as surrogate health care decision maker, can provide informed consent for:

- Elective and other surgeries
- Diagnostic procedures
- Other treatments and procedures requiring consent

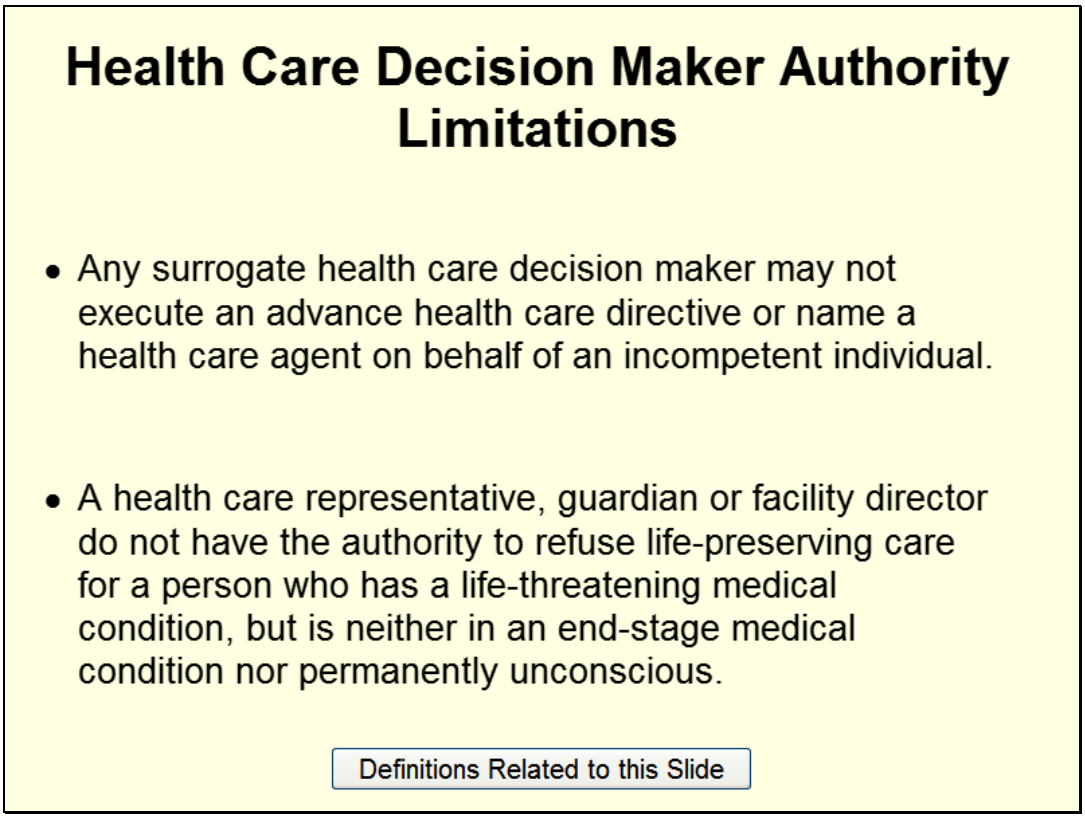
Section 417 (c) explicitly states that the facility director or CEO can consent to elective surgery. In 1966, only elective surgery required explicit informed consent. Even today in Pennsylvania, only a limited number of procedures require informed consent under law. Using the legal doctrine that "the greater power includes the lesser," the power to consent to elective surgery includes the power to consent to diagnostic procedures to determine appropriate treatment. Similarly, the director's authority under 417 (c) is construed to include authority to consent to procedures other than just elective surgery.

As stated in the MH/MR Act of 1966, the facility director's or CEO's authority to provide consent for procedures outside of the facility requires the advice of two physicians not employed by the facility.



When a facility director or CEO acts as the surrogate health care decision maker for an individual, the director should 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 decision. The director should gather information on the individual's prognosis and medical alternatives in regard to the diagnosis, treatments and supportive care. This information should distinguish between curative, palliative and alternatives which merely serve to prolong the process of dying.

The facility director or CEO must be informed of the decision to be made and gather information based on the direct knowledge of those familiar with the individual. In this manner, the director will have sufficient information to make the decision that the individual would make if able to do so. In making the health care decision, the director should take into account the preservation of life, relief from suffering and the preservation or restoration of functioning.



There are two limitations on authority for surrogate health care decision makers.

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. As we discussed before, advance health care directives, health care power of attorney and/or living will must be made by the individual, while competent.

In regard to the duties of an attending physician and other health care providers, Act 169 of 2006 in 20 PA.C.S. section 5462 (c)(2) states that:

“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.”

It follows then that health care representatives, guardians or facility directors and CEOs do not have the authority to refuse life-preserving care for an individual who has a life-threatening medical condition, but is neither in an end-stage medical condition nor permanently unconscious. Act 169 of 2006 explicitly states that health care representatives may not refuse life-preserving care for someone who does not have an end-stage medical condition or permanent unconsciousness. Case law also supports the premise that none of these potential surrogate health care decision makers can refuse life-preserving care in this situation.

End-of-life Decision Making for Health Care Agents, Guardians and Health Care Representatives

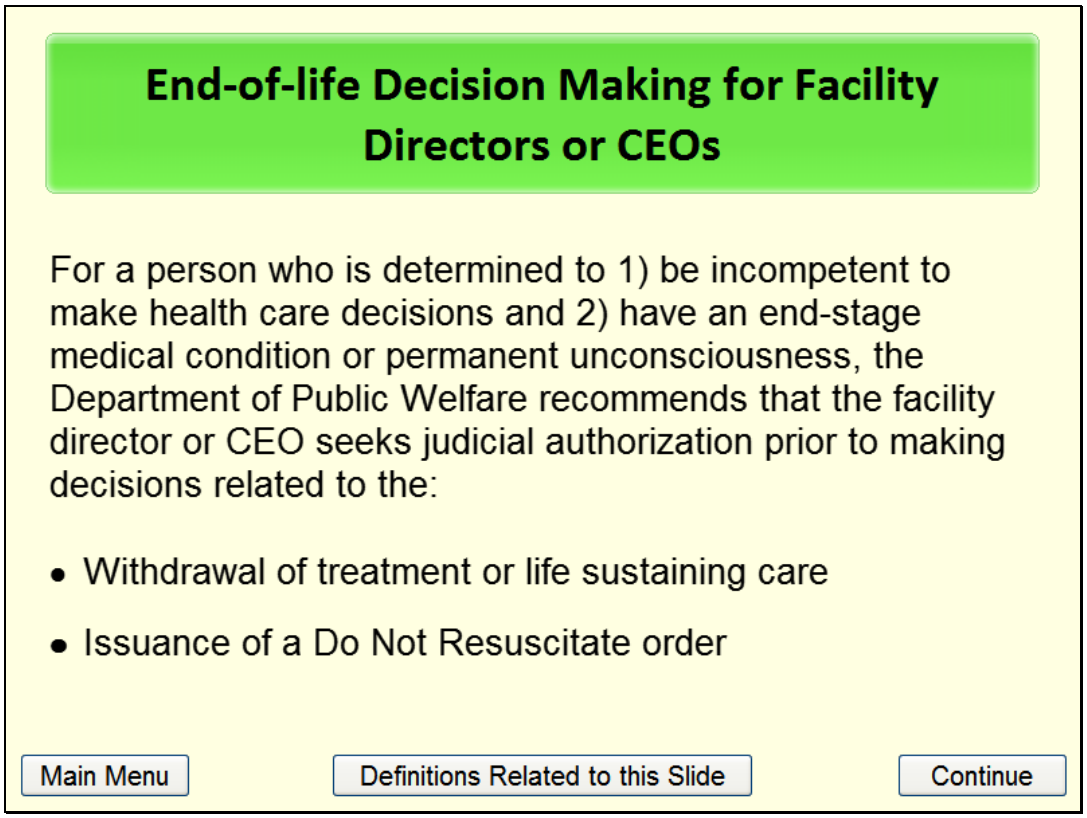
For a person who is determined to 1) be incompetent to make health care decisions and 2) have an end-stage medical condition or permanent unconsciousness, the surrogate health care decision maker can:

- Implement palliative care
- Request a Do Not Resuscitate order
- Remove life support

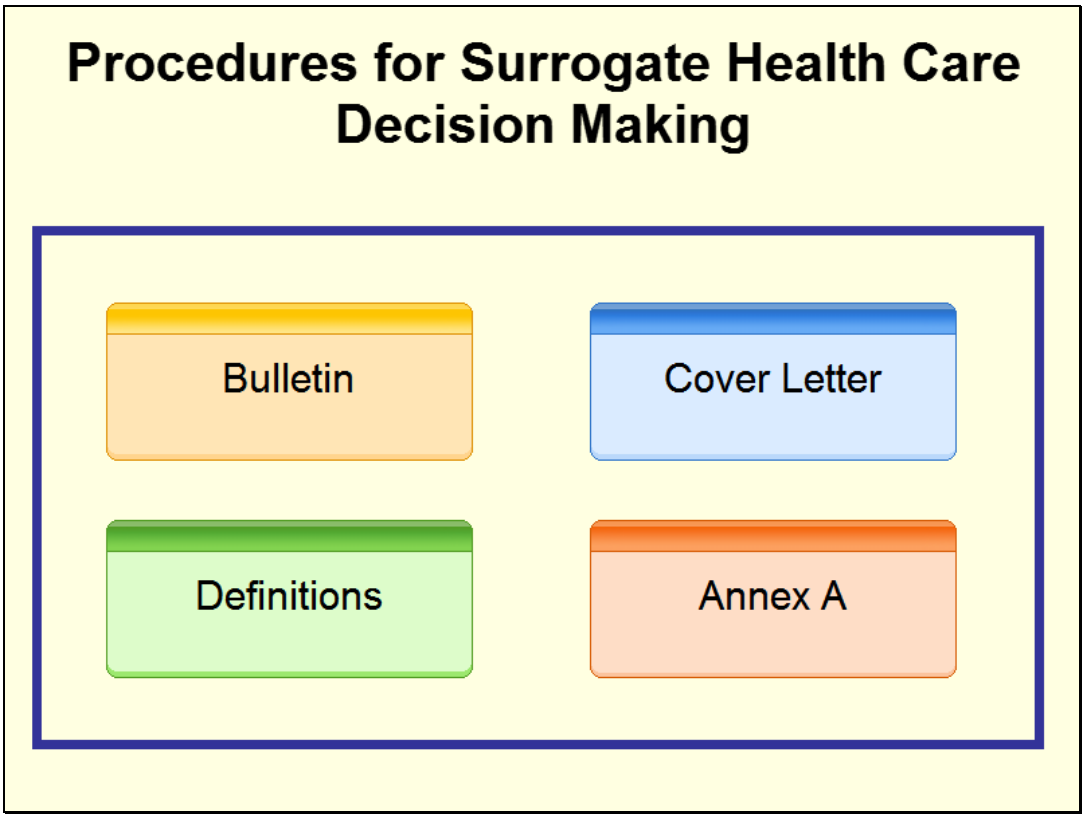
Definitions Related to this Slide

If the individual is determined not competent by a health care professional and does have either an end-stage medical condition or is permanently unconscious, then end-of-life decision making becomes appropriate.

When the surrogate health care decision maker is a health care agent, guardian or health care representative, then the attending physician determines the presence of an end-stage medical condition or permanent unconsciousness. The surrogate health care decision maker then makes the health care decisions based on the recommendations of the medical team using his or her knowledge of the individual. This decision can include the implementation of palliative care, a Do Not Resuscitate order and removal of life support.

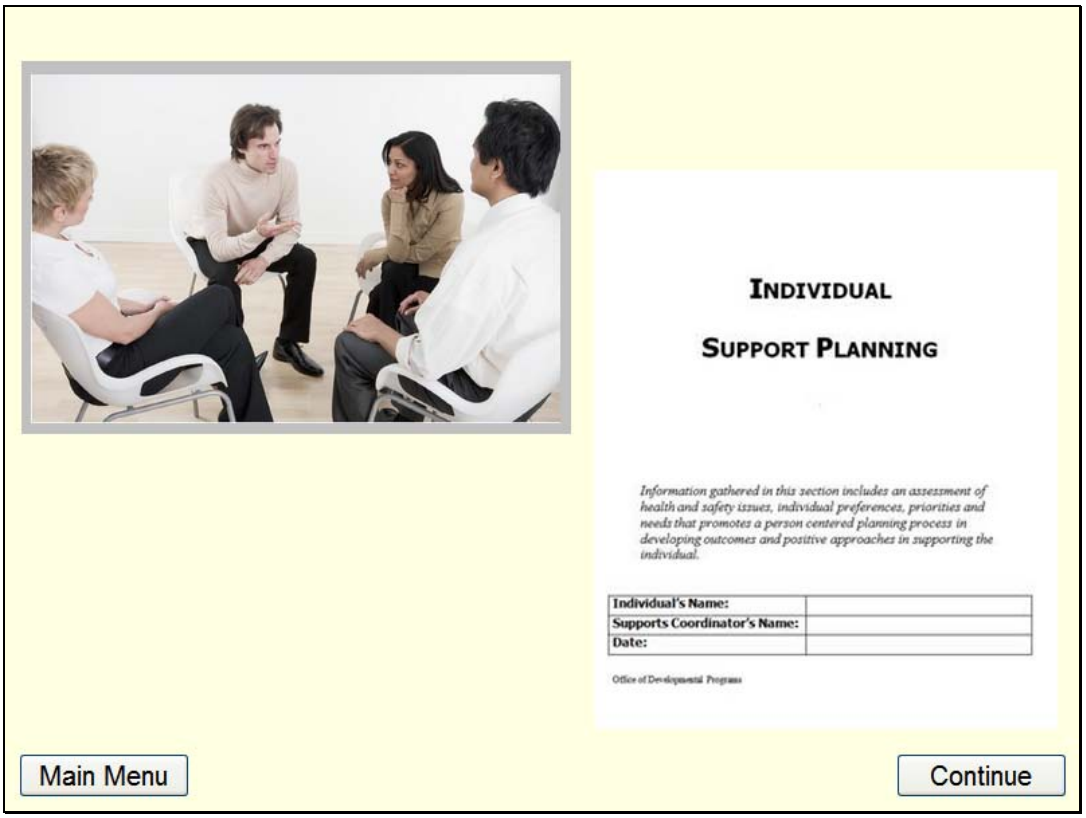


When the surrogate health care decision maker is a facility director or CEO, then the advice of two physicians is required before the facility director or CEO can make a health care decision.



As was mentioned in the beginning of the webcast, not all topics from the bulletin or associated attachments are covered in this webcast. In particular, there is information about access to records and other issues in Annex A that was not mentioned. Therefore, be sure to read the bulletin and attachments in their entirety.

If provider agencies have questions about the implementation of the statutes discussed in the statement of policy, they are encouraged to consult their own legal counsel for advice. If needed, the legal counsel for the provider agency may consult with counsel from the Department.



The time to find a decision maker is not when one is needed. This might be a crisis situation or a stressful time to make such an important decision. In thinking about using the information from this webcast, it is recommended that each individual's team has a conversation about health care decision making. By having this conversation before the decision maker is needed, the individual and the team will be prepared to handle a health care decision when one needs to be made.

The annual team meeting is one time to have this conversation. Anyone on the team can initiate the conversation and the information can be captured in the plan. For those using the ISP in HCSIS, the Health Care screen in the Health and Safety section may help guide the team in its discussion.

This webcast has reviewed the four health care decision maker roles and the decision making ability for each one. To view a summary of this information, please access the document titled “Selection and Limitation of Surrogate Health Care Decision Makers” where you launched this webcast.

If you are a supports coordinator, complete the confirmation of viewing and the post-test to receive credit for participating in this webcast. For others, please use your existing policies and procedures for documentation of training completion.

Thank you for watching this webcast and have a great day.