



Substitute Decision-Making and End of Life Care

Long Term Care Social Workers of Iowa
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Objectives

1. Understand key differences between power of attorney and guardianship
2. Identify appropriate decision-making supports for different situations
3. Understand the decision-making standards used by guardians and healthcare attorneys-in-fact
4. Outline the order of priority in Iowa law for making end of life decisions
5. Identify who has authority to make medical and end-of-life decisions in various circumstances

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Decision-Making Capacity & Supports

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Decision-Making Supports

- Supports that help a person make decisions
- Supports that authorize one person to make decisions for another

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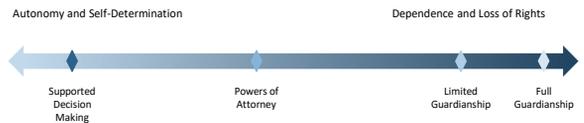


The Right to Make Decisions

- A basic legal right
- All adults are presumed to be capable of making their own decisions
- Adults have the right to make bad decisions
- Having a disability doesn't automatically mean a person needs a guardian

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Decision Making Spectrum



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Decision-Making Capacity

- **Understand**
 - **Appreciate**
 - **Reason**
 - **Express a choice**
- Ability to learn information about a topic
 - Ability to apply information to their own situation
 - Ability to weigh the pros and cons of different options
 - Ability to make and communicate a choice based on this process

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Ways to Maximize Decision-Making Capacity

- Explain things in plain language**
 - Avoid jargon, use common words, explain technical terms
- Ask questions to ensure understanding**
 - Open-ended versus yes/no questions
 - Have them explain back in their own words
- Use needed communication supports**
 - Glasses, hearing aids, communications devices
 - Alternate formats (large print, Braille, audio, video)
 - Interpreters & translators

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Ways to Maximize Decision-Making Capacity

- Identify and reduce temporary impairments**
 - Medication effects, time of day, illness or infection, alcohol/drug use
- Recognize the effects of stress**
 - Grief, family conflict, trauma (recent or past), natural disaster, life changes
- Establish rapport and relationship**
 - Personal decisions
 - Sensitive topics
 - Fear of being judged
 - Fear of unwanted consequences

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Decision-Making is a Learned Skill

- Use social stories and personal examples**
 - Provide concrete examples of similar decisions
 - Learn to apply information
 - Learn to weigh pros & cons
- Break big decisions into smaller steps**
 - Helps avoid overwhelm
 - Helps refocus on goals and priorities at each step
- Model the decision-making process**
 - Provides real-life examples and experience
 - Learn to follow the whole process
 - Great for guardians and conservators

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Capacity versus Competence

- | | |
|--|--|
| <p>Capacity</p> <ul style="list-style-type: none"> • Clinical/functional term • Reflects the ability to perform a certain task or make a certain type of decision • Context-specific • Variable | <p>Competence</p> <ul style="list-style-type: none"> • Legal term • Refers to the status of having the legal rights and responsibilities of an adult • Is generally seen as a binary |
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Alternatives to Guardianship

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Ways to support a person in making decisions about their life

Supported Decision-Making

- People chosen by the person to help them understand information, make decisions, and communicate those decisions to others.

Release of Information

- A person can give permission to have information released to people who are supporting them

"Appointed Representative"

- Many government agencies let an applicant or beneficiary name someone to help them with the process. (Social Security, Medicaid, IRS and Iowa Dept. of Revenue, unemployment insurance, etc.)



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Tools to help people with medical decisions

Supported Decision-Making

- People chosen by the patient to help them understand information, communicate with their providers, and make treatment decisions

Release of Information

- Gives medical providers permission to share information and medical records with people or organizations

Durable Healthcare Power of Attorney

- Names a person who the patient wants to make medical decisions for them if they are unable

Declaration Regarding Life-sustaining Procedures ("Living Will")

- Expresses the patient's wishes regarding life-sustaining procedures if they have a terminal condition or are in a persistent vegetative state

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Durable Power of Attorney for Health Care

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Power of Attorney

- A written legal document in which one person gives another the authority to act on their behalf
- Sharing of decision-making authority
- The person who signs the document and gives someone else authority to act for them is called the principal
- The person who is given authority to act for the principal is called the agent or attorney-in-fact

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Durable Power of Attorney for Healthcare

- **Healthcare decisions**
- Takes effect only when the attending physician certifies the patient's inability to make their own medical decisions
- Can include instructions about the principal's wishes and preferences

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Things to Know About HCPOAs

- Must be "activated" before the agent/attorney-in-fact has authority to make decisions
- Capacity is not the same as competence
- Principal retains the right to make other decisions
- Revocable
- No reporting requirements

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Executing the Document

- Principal must be an **adult**, have **capacity**, and it must be **voluntary**
- Document must be in **writing** (handwritten, typed, form)
- Name of the attorney-in-fact or agent
- Responsibilities and authorities being granted
- Signed and dated by the principal
- Notarized or signed by two witnesses (healthcare POA only)

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POAs From Other States

- A POA document executed in another state or jurisdiction is valid and enforceable in Iowa if:
 - It was executed in compliance with the laws of the other state
 - It is consistent with the laws of Iowa
- A POA document executed by a veteran of the armed forces which is in compliance with the federal department of veterans affairs advance directive requirements is valid and enforceable in Iowa

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How Do Attorneys-in-Fact Make Decisions?

- Duty to act in accordance with the desires of the principal
 - Expressed in the DPOA
 - Otherwise made known to the attorney-in-fact
- If the principal's desires are unknown, the attorney-in-fact has a duty to act in the best interests of the principal, taking into account the principal's overall medical condition and prognosis

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Guardianship

- Guardians are appointed by the court to make decisions for someone else
- A guardian is only appointed for a person who is unable to make or communicate their own decisions
- A person who has a guardian appointed for them is called a "protected person"

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What is a Guardian?

Guardian: someone appointed by the court to make decisions about the protected person's **physical care**



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Legal Standard for Guardianship

A person whose **decision-making capacity is so impaired** that they are unable to care for their personal safety or to provide for their basic necessities, such as food, shelter, clothing, or medical care, without which physical injury or illness might occur.

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Establishing Guardianship

Required

- File petition
- Notice to respondent
- Attorney for respondent
- Background check
- Hearing

Optional

- Professional evaluation
- Court visitor
- Mediation



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Limited Guardianship

Guardian only has authority to make decisions in certain areas

Protected person retains the right to make decisions in other areas

Judges are required to consider limited guardianship, but in practice many do not

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Duties of Guardians

Duties to the Court

- File an initial care plan
- File annual reports
- File a final report when the case ends

Duties to the Protected Person

- Fiduciary duty
- Make decisions for the protected person that put the protected person's interests first
- Help the protected person develop and maintain self-reliance

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What Does a Guardian Do?



- Helps the protected person develop and maintain self-reliance
- Makes decisions about the care, maintenance, health, education, welfare, and safety of the protected person



- Establishes the protected person's permanent residence*
- Takes care of the protected person's personal property
- Consents to medical and dental care and education, training, vocational, and other professional services for the protected person



- Helps the protected person develop and maintain supportive personal relationships

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Powers Requiring Specific Court Approval

- Changing the protected person's permanent residence to a nursing home, other secure facility, or secure portion of a facility that restricts the person's ability to leave or have visitors
- Consenting to the withholding or withdrawal of life-sustaining procedures
- Consenting to the performance of an abortion on the protected person
- Consenting to the sterilization of the protected person

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Things A Guardian Cannot Do

- Adults have the right to make their own decisions – including bad decisions!
- A guardian cannot force someone to
 - Eat healthy foods or exercise
 - Take their medications
 - Cooperate with service providers
- A guardian cannot stop
 - Aggressive, violent, or self-harming behavior
 - Taking things that belong to others
 - Consensual sexual activity
 - Staying up late, sleeping late, skipping work or school, etc.
 - Smoking, alcohol use, drug use

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How Do Guardians Make Decisions?

- Two decision-making standards
- **Substituted judgment** – attempts to make the decision that the protected person would make if they had the capacity to do so
 - Involve the protected person
 - Consider the protected person's past decisions and known wishes, preferences, values, and goals
- **Best interests** – when the protected person's wishes cannot be known, make decisions based on what would be in the best interests of the protected person

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Guardianships can be changed or ended.

- Many people who have guardians can develop or regain the ability to make decisions.
- Guardianships can be limited or expanded as the protected person's needs change
- Guardians have a responsibility to help the protect person become self-reliant.
 - A guardian involves the protected person to the greatest extent possible in all decision-making.
 - A guardian maximizes the self-reliance and independence of the protected person.

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Resources for Guardians

Guardianships Association of Iowa Network (GAIN)

GAIN is a membership association focused on providing advocacy, education, and resources to members and the community for the purpose of promoting best practices and the provision of ethical substitute decision making services in the least restrictive manner.
www.iowaguardship.org

National Guardianship Association (NGA)

National organization dedicated to improving the standard of excellence in guardianship.
www.guardianship.org

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End of Life Decisions

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Declarations Regarding Life Sustaining Procedures

- Sometimes called a "living will"
- Can be executed at any time by a competent adult
- Similar execution requirements as for a DPOA
- Only effective when
 - The patient has an incurable or irreversible condition that will result either in death within a relatively short period of time or a state of permanent unconsciousness from which, to a reasonable degree of medical certainty, there can be no recovery
- AND
- The patient is unable to participate in their own health care decisions

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Withholding or Withdrawing Life-Sustaining Procedures

- Iowa law provides a priority list of people who can consent to the withholding or withdrawal of life-sustaining procedures if a person is unable to give or refuse consent and has no signed a living will
 - Agent under a durable healthcare power of attorney
 - Guardian, with authorization from the court
 - Spouse
 - Majority of adult children
 - Parent or parents
 - Adult sibling

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Out-of-Hospital Do-Not-Resuscitate Orders

- Issued by the patient's attending physician
- Form created by the Iowa Department of Public Health
- Intended to carry out the patient's wishes regarding the withholding or withdrawal of life-sustaining procedures
- **Does not apply** when the patient is in need of emergency medical services for some reason outside the scope of the patient's terminal condition (e.g. car accident, fire, natural disaster, or other accident or injury)
- Health care providers still provide appropriate comfort care and pain relief
- Can be revoked by the patient or an individual authorized to act on the patient's behalf (agent, guardian) at any time and without regard to the patient's physical or mental condition

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Physician Orders for Scope of Treatment (IPOST)

- Issued by the patient's attending physician
- Form created by the Iowa Department of Public Health
- Intended to carry out the patient's wishes regarding the withholding or withdrawal of life-sustaining procedures
- For use by patients who are frail and elderly or who have a chronic, critical medical condition or terminal illness for which an IPOST is consistent with the individual's goals of care
- Can be revoked by the patient or patient's legal representative (priority order) at any time and without regard to the patient's condition
- An IPOST does not supersede a declaration regarding life-sustaining procedures, a DPOA, or an out-of-hospital DNR order

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