



Using Advance Directives

The ALS Association supports a person's rights to make their treatment decisions known and to complete written advance directives. The Patient Self-Determination Act (PSDA), which Congress passed in 1990, ensures patients' right to give informed consent and refusal, with the use of advance directives to guide treatment when a patient cannot give informed consent or refusal.

The ALS Association suggests that persons with ALS be aware of several items when formulating their advance directive. Terminology and interpretation of fine points of the advance directive law may be unique to each state, but the overall purposes of advance directives are similar.

Before patients can intelligently decide their treatment preferences, they need to understand what types of treatments – such as CPR, intubation, and artificial nutrition – they may later want to refuse or request. They should also become familiar with technical terms.

Patients should ask their physicians if they would honor refusal of certain medical treatments. Federal law requires physicians to inform a patient when they first receive an advance directive if they would be willing to comply with it. A physician who cannot honor the patient's choices is obligated to transfer care of the patient to another practitioner.

If the patient has selected a proxy (a person who is willing to make your decisions known if you are unable), he or she needs to be certain that the proxy is available and is comfortable with the patient's care decisions. The patient must enter the proxy's full name, address, and phone number on the forms. Patients should identify at least one alternate in case the first proxy is not available when the need arises.

Patients should be encouraged to review their advance directive periodically to evaluate whether the written preferences still mesh with their desires.

Patients who want to complete advance directives should be encouraged to follow several important steps. The following checklist covers the process of planning, completing, distributing, and evaluating an advance directive; it can serve as a starting point for discussion or a guideline for patients when they prepare to complete an advance directive.





Checklist for Completing An Advance Directive

Planning

Assess your values

- Obtain and review the advance directive forms.
- Determine what is the most important to you.
- Identify your wishes about quality of life and health care.
- Consider why you want to create an advance directive at this point in your life.
- Discuss your thoughts with family, clergy or others close to you.

Identify and discuss choices

- Based upon the values you identified, decide what care you would not want in case of a permanent unconscious condition, terminal illness, or other serious health condition.
- Ask for information about life-sustaining medical treatments that you should consider.
- Inform your physician, nurse, or home caregivers of your wishes.
- Discuss your wishes with those close to you.

Select an agent or proxy

- Be sure the person is willing to be your agent or proxy.
- Select at least one alternate agent/proxy.
- List your agent's address(es) and phone number(s).
- Discuss your wishes with your agent(s)/proxy.
- Identify any limitations or restrictions to the agent's authority.

Complete chosen forms

- Assure you have your chosen forms from a healthcare provider or other source.
- Specify what you want provided, withheld, or withdrawn.
- Sign, witness or notarize the forms as appropriate and date them.
- Discuss the forms with your physician, family, and agent(s).





Distribute advance directives

- Keep the original directive in a safe place at home.
- Have a copy placed in your medical record.
- Give copies to your family, agent(s), and physician.
- Take a copy with you when you travel.

Evaluating advance directives

- Reconsider and update the decisions you have made.
- Discuss your choices with loved ones. Inform your agent and loved ones if you change or revoke your advance directive. (You may revoke a durable power of attorney for health care if you are mentally competent to do so, and you may revoke a natural death act declaration at any time by informing your treating physician.)

Additional information about advance directives can be obtained from community or state agencies. Advance directive forms are available from hospitals, physician offices, HMOs, senior citizen centers, bar associations, and religious organizations.

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