

Advance Directives

Advance directives are written documents that you can complete to let everyone know what type of medical treatment you would—or wouldn't—want in the event of a medical emergency. If you become unable to make decisions, advance directives will make your wishes clear to your loved ones and to the medical professionals caring for you.



Why should I do this?

If you do not create advance directives ahead of time, your loved ones may find themselves in the challenging position of trying to make a decision for you. Advance directives can provide peace of mind for you and clarity for your loved ones.

It is very important to have a discussion with your loved ones and decide in advance whether or not you would want to have a tracheostomy procedure and be placed on invasive mechanical ventilation. If you do not discuss or write down your decision, the decision could be made for you in an emergency situation—and it may not be what you want.

Advance directives are simple forms. You do not need a lawyer to fill them out, though you can always seek legal advice if you'd like. You can change your advance directives whenever you'd like. The most important thing is to put your current decisions in writing so there is never any doubt about what you want.

These are the three main types of advance directives for people living with ALS:

A living will is the core document that describes the type of life-prolonging support you would or wouldn't want to receive, such as CPR, ventilation, a feeding tube, and pain management. A living will is different from the type of will that assigns property and money to loved ones upon death.

A medical power of attorney (POA), also called a health care proxy or durable power of attorney for health care, is a legal document that designates the person or persons you would like to make medical decisions on your behalf should you become unconscious or unable to make decisions. This person may be called a proxy, agent, surrogate, or representative.

A do not resuscitate (DNR) order will let first responders or medical professionals know if you do not want to attempt life-saving measures should you stop breathing or should your heart stop beating. Your DNR will not be valid unless your doctor completes it and signs it.

Where can I find these forms?

The social worker at your ALS clinic, local ALS Network care manager, or local hospice should be able to give you the forms, help you fill them out, and answer your questions. Your hospital should have forms available, too. You can also search online for advance directives in your state. The National Hospice and Palliative Care Organization (www.caringinfo.org/planning/advance-directives) makes it easy to find and download your state's advance directive forms. They also provide state-specific information and step-by-step instructions that walk you through the process. Every state has its own forms and laws about advance directives.

What else do I need to do?

We recommend starting with the social worker at your ALS clinic, local ALS Network care manager, or local hospice. Review the forms together, ask questions, and discuss your options.

Though this can be a difficult topic to discuss with your loved ones, it is important to explain your decisions and make sure that everyone understands your wishes, even if not everyone agrees. If you are worried about initiating this conversation, ask your social worker to facilitate, answer questions, and educate everyone.

Once you have made your decisions, you will need to fill out the forms and sign them with a witness present, and possibly a notary, depending on your state's laws. If you comply with your state's requirements, your forms will become legal documents when you sign them.

Give copies to your proxy, loved ones, medical teams, and the hospital where you would go in the case of an emergency. Keep your original in a safe place that others know about and can access in the case of an emergency. Also be sure to tell your loved ones who you have designated as your proxy. Explain that this person's role is to carry out your wishes.

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