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LIVING WILL - General Information

Living Will

WHAT YOU NEED TO KNOW:

What is a living will? A living will is a type of written legal document called a medical advance directive. It describes the medical care you want in certain situations. Some medical treatments can prolong your life, even when recovery is not possible. If you are not likely to recover, a living will can list the treatments you want and do not want.

Why may I want to have a living will? If you are in the hospital, you or your family will be asked if you have any advance directives, such as a living will. If you do not have a living will or other advance directive, your healthcare providers may give you treatments to prolong your life. They may give you treatments you do not want. You could live for months or years with these treatments, but not be conscious or aware. You may want to limit your treatments, but your family may want you to have all treatments. If you have a living will, your healthcare providers can follow your wishes for treatment.

When does a living will take effect?

- **You cannot make your own medical decisions:** Your living will takes effect when you can no longer let healthcare providers know what care you want. Depending on the state you live in, 1 or 2 doctors have to decide that you can no longer make medical decisions. You may not be able to communicate what you want. You may lack the ability to understand the choices that need to be made about your medical care and the effects of the choices.
- **You have a terminal illness:** The doctors must also decide that you have a terminal or other condition that falls under your state's living will law. Each state may define terminal illness in a different way. Your state may use terms such as permanent unconsciousness (not awake or aware), or irreversible condition (a condition that will not get better). Your state may have other rules that control when a living will takes effect.
- **You are in a vegetative state:** A living will may also take effect if you stay in a long lasting or permanent vegetative state. A vegetative state means that your mental functions are reduced or lost, but your basic body functions still work. Your mental functions include your ability to think, be aware, or be fully conscious or awake. Your healthcare providers will not expect you to regain these functions if you are in a vegetative state. You will not be able to communicate, interact with others, or live as

you did before. A severe brain injury can sometimes lead to a persistent or permanent vegetative state.

What do I need to think about when I prepare my living will? Ask your healthcare provider for worksheets or forms to help you write your living will. These will help you to prepare your living will's written instructions for your end-of-life care. Think about the situations where you may want to limit your medical treatments. Treatment options include the following:

- All treatment to try to save your life.
- All treatments, but stop them if they are not working within a certain time.
- Only treatments that do not cause pain or discomfort.
- Only palliative (comfort) care. Comfort care provides medicine to take away pain, but not treatments to save or prolong your life.

What kinds of treatments can be covered in a living will? With a living will, you can make decisions to have or not have treatments to prolong your life. You are able to do this before you need them. You can choose to stop, limit, or not have certain medical treatments. Think about how you want to feel and how long you want to be able to live. For example, you may be willing to have some pain with a treatment if it allows you to live longer. You may want to refuse or stop treatments that prolong life, but cause you constant or severe pain. Some of your treatment choices include:

- **Types of treatments:** Determine the treatments you always want to receive, such as pain medicine. Determine the treatments you never want to have, such as long-term ventilator care or dialysis.
- **Short-term and long-term treatments:** You may want short-term treatments when there is a good chance that you will get better. For example, you may want a feeding tube for a short time while you recover from surgery. You may not want a permanent feeding tube if you have a severe and long-term brain injury. You may want to have a limit on the amount of time you want to have other life-sustaining treatments.
- **Invasive tests and treatments:** Invasive tests and treatments may be uncomfortable or painful. They can include lab tests, blood transfusions, antibiotic treatment, and surgery. These tests and treatments can prolong your life, even when recovery is no longer possible.
- **Tube feeding:** Healthcare providers may also refer to tube feeding as artificial nutrition and hydration. If you are unconscious or cannot swallow, tube feeding gives you the liquids and nutrients you need to stay alive. Healthcare providers put a tube into your stomach to do this.
- **Life support:** Life support treatments can take over when some of your organs no longer work. If you cannot breathe on your own, you may need a ventilator machine. If your kidneys stop working, you may need dialysis to remove wastes from your blood.

- **CPR and DNR:** Healthcare providers use CPR to try to restart your heart if it stops beating. Sometimes electric shock is used. Consider when and how long you want CPR if you have a terminal disease or are in a long-term coma. If you do not want CPR, you can add a DNR (do not resuscitate) order to your living will. A copy of the DNR order must also go in your medical records.

In what situations may I want to limit treatment? Think about the following situations. Then think about the treatment you would want if there is little chance you will get better:

- You cannot walk, but you can use a wheelchair.
- You have constant and severe nausea (upset stomach) or diarrhea.
- You cannot control when you urinate or have bowel movements.
- You need healthcare providers to feed, bathe, and help you with toileting.
- You must use a ventilator to breathe.
- You must use a feeding tube to eat.
- You need kidney dialysis to live.
- You cannot think or communicate well.
- You no longer know your family or friends.
- You are in constant or severe pain.

Do living will forms allow me to express my values, beliefs, and quality of life preferences? It is not possible with a living will to determine what your wishes may be for every end-of-life situation. Your living will should include important ones. Think about your answers to questions like these:

- What would you want done if you were in a long-term coma or persistent vegetative state?
- What are your fears about the end of your life? Is it important to have pain relief? Or do you want to remain aware and alert, even if you are in pain?
- What do you want others to know about your religion or beliefs? Are there certain practices in your religion, such as prayers or blessings, that you want followed before you die?
- What kinds of support do you want at the end of your life? Who do you want with you? Would you like to be at home or in hospice care?

Where can I get a living will form? Your hospital and healthcare providers should have the forms or worksheets that are used for your state. Each state has rules for living wills and other advanced directives. Most states allow advanced directives prepared in one state to

be used in another state. You may still want to create living wills for more than one state if you travel often or spend time in another state.

How do I prepare a living will?

- **Talk with your family and healthcare providers about your wishes.** They will have questions for you. These questions may help you better prepare your living will. Your healthcare provider may not agree with your wishes. If this happens, you will need to find another healthcare provider to help you.
- **Review your medical treatment options.** Ask your healthcare providers to explain anything you do not understand.
- **Write down any other end-of-life instructions you want followed.** This includes burial or cremation, and whether you want to be at home or in a hospice when you die.

What are the legal requirements for signatures on a living will? Sign your living will according to your state's rules. Many states require at least 1 witness to watch you sign the form. The witness must be someone who is not your relative, healthcare provider, or legal agent. Some states will not accept your living will as valid without the right witnesses. Check with your lawyer if you are not sure about the state laws for living wills.

How do I make sure that my wishes are known?

- **Tell healthcare providers and family or friends that you have a living will.** When you finish writing your living will, talk with your family and healthcare providers about it. This will help everyone understand your wishes. Keep a card in your wallet or purse that says you have a living will.
- **Keep the original and make copies of your living will.** Keep your living will original document in a safe place that is easy to find. **Do not** put your living will in a hidden or locked place in your home, or in your safe deposit box at the bank. Give your healthcare providers and family members copies of your living will. **Make sure healthcare providers put a current copy in your medical records where you get care, such as the hospital.**
- **Consider other places to keep copies of your living will.** Some states have registries that keep copies of your living will and other advance directives for you. Some services allow healthcare providers to access your living will by computer. Your church or house of worship may also be able to store a copy of your living will for you.

When should I review my living will? You can always change or cancel your living will. To do so, fill out new living will forms according to your state's rules. After you make changes, give copies of the new living will to your family and healthcare providers. Review your living will whenever one of the following occurs:

- **Decade:** You start each new decade (10 years) of your life.
- **Death:** Someone close to you dies.

- **Divorce:** You get divorced or there are changes to your family or personal relationships.
- **Diagnosis:** Healthcare providers diagnose (find) a serious disease or health problem.
- **Decline:** Your health worsens, and you find it harder to care for yourself.

Where can I get more information about living wills? This information is not legal advice. For more information, contact:

- Caring Connections
National Hospice and Palliative Care Organization
1731 King Street, Suite 100
Alexandria , VA 22314
Phone: 1- 800 - 658-8898
Web Address: <http://www.caringinfo.org>

CARE AGREEMENT:

You have the right to help plan your care. To help with this plan, you must learn about living wills and how they are used. You can then discuss treatment options with your healthcare providers. Work with them to decide what care will be used to treat you. You always have the right to refuse treatment.

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