

# Do You Have an Advance Directive?

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**SCLERODERMA FOUNDATION NATIONAL  
CONFERENCE**

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## About me...

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- 18 years as director of Oregon Hospice Association
- MBA in not-for-profit management
- Published in NEJM and other journals re end of life care, including assisted suicide and stopping eating and drinking
- Speaker re end of life care choices
- Member of Oregon and national task forces
- Hospice caregiver in 1996
- Diagnosed with MS in 1990
- Diagnosed with scleroderma in 2001

## About Oregon Hospice Association

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- Charitable, public benefit organization incorporated under 501(c)(3) in 1977
  - Dedicated to ensuring that all Oregonians—and all Americans—can have high quality hospice and comfort care when facing the end of life
  - Has played significant role in making Oregon the nation's best place to die!
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## Objectives

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- Discuss *Five Wishes*, an advance directive valid in most states
  - Watch a video at *The New York Times* website
  - Introduce *Five Wishes*
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## *Five Wishes*

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The popular, easy-to-use document that helps you to plan for and receive the care you want and deserve

## About Aging With Dignity

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- National, non-profit organization founded in 1996
- Helps people to plan for and receive the care they want in case of serious illness
- Has grown to serve nearly four million Americans by creating and distributing *Five Wishes*

## This presentation will cover:

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- Practical steps to make your wishes known and honored
  - How to be there for your loved ones when needed the most
  - Follow-up steps for communicating your wishes to others
  - Answers to common questions
  - Additional resources and support
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## What people want...

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- When facing end-of-life decisions, most of us would want the following wishes honored:
    - To die at home
    - To be free from pain
    - To be in the company of loved ones
    - To retain control of the care we receive
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## and the contrast of reality

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- ❑ Less than 25% of Americans die at home, although more than 70% say that is their wish
  - ❑ (Harvard Public Opinion Poll, 1999)
- ❑ Dying is often unnecessarily painful and isolating
  - ❑ (SUPPORT Study, JAMA, 1995)
- ❑ Only 15 to 20% of the population has completed an advance directive
  - ❑ (Archives of Internal Medicine study, July 2002)

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## Reasons for this stark reality

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- ❑ The end of life is often treated ONLY as a medical moment
- ❑ People lack the care they want—almost everyone has a “horror study” of a loved one dying in pain or isolation that could have been avoided
- ❑ Feelings of helplessness and fear lead to the appeal of assisted suicide as a “solution”

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## Five Wishes as a solution...

- ❑ Meets legal requirements in 38 states and DC, but helpful for all 50
- ❑ Simple format, not written in “legalese” or medical jargon
- ❑ Distributed by Aging With Dignity and 1,000 organizations to more than 6 million Americans
- ❑ First living will to address personal, emotional and spiritual needs, along with medical wishes
- ❑ Created with help of American Bar Association and health care experts

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## A tool to promote human dignity

- ❑ People don’t want to be an object on a medical care “conveyor belt”
- ❑ Sometimes medicine doesn’t know when to stop
- ❑ *Five Wishes* helps you to communicate what you want—or don’t want
- ❑ It guides discussions with your loved ones and physician

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## Why fill out *Five Wishes*?

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- End bed-side guessing game and guilt
- Create a discussion tool for your family and physician
- Get the care you want and deserve—even if you can no longer make your own decisions

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## The media's response...

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- Five Wishes* has been featured on the NBC Today Show, CNN and NPR, and in *USA Today*, *The Wall Street Journal* and many other publications

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## And what people are saying

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- “We found an article on Five Wishes at a doctor’s office, after my husband had been diagnosed with cancer. We ordered it and we filled it out together. It was great peace of mind... It certainly took a lot of responsibility off me and his family was fully aware of the choices he made”.

■ Mary H. of Arizona

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## Who should use *Five Wishes*?

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- Anyone age 18 or older, whether single or married, a parent or an adult child, in good or poor health
- Also distributed by doctors, nurses, lawyers, hospitals and hospices, faith communities and a variety of employers and retiree groups

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## *Five Wishes* is valid 38 states and DC

Alaska	Iowa	New York
Arizona	Louisiana	North Carolina
Arkansas	Maine	North Dakota
California	Maryland	Oklahoma
Colorado	Massachusetts	Pennsylvania
Connecticut	Michigan	Rhode Island
Delaware	Minnesota	South Carolina
District of Columbia	Mississippi	South Dakota
Florida	Missouri	Tennessee
Georgia	Montana	Virginia
Hawaii	Nebraska	Washington
Idaho	New Jersey	West Virginia
Illinois	New Mexico	Wyoming

## What if I live in another state?

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- In 14 states, *Five Wishes* does not meet technical requirements
  - But it may be respected anyway
  - Law before Congress now
- Laws in some states may require mandatory and complicated forms
- Residents may still find it helpful to complete *Five Wishes* as an attachment

## What does *Five Wishes* cover?

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- 1. Which person you want to make health care decisions for you when you can't make them yourself
  - 2. The kind of medical treatment you want or don't want
  - 3. How comfortable you want to be
  - 4. How you want people to treat you
  - 5. What you want your loved ones to know
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### Wish 1. Which person you want to make health care decisions for you when you can't make them yourself

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- Known in legal terms as "durable power of attorney for health care"
  - Allows you to name a person to act on your behalf—temporarily or permanently
  - Offers suggestions for choosing the right person and naming "alternates" (back-up) choices
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## Wish 2. The kind of medical treatment you want or don't want

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- Part commonly known as "living will"
- Expresses general instructions for your caregiver, such as the need to take medicine for pain, even if it leaves you sleepy
- Includes examples of "life support" such as tube feeding or CPR
- Gives you space to write instructions based on personal beliefs

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## Special note

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- Medical staff may look for a "Do Not Resuscitate" form or bracelet during emergency situations
  - The form shows that you don't want life support treatment when you are dying
  - Many states require the form to be filled out and signed by a doctor
  - Check with your doctor for more information
  - Go to [polst.org](http://polst.org) to learn more about "physician orders for life sustaining treatment", a new national initiative

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### Wish 3. How comfortable you want to be

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- Stresses that you want your pain managed
- Expresses your choices for types of care, such as having a cool, moist cloth placed on your forehead if you have a fever, having your favorite music played, etc.
- You cross out items based on your preferences

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### Wish 4. How you want people to treat you

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- What others should keep in mind if you become seriously ill
- Whether you want to have people around or your hand held when possible
- Whether you want prayers said
- Ideas for your surroundings, such as having pictures of loved ones handy

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## Wish 5. What you want your loved ones to know

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- A truly unique part of *Five Wishes*
  - Encourages you to express matters of deep importance in an age where families often live apart
  - Allows you to offer love and forgiveness to those who have hurt you
  - Communicates practical matters such as preferences for memorial or burial
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## Signing *Five Wishes*

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- Print your name
  - Read the statement carefully
  - Ask two witnesses to be present (see witness statement)
  - Sign your *Five Wishes* in front of witnesses
  - Witnesses don't have to read your wishes
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## After you complete *Five Wishes*

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- Make copies of your completed *Five Wishes* for your family, friends, health care agent and doctor
- Discuss your wishes
- Keep it available (in your top drawer, not your safe deposit box)
- Carry a wallet card

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## Conversation starters to share *Five Wishes* with others:

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- "A TV show featured a woman on life support, and how her family argued about her health care. I thought about you being in that situation and realized that I don't know what you would want."
- "I know you are healthy now, but in case you get sick I need to know a few things. Here is a document called *Five Wishes* that I would like to leave with you now, and talk about later once you have read it over."

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## Frequently asked questions

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- When do I need to use *Five Wishes*?
- When does *Five Wishes* take effect?
- How do I use *Five Wishes*?
- What if I change my mind?
- What if I still have questions?

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## When do I need to use *Five Wishes*?

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- The best time to fill out *Five Wishes* is before you face a health crisis. The best place to fill it out is home. You never know when you will need *Five Wishes*, and many people wait until too late. If you are 18 or older, you should complete *Five Wishes* now. If you are married, both you and your spouse need to fill out your own *Five Wishes* documents.

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## When does *Five Wishes* take effect?

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- You will always make your own health care decisions if you can talk with your doctor and understand what is being said. *Five Wishes* only takes effect when you are too ill to communicate. Your *Five Wishes*—and the person you chose as your health care agent—can help direct your care with your doctor if you become unable to make your own decisions.

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## How do I use *Five Wishes*?

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- Carefully review and fill out the document
- Follow the directions for signing it
- Discuss it with your health care agent and doctor and give each of them a copy
- Make sure a copy of your *Five Wishes* is placed in your medical file by your doctor
- Discuss *Five Wishes* with your family and friends and give them a copy

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## What if I change my mind?

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- You may change your wishes at any time, but you should review and update your *Five Wishes* at least once a year
- Review *Five Wishes* more often if your health changes
- Make sure you inform your health care agent, family, friends and doctor of any changes
- Destroy all out-of-date copies of the document and distribute copies of your new *Five Wishes*

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## What if I still have questions?

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- You may need to talk with a medical or legal expert for advice
- For more information about *Five Wishes*, visit Aging With Dignity's website at [www.agingwithdignity.org](http://www.agingwithdignity.org) or call toll free at 1(888)5WISHES (1-888-594-7437)
- Email Aging With Dignity at [fivewishes@agingwithdignity.org](mailto:fivewishes@agingwithdignity.org)

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## Additional *Five Wishes* resources and support

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- ❑ *Five Wishes* 25-minute video designed to help present to groups or families
- ❑ *Next Steps* guide, a companion booklet, with conversation starters, commonly asked questions and answers, etc.

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## Other resources for advance directives and information about the end of life and hospice

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- ❑ Oregon Hospice Association
  - [www.oregonhospice.org](http://www.oregonhospice.org)
  - [jackson@oregonhospice.org](mailto:jackson@oregonhospice.org)
- ❑ Physician Orders for Life Sustaining Treatment
  - [www.polst.org](http://www.polst.org)
- ❑ Advanced directives for every state
  - [www.caringinfo.org](http://www.caringinfo.org)
- ❑ Medicare Hospice Benefit
  - [www.medicare.gov](http://www.medicare.gov)

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## *The New York Times*

Published: June 17, 2005

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**Many Still Seek One Final Say on Ending Life**

■ By John Schwartz and James Estrin

**Preparing for the End of Life**

■ By James Estrin

Sister Carol Thayer

Marilyn Saviola

Helen Obler

Dr. Strahid Athar

Joseph Westmoreland

Judy Schwartz

Rev. Paul Smith