

# **SHARING THE GIFT:** A GUIDE TO PRESENTING FIVE WISHES

# THE GIFT OF FIVE WISHES

#### Five Wishes My Wish for:

- The person I want to make care decisions for me when I can't
- 2. The kind of medical treatment I want or don't want
- 3. How comfortable I want to be
- 4. How I want people to treat me
- 5. What I want my loved ones to know

# YOU CAN MAKE A DIFFERENCE FOR YOUR FAMILY AND COMMUNITY

It brings tremendous peace of mind to know that your health care wishes will be respected in the event you can't speak for yourself. Not expressing your wishes could lead to family disagreements. So why have only one in five Americans completed an advance directive or living will?

Many say it's because the subject of illness and dying is a difficult one most people would just rather avoid. Others say it's because many advance care planning documents are written in often confusing medical and legal language and don't cover what's really important to people.

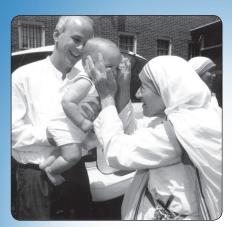
*Five Wishes* is America's most popular living will because it's written in everyday language and helps people express their wishes in areas that matter most—the personal and spiritual in addition to the medical and legal. It's also a blueprint for describing what good care means to you, whether you are seriously ill or not. It helps your caregiver know exactly what you want.

Completing *Five Wishes* is a gift to your family, friends and your doctor because it keeps them out of the difficult position of having to guess what kind of treatment you want or don't want in case you can't speak for yourself. In *Five Wishes*, you clearly state it.

# WHO USES FIVE WISHES?

- **Families** use *Five Wishes* because it helps start important conversations that enable adult children to honor their parents' requests. When health care wishes are clearly stated in writing, there is no second-guessing of what is or isn't wanted. Guilty feelings and family disagreements can be avoided.
- **Faith communities** of all traditions use *Five Wishes* because it assists health care providers in respecting your religious beliefs in case you become seriously ill. It also emphasizes the important role of faith communities during times of serious illness, thus affirming the God-given human dignity of all.
- **Medical providers and facilities** use *Five Wishes* because it sends a powerful message about the importance of patient-centered care.
- **Hospice** organizations use *Five Wishes* because it allows those nearing the end of their lives to clearly state how they want to be treated, how their pain is to be managed and what their family members and others are to know.
- **Companies** of all sizes use *Five Wishes* as an affordable employee benefit that helps reduce employee absence and turnover due to family caregiving obligations.

# THE FIVE WISHES STORY



#### THE BEGINNING OF A NATIONAL MOVEMENT

The inspiration for Five Wishes came when Aging with Dignity founder Jim Towey visited Mother Teresa's home for the dying in Calcutta, India. In those humble surroundings he saw how people were treated with compassion and love. Later,

living for a year as a volunteer in her home for AIDS patients in Washington, D.C., Towey saw how every person's dignity was respected and their emotional needs met.

In 1997, Five Wishes was introduced in Florida with the help of a grant from the Robert Wood Johnson Foundation. It was immediately popular because it filled a real need for people to express things important to them, and it was also legally valid. First came requests from individuals, then from groups as diverse as health care providers, hospice organizations and law firms.

A year later and with the help of the American Bar Association's Commission on Law and Aging, Five Wishes was introduced to the nation, along with Cinco Deseos, the Spanish version of Five

Wishes. In 2007, a grant from the United Health Foundation made possible the translation of Five Wishes into additional languages. Today, more than 14 million copies of Five Wishes are in circulation, distributed by more than 23,000 organizations. It is now available in 26 languages.



54A A.J.C. Bose Rd., Calcutta 700 016 7 August 1996 "As long as you did it to one of these My least brethren. You did it to Me"

Dear People of Florida,

There are among us so many who are poor and elderly, in need of our understanding, respect, love and compassion, especially if they are sick, handicapped, helpless or alone. Whatever we do to them, we do to Jesus for He has said, "Whatever you do to the least of My brothers, you do it to Me."

Jim Towey has founded the Florida Commission on Aging with Dignity to defend and protect life, the most beautiful gift of God and to bring God's love and compassion to the elderly poor. Jim has been a friend to me and the Missionaries of Charity for eleven years, helping us in legal matters, doing everything in a spirit of humble service.

My prayer is that God may bless Jim and his beautiful work of being a channel of God's love to His little ones.

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#### Thank you for making it happen

Dear friend:

We have always relied on people like you to conduct Five Wishes presentations in communities across America. In doing so, you become a vital part of a grassroots movement aimed at empowering health care consumers and improving care for those who are seriously ill or near death.

The intention of this presenter's guide is to give you the basic information you'll need to effectively encourage others to discuss and then put in writing their health care preferences. Use the information in this guide to customize your presentation so that it best suits your audience.

Over the years we've received cards, letters and messages from all over the country from people who told us how completing *Five Wishes* helped make a very difficult family time more meaningful. We've also heard from people who chose Five Wishes because they vowed never again to be in a position of guessing what kind of care a spouse or loved one would have wanted or not wanted.

We're proud that Five Wishes has helped start millions of conversations in living rooms across the nation. Thank you for sharing this gift with your loved ones and others in your community.

Sincerely,

Paul Malley President, Aging with Dignity

# **SETTING THE STAGE**

#### HOW YOU PROMOTE YOUR FIVE WISHES PRESENTATION CAN DETERMINE ITS SUCCESS

#### Preparing

A great way to prepare for a *Five Wishes* presentation is to fill out your own *Five Wishes*, then talk about it with your family. Doing this gives you insight into what you'll be asking others to do. Read the *Next Steps* guide and watch the *Five Wishes* instructional DVD.

#### Planning the date, time and place

Consider the needs of your intended audience when selecting a date, time and location for your presentation. For example, a presentation at night is less likely to attract older attendees. A lunchtime presentation during the week is convenient for business and civic groups. Sunday afternoon could be an attractive time for faith groups. Try not to schedule your presentation during a holiday or opposite a major event, such as a home football game.

#### Invitation

Most people are not likely to turn out for a discussion on death and dying, so how you frame the noticing and advertising of your presentation is key to its success. We've found that it helps to avoid words like death, dying, getting old, end-of-life care, life support, etc.

Positive messages are more likely to attract an audience. The focus should be on "preserving dignity," "providing peace of mind to you and your family," "maintaining control," etc. Some presentation titles that have worked in the past include:

"Getting the Care You Want When You Need it the Most"
"Maintaining Your Human Dignity and Getting Your Needs Met"
"Mother Teresa's Way of Aging with Dignity"
"Being There for Those You Care About When They Really Need You"
"Being a Good Son or Daughter When Mom or Dad is Seriously Ill"
"Having a Winning Endgame Strategy"
(appropriate for business/corporate presentations)

#### **Telling the media**

Local news media first need to know the who, what, when and where of your presentation. Many can be alerted by e-mail or via the "news tips" or "community calendar" section of websites. Be sure to give them your contact information: name, telephone number(s) and e-mail address in case they need additional information.

#### **Staging the event**

Set up the room so there is minimal distance between presenter and audience. Dress professionally and, if possible, greet attendees individually as they arrive. Be sure any sound amplification and/or visuals you intend to use are properly configured and ready to go.

The best time for people to be given the *Five Wishes* document is after you've completed your introduction and overview and are ready to walk through each of the wishes. Do what feels most comfortable to you.

# PRESENTATION OPTIONS

# FIVE WISHES PRESENTATIONS CAN BE MADE WITH OR WITHOUT THE FIVE WISHES INSTRUCTIONAL DVD.

#### FIVE WISHES DVD

#### **Table of Contents**

Use the DVD menu to choose the portions you wish to use, if any. Choosing "Play All" runs both the *Five Wishes* program and the Question and Answer program.

#### "Play All"

FIVE WISHES

#### "Five Wishes Program" (16:44)

- » Introduction | 4:55
- » Wish 1 | 1:25
- » Wish 2 | 3:40
- » Wish 3 | 1:05
- » Wish 4 | 1:16
- » Wish 5 | 1:23
- » Signing | :48
- » After You've Completed *Five Wishes* [2:19

"Question and Answer Program" (11:10)



#### Choose an option that best works for you

#### **OPTION 1: All You**

- » Greet audience, introduce/distribute *Five Wishes* document
- » Give oral presentation, detailing Wishes 1 and 2
- » Open floor for questions, discussion
- » Continue oral presentation, detailing Wishes 3, 4 and 5
- » Open floor for questions, discussion

#### **OPTION 2: Some You, Some DVD**

- » Greet audience, introduce/distribute *Five Wishes* document
- » Show the Five Wishes Program (16:44)
- » Open floor for questions, discussion

#### **OPTION 3: All DVD**

- » Greet audience, introduce/distribute *Five Wishes* document
- » Select "Play All" from DVD menu (27:54)

#### **OPTION 4: More You, Some DVD**

- » Greet audience, introduce/distribute *Five Wishes* document
- » Raise topic of advance care planning and history of *Five Wishes*
- » Que DVD to begin with Wishes 1 through 5
- » Open floor for questions, discussion

#### **OPTION 5: DVD Intro, Then All You**

- » Greet audience
- » Play the Introduction portion only
- » Give oral presentation covering Wishes 1 through 5 and follow up
- » Open floor to questions, discussion

# CONDUCTING THE PRESENTATION

Effective *Five Wishes* presentations begin with a discussion of the concepts of a "health care agent" and "living will," which are covered in Wishes 1 and 2, respectively. Wishes 3, 4 and 5 deal with issues of comfort, dignity and reconciliation.

#### WISH 1

# The person I want to make health care decisions for me when I can't make them for myself

- Also known as a "health care agent" or "durable power of attorney for health care"
- Allows you to name a person to make health care decisions for you if you're unable to speak for yourself. You can also name two alternates
- Be sure to read the section under "Picking the Right Person to be Your Health Care Agent." Choose the person who will honor your wishes and stand up for you. That person may or may not be a relative
- Health care agent can interpret the instructions you give in *Five Wishes* and make decisions based on his/her understanding of your wishes and values
- Legal requirements: At least 18 years old; not a health care provider or the spouse or employee of a health care provider; a person who can pay adequate attention to your needs
- Cross out anything you don't want your health care agent to do

#### Question&Answer

- Q: May a husband and wife fill out Five Wishes together and, say, authorize their children to make their health care decisions?
- A: No, each person should have his or her own *Five Wishes*. You should designate only one person and two alternates to speak on your behalf when you cannot. You can add specific instructions, such as asking your healh care agent to consult with your family, with a goal of reaching consensus. Use blank lines after Wish 1.
- Q: What if I change my mind?
- A: If you want to change or give better instructions to your health care agent, or if you want your family members to know more or different things, you can do so by filling out a new *Five Wishes*. Revoke your previous form by writing REVOKE on it, destroy the old copies and tell your health care agent and others that you have a new *Five Wishes* document.



#### WISH 2

#### My wish for the kind of medical treatment I want or don't want

- This part is commonly known as a "living will"
- Allows each person to define what life support treatment means to him or her. A standard definition from medical and legal experts is provided on page 6. People may customize this definition by writing on the blank lines. It is very important that each person pays special attention to this section so that it reflects their personal beliefs
- Expresses general instructions for your health care providers and caregivers, such as providing medicine for pain
- Five Wishes is not a Do-Not-Resuscitate order. A DNR is a medical order signed by your doctor. See "In Case of Emergency"
- Clarifies your wishes in several scenarios (terminal condition, coma, severe brain damage, etc.). Choose one of the options in each scenario
- Gives you space to write additional instructions based on your personal beliefs

#### Question&Answer

- Q: What if I already have a living will? Can I change to Five Wishes?
- A: Follow the instructions in the booklet under "How Do I Change to *Five Wishes*?" Fill out your *Five Wishes* and follow the signing and witnessing requirements. Then make sure your health care agent and others know you've filled out *Five Wishes* and give them a copy of your newly completed form.
- Q: Why are there three choices given in the Wish 2 scenarios?
- A: These cover all the foreseen scenarios and allows you to choose the one that best reflects your beliefs and wishes. The third choice adds emphasis to your doctor's opinion.

#### How to be a good health care agent

Know your loved one's wishes ahead of time. Ask detailed questions and be sure you understand what he or she would want. If you feel you cannot follow their wishes to act on their behalf, ask that someone else be chosen.

Be sure the doctors and nurses know you are the health care agent and know how to contact you. Be sure they have copies of the signed *Five Wishes* document.

Ask questions of the doctors and nurses and politely follow up to be certain they are following your instructions. Be courteous but firm.

If you encounter problems, ask to speak with the social worker, patient representative or chaplain. If the doctor doesn't want to follow your loved one's wishes, contact the ethics committee of the hospital, nursing home or hospice.

# CONDUCTING THE PRESENTATION

Wishes 3, 4 and 5 are what make *Five Wishes* different from all other living wills. When people are asked what would be most important to them if they get very sick, the most common answers are: I want to be home; I don't



want to be in pain; I want my family to know that I love them; I want to tend to religious and spiritual matters. It only makes sense that those issues are included in the discussion.

Wishes 3, 4 and 5 include some of the most common requests. Cross out anything you don't want and use the blank lines to clarify or add wishes.

#### WISH 3

#### My wish for how comfortable I want to be

- Stresses that you want your pain managed properly
- You can express 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.
- Asks that you be given information about hospice and comfort care
- Cross out anything that you don't agree with and/or add other wishes on additional sheets

#### Question & Answer

- Q: Won't my pain be adequately managed?
- A: Great progress has been made in pain management, but too often there can be more attention paid to your treatment than your comfort. Some people will want to be alert for as long as possible and some will want to be as pain-free as possible even if it means being more heavily medicated. Be very clear about this with your doctor, health care agent and family.
- Q: When might I request hospice care?
- A: Anyone with a diagnosis of from six months to a year to live is appropriate for hospice, when the goals of care are comfort and no longer cure. The earlier a patient is admitted the better the hospice is able to provide the full scope of services and help the family. Wish 3 encourages this doctor-patient conversation.

#### WISH 4

#### My wish for how I want people to treat me

- 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 nearby
- Cross out anything that you don't agree with and/or add other wishes on additional sheets

#### Question&Answer

- Q: Are my health care providers required to follow all my personal care preferences?
- A: See the prelude statement in Wish 3. It's important that you discuss the topic and speak up in advance so that your wishes are respected and honored.
- Q: Why do you go into such personal detail with these care preferences?
- A: Yes, they're very specific. It's that detailed because it's important that people don't have to guess what will make you comfortable.

#### WISH 5

#### My wish for what I want my loved ones to know

- A truly unique part of *Five Wishes* that deals with "closure" matters
- 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 may have hurt you
- Communicates practical matters such as preferences for memorial or burial
- Many people get very creative in Wish 5
- Cross out anything that you don't agree with and/or add other wishes on additional sheets

#### Question&Answer

- Q: May I arrange for organ donation using Five Wishes?
- A: See the very last part of Wish 5. You may express your wish to do so, but you may need to take further action.
- Q: Will my burial and memorial service wishes be respected?
- A: *Five Wishes* allows you to express your preferences, but you may wish to take additional steps, such as talking with an attorney, to make certain they are.

#### Completing Five Wishes

#### Signing, witnessing

- Carefully complete the "Signing the *Five Wishes* Form" section
- 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

#### **Following up**

- Make copies of your completed *Five Wishes* for your family, friends, health care agent and doctor. Keep the original
- Discuss your wishes with them
- Keep your completed *Five Wishes* readily available (not in your safe deposit box)
- Carry your completed (and laminated) wallet card

#### Question&Answer

- Q: May I make photocopies of Five Wishes?
- A: Yes, if you're making copies of your completed document. No, if you want to make copies of the blank *Five Wishes*.



### *Facts about* Five Wishes

FIVE /ISHES

- Five Wishes meets the legal requirements in 42 states. It is used in all 50 states by attaching the completed Five Wishes document to the state forms that are required in the other eight states.
- Companies as diverse as 3M, MTV and the U.S. State Department have offered *Five Wishes* as an employee benefit.
- Five Wishes has been featured on the "Today Show," NBC, CBS and ABC-TV evening news programs, on NPR and in *Time* magazine, the *Wall Street* Journal, New York Times, Washington Post and USA Today.
- Five Wishes and Five Wishes resources have received recognition from the National Health Information Awards; the Alliance of Work Life Professionals; the National Mature Media Awards; and the National Healthcare Consumer Advocacy Award presented by the Society for Healthcare Consumer Advocacy.

# GETTING OTHER CONVERSATIONS STARTED

# DON'T JUST FILE YOUR COMPLETED FIVE WISHES AND FORGET ABOUT IT

Emphasize to your audience that once you've completed *Five Wishes* and it's been signed and properly witnessed, the job has only begun. It's important to continue the discussion with others.

#### With Your Spouse and Family

Once you've completed *Five Wishes*, simply telling others that you have done so and that you're glad you did can encourage them to try. Anything from the death of someone you know or, perhaps, a movie you saw can be good opportunities to raise the issue of planning in advance of a serious illness. Assure loved ones you want to "be there for them." In fact, *Five Wishes* itself is a great discussion tool; many people start with Wish 5 and work backwards!



#### With the Doctor

This is a very important conversation and you should strongly encourage those in your audience to have it. Give your doctor a copy of your Five Wishes and go over Wishes 1 and 2 very carefully. Also be clear about how you want to deal with pain (Wish 3) and how much you want to know about your illness (and chance of recovery) if the time comes that you are very sick. Do you want others to know? Ask your doctor to put your Five Wishes in your medical record and to write notes about your conversation in your record.

#### With Each Other

Emphasize "planning for the future," not sickness and dying, in starting discussions with others. Talk about raising the issue in a non-threatening way and of being persistent until the time is right.

# **OTHER RESOURCES**



*Five Wishes* (Spanish language *Cinco Deseos*) is available via the Aging with Dignity website, *www. agingwithdignity.org.* Quantity discounts and custom versions are available. Many *Five Wishes* partner organizations provide free copies to members of the community.



#### Five Wishes at Work is

designed for workplaces that are offering *Five Wishes* as an employee benefit. Go to *www. agingwithdignity.org* for all the information needed to promote and distribute *Five Wishes* to employees and their families.



#### Five Wishes instructional DVD

The *Five Wishes* instructional DVD is ideal for groups that distribute *Five Wishes*, as well as families that are using the document. It is easy to follow and goes through completion of *Five Wishes* step by step. A second section answers frequently asked questions about *Five Wishes*.



#### Cinco Deseos instructional DVD

The Spanish language version of the same step-by-step guide.



Next Steps (Spanish language Siguientes Pasos), a guide on discussing and coping with serious illness, is a companion to Five Wishes. The guide includes information on completing Five Wishes, talking to family members about completing a living will, and discussing Five Wishes with your doctor. There is helpful advice on serving as a health care agent and being at the bedside of someone who is seriously ill.



#### Translations

Translated versions of *Five Wishes* are available in Albanian, Arabic, Bengali, Chinese Traditional, Chinese Simplified, Croatian, French, German, Gujarati, Haitian Creole, Hebrew, Hindi, Hmong, Ilocano, Italian, Japanese, Korean, Polish, Portuguese, Russian, Somali, Spanish, Tagalog, Urdu and Vietnamese. *Five Wishes* is also printed in Braille.





#### E-Newsletter

Subscribe to the free periodic "Five Minutes with *Five Wishes*" e-newsletter and keep current on *Five Wishes* activities across the nation. To sign up, go to *www.agingwithdignity.org*.

My Wishes (Spanish Language Mis Deseos) is a simple booklet that helps children express how they want to be cared for in case they become seriously ill. My Wishes is not a legal document; it is best used as a tool for discussion, for reassuring the child and to give him or her a measure of control during an often frightening time.



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