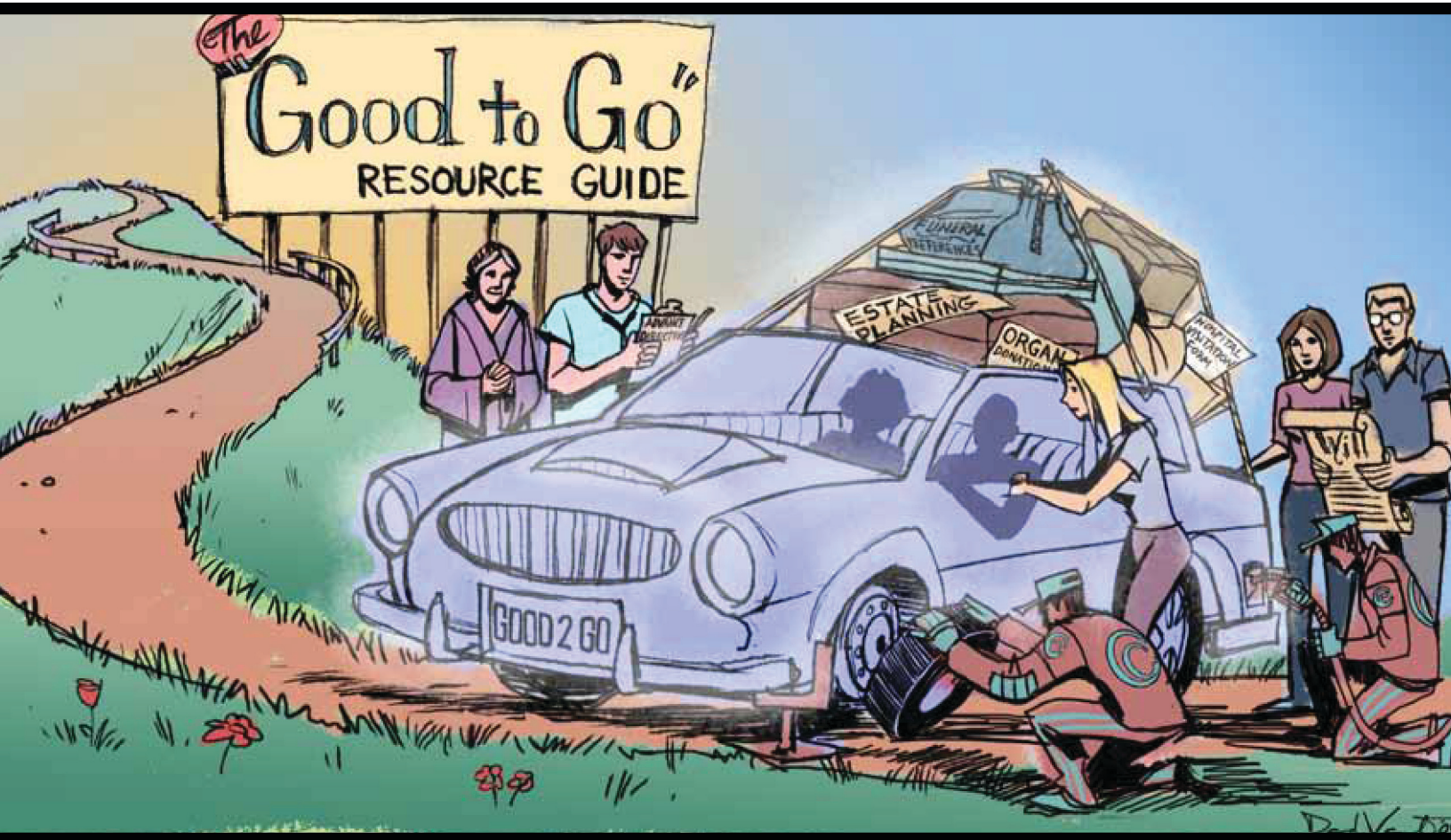


Compassion & Choices

MAGAZINE
Special Resource Issue



BASICS YOUR WISHES GLOSSARY CONVERSATIONS MYTH & FACT

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MAGAZINE
Special Resource Issue

2012 Reprint

The *Good To Go* Resource Guide

We feel everyone should have a copy of this special resource issue. Please use and share. - Compassion & Choices

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Letter from the Board

Dear Members, Supporters & Friends,

We know the personal is political. At Compassion & Choices we take on the educational, legal and legislative work to improve health care practice. We inform policy-makers, influence public opinion and empower individuals to secure comprehensive and compassionate options at the end of life.

We also know that the personal remains paramount. Ultimately each of us must explore our individual priorities and desires for the end of life. That work represents the equally important, personal aspect of our mission. Our professional end-of-life counselors and trained volunteers work with thousands of clients each year, explain options and offer non-judgmental support to help them make and communicate their decisions.

The process of considering options, making decisions and communicating with family and physician emerges as the most potent factor in a peaceful death. That is why we offer you this Good to Go Resource Guide. As you consider how your values and beliefs might influence your decisions for the future, this guide will help you identify your priorities and ensure your wishes are honored.

Perhaps you already understand the importance of completing an advance directive. Regardless of age or health status, none of us knows when a future event might leave us unable to speak for ourselves. If you become unable to make or communicate

health care decisions, talking with your loved ones, appointing a representative and preparing a written record of your wishes will be invaluable. End-of-life planning also yields secondary, less obvious benefits.

Conversations with your physician and those close to you can lead to important discoveries and closer connections. Discussing your choices can create deeper intimacy with the people who love you. Talking with your doctor should give you a feeling of authority over your own healthcare decisions. (If not, it may give you the feeling that it's time to look for a new doctor!)

Go ahead and have these necessary conversations. Put your documents in order. Then move forward knowing you are "*good to go*." Conscious of both life's sweetness and death's certainty, you can fully enjoy everything your life offers. Like a spare tire in the trunk, extra socks in your backpack or a safe copy of your passport, preparations for the worst free you to relish the best.

For some, the process can be daunting. We hope this resource guide will make it easier because we want your wishes to be honored. Take a look at some of the resources in the Good to Go Toolkit and contact us with any questions. We are here, with maps, tools and compass, to help you travel smoothly through what could otherwise be a legal and medical maze.

Barbara Coombs Lee,
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The Basics

Advance Directive

(Advance Directive for Health Care)

Advance Directive is a generic term for documents that typically include a written statement of preferences and durable power of attorney for health care. These documents allow you to provide instructions relating to your future health care, such as when you wish to receive treatment or when you wish to stop or refuse life-sustaining treatments.

The part often referred to as the living will is a place for you to specify what kinds of treatments and care you would or would not want if you were unable to speak for yourself. A living will is a good tool to use for writing down your wishes. The most important piece is the conversation you have with your loved ones.

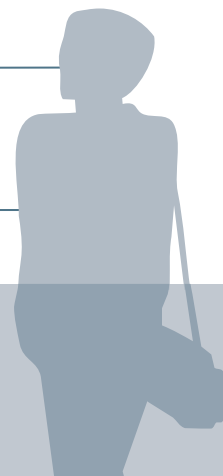
The other part, often called a durable power of attorney for health care, allows you to appoint someone to act on your behalf in matters concerning your health care when you are not able to decide for yourself due to illness or incapacitation.

This document covers health issues only; it does not include finances, estate or business concerns. The person you appoint might be called your health care agent, proxy or representative. This publication uses the term agent.

Advance directives are only useful when they are available during emergency healthcare situations.

Decisions

How to Make Your Health Care Decisions Known



What Are Your Wishes?

Beginning the process of creating an advance directive can seem daunting. What should go in it? How detailed should it be? There are so many scenarios to consider that it can be overwhelming. Rather than trying to think of everything that could happen, focus on specific situations. Begin by asking yourself some questions and write down your thoughts about each.

- Are there basic functions you believe you must have in order to feel that you would want to continue to live? Do you feel you must be able to recognize loved ones or to respond to others?
- Do your spiritual or religious beliefs affect your attitudes about a terminal illness, treatment decisions, or death and dying? Do you believe life-sustaining treatments should never be withheld or withdrawn? Or do you believe that when there is no hope of recovery, death should be allowed?
- Are there specific kinds of life-sustaining treatment you would want to have if you were diagnosed with a terminal condition? If you could not eat or drink, would you want a feeding tube?
- Are there specific life-sustaining treatments you would not want to have if you were diagnosed with a terminal condition?
- Is there a particular doctor you want to help your family make decisions about your care?
- Is there anyone you do not want involved in your health care decisions? (Example: specific family members, friends, or professionals.)

(Adapted from documents produced by Oregon State

Many states' advance directive forms mention at least two scenarios, permanent unconsciousness and terminal illness. They make it easy for you to state whether or not you would want continued life support under those circumstances. Some forms mention two or three more prototypical scenes. You can cross out and initial any of the scenarios you don't wish to include in your choice to accept or reject life support. You can also write anything you feel is important on these documents.

In addition to the choices on the forms, it's important to include your considerations in making your choice. In an increasing number of states, the law presumes you would want to be fed and hydrated artificially, unless you have a written instruction that specifically rejects this treatment and overrides the presumption. Also keep in mind that you will be fed as long you have the ability to chew and swallow, even if you have lost all cognitive abilities. If such a situation is a concern, you might want to refuse spoon feeding in your advance directive.

Your advance directive is very helpful to your physician, family, and your health care agent when they must make choices on your behalf. It is important to understand that these documents alone do not guarantee enforcement. The more you can do to prevent conflicting opinions about your wishes, the greater the likelihood those wishes will be followed. *(For more information on the decisions you can make see section Your Wishes on page 11.)*

Who Will You Appoint?

In your durable power of attorney for health care, you appoint a health care agent to carry out your wishes. This legal document gives the person you appoint the right to direct your health care if you are unable to make or communicate decisions. Your agent can be anyone you choose who is at least 18 years of age—your next of kin or another family member, or someone outside the family. To prevent conflicts of interest, avoid choosing your primary care physician or any other health care practitioner involved in your care. Many states will prohibit you from doing this, unless the practitioner is related to you by blood, marriage or adoption.

You will also want to name an alternative agent, and cover the same questions with that person. The alternative agent will step in if your first choice is unavailable or otherwise

POLST/MOLST

POLST/MOLST, Physician/Medical Orders for Life-Sustaining Treatment, programs are emerging as a recognized and accepted tool to consolidate the key components of the advance-care planning documents in a readily-identifiable form to better respect and implement the wishes of the individual. Like out-of-hospital DNR forms, the POLST/MOLST forms are usually only given to individuals who are terminally ill or extremely elderly and frail.

Why are there different names?

The documents are defined by state law and regulatory processes. Different states have chosen different names.

What's included?

The POLST/MOLST forms provide default orders that reflect the patient's wishes for use by emergency medical technicians, doctors and nurses. Ask your health care professional to use the forms to write orders that indicate what types of life-sustaining treatment you desire if you become seriously ill and those you don't want.

Is it the same as an Advance Directive?

The POLST/MOLST does NOT replace an advance directive; it is a supplement. POLST/MOLST forms are medical orders issued by medical personnel.

Is it like an Out-of-Hospital DNR?

The POLST/MOLST forms do state resuscitation options in addition to many other treatment choices, including antibiotic use and the artificial administering of fluids and nutrition. They essentially take the place of the out-of-hospital DNR (do not resuscitate) form.

Where can I get a copy?

From your physician. A MOLST/POLST is always completed with a health care professional who can give you information about the risks, benefits, and other implications of different types and levels of medical treatment.

Can my physician refuse?

Yes, if they do not agree with the POLST/MOLST options you have requested, they may choose not to participate.

To find out what states have POLST/MOLST forms, go to www.ohsu.edu/polst or ask your physician if they are available in your state.

Out-of-Hospital DNR

An out-of-hospital DNR (do not resuscitate) order is for people who do not want to be resuscitated or have CPR (cardiopulmonary resuscitation) if they have problems at home or anywhere outside of a medical facility. It is a document signed by a physician and usually only written for terminally ill or extremely elderly and frail individuals.

If a physician approves your request for an out-of-hospital DNR, then you will be informed about how to properly display the document and whether you may need to wear a bracelet or necklace indicating that you have such an order. Some states require a specific colored paper copy of your order to be posted on a refrigerator.

Please contact your physician if you would like to obtain an out-of-hospital DNR or have additional questions.

At a Glance

- An advance directive records your health care instructions. You describe what medical care and treatments you do or do not want to receive.
- A durable power of attorney for health care allows you to name a person to direct your health care when you cannot do so. Choose someone who will follow your instructions and insist that your end-of-life wishes be respected.
- Together these documents make up your advance directive. Some states combine them in one form. • It is not enough just to have an advance directive and durable power of attorney for health care. Discuss your choices with your doctor and your family.
- Your doctor should be willing to honor your advance directives or refer you to one who will.

**Living Will + Durable Power of Attorney
= Advance Directive**

your health care agent might make decisions while you are unconscious, but once you are conscious again, you will make your own decisions.

As you consider potential agents, ask yourself, “Are they assertive? Do they live nearby? Are they comfortable talking about death? Will they respect my values?” In any case, your family should know and understand how you have instructed your agent and whom you have appointed as your agent. Whatever you say, make sure to explain things in detail. *Many people complete advance directives too hastily, without considering all options and without describing fully their wishes for end-of-life treatment.*

During these conversations, tell your agent just what you think about “extreme measures” doctors might use to prolong your life. Do you want every treatment available, no matter how limited the benefit might be? Or would you rather forgo treatment once it becomes clear that death is inevitable?

There may be instances when a person has no one appropriate to serve as their agent. If this is your situation, please contact our End-of-Life Consultation Program at 800.247.7421. We may be able to suggest some resources to assist you. There are still effective means of expressing your wishes.

What Should You Do Next?

Experience tells us that advance directives, when easily accessible, carefully prepared and appropriately communicated, can go a long way toward making sure you get the type of care you want.

A frequent problem is disagreement among loved ones. If physicians hear of such disagreement, they could be justified in continuing life-sustaining treatment, to avoid a possible lawsuit or licensing complaint. Talking to family members about your wishes is the single most important step in this process. *(Sound difficult? On page 7 you’ll find some ideas on how to get started.)*

Unlike speaking to your family about your wishes, making your advance directive accessible is an easy thing to do. Give copies to your agent, your alternative agent, doctor, and anyone who would be contacted if you were found unconscious.

Glossary

Important terms for a more thorough understanding of the issues related to decision making.



Coma A coma is a profound or deep state of unconsciousness. The patient is alive, yet is not able to react or respond to the environment.

CPR Abbreviation for cardiopulmonary resuscitation, an emergency procedure often employed after cardiac or respiratory arrest, in which cardiac massage, artificial respiration, and drugs are used to maintain the circulation of oxygenated blood to the brain.

DNR Abbreviation for a Do-Not-Resuscitate order. A DNR is a specific physician order that alerts medical staff of your desire not to be resuscitated in the event that your heart stops beating (cardiac arrest) or you stop breathing (respiratory arrest).

Living Will A document where you specify what kinds of treatments and care you would or would not want if you were unable to speak for yourself.

Palliative Care Also referred to as comfort care or hospice care. An active, compassionate approach to the care of the dying that emphasizes pain relief and comfort rather than curing illness or prolonging life. The goal is to achieve the best quality of life possible by relieving suffering and controlling pain and symptoms.

Persistent Vegetative State Refers to a condition in which an individual has lost all cognitive function and awareness of the environment, but retains non-cognitive function, including some sleep-wake cycles. A patient in this condition is still able to breathe and may exhibit various spontaneous movements.

POLST or MOLST Abbreviation for a Physician (or Medical) Order for Life-Sustaining Treatment. The POLST/MOLST form is a brightly colored, one-page form your physician can use to turn your wishes into specific written medical orders. Your physician may use the POLST/MOLST to write orders that reflect the types of life-sustaining treatment, such as CPR or tube-feeding, or focus on comfort that you do or do not want and that are appropriate for your medical situation.

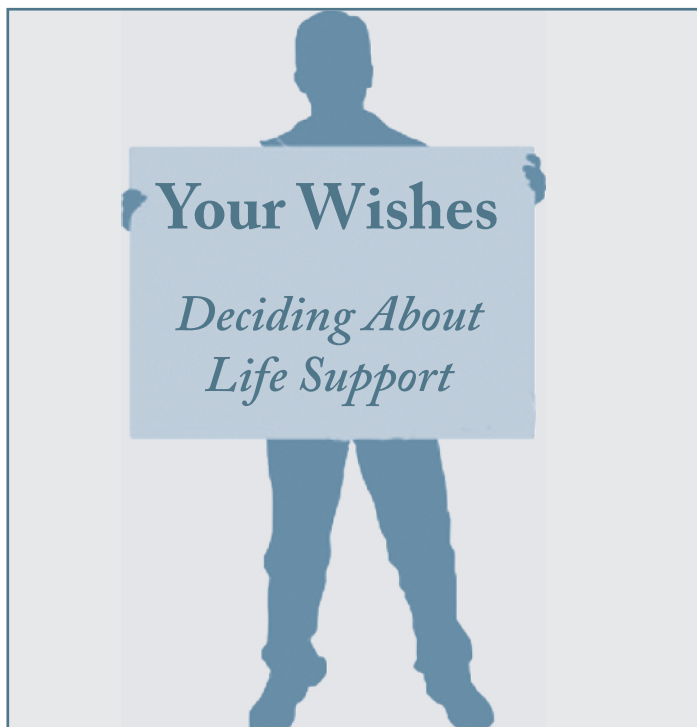
It is not an advance directive but rather a means to translate an advance directive into physician orders to be followed by all medical personnel. Currently, only about one-third of all states have POLST/MOLST forms available. Make sure to check with your physician, as more states are introducing them.

Total Sedation Also referred to as palliative or terminal sedation. The continuous administration of medication to relieve severe, intractable symptoms that cannot be controlled while keeping the patient conscious. This treatment renders the patient unconscious and relieves suffering by inducing an artificial coma. The unconscious state is maintained until death occurs.

Ventilator A ventilator is a mechanical device that supplies air to the lungs when natural breathing is impaired.

Voluntary Stopping of Eating or Drinking This means voluntarily refusing food and liquids, with the understanding that this will result in death. If food and fluids are taken through a stomach tube, the decision would be to stop this treatment. Contrary to popular belief, the patient does not starve to death. Rather, death usually results from dehydration. It is important to note that hunger and thirst diminish and the desire for food becomes practically non-existent as death nears.

Withholding, Refusal or Withdrawal of Treatment An ethically and legally accepted practice that may be specified in advance directives. You always have the right, as a mentally competent adult, to refuse or discontinue any treatment or procedure such as ventilator support, kidney dialysis, cardiac pacemaker or other intervention.



There is no question that western medicine has made amazing advances in recent decades, but for people whose illness cannot be cured, this medical progress presents a modern dilemma. Only you can decide how much treatment is enough, where the line is between therapeutic and futile treatment, and the most difficult decision for many—how long your life should be prolonged after it has ceased to be “life” as you define it. These questions don’t have any easy answers.

This section provides information about the options you should have in deciding which medical interventions can be used when biological functions cannot maintain themselves. These are commonly called “life support” and are also known in the medical world as “life-sustaining measures.”

These terms usually refer to medications to stimulate heart function, artificial food and water, or artificial ventilation. People who are terminally ill often do not want such interventions, which would only prolong their dying process. Others must consider what they would want in the case of sudden cardiac arrest or traumatic brain injury, debating what would be best for them and for their loved ones.

Usually interventions are stopped because the patient recovers or because the treatment is not achieving the desired goal.

WITHHOLDING AND WITHDRAWAL OF TREATMENT

Life support is considered “withheld” when the patient or the patient’s health care agent instructs health care providers not to begin a medical therapy, and the expected result is that the patient will die without it. This option is often selected by patients who are already terminally ill and in the dying process. Life support is considered “withdrawn” when a therapy that has been initiated is stopped. Often, the patient or patient’s agent, other loved ones, and the attending physician agree on a time-limited trial of life-support therapy, hoping for improvement. If the patient does not improve, the therapy is stopped.

While you can always direct your own medical care if you are conscious and capable, this can change if you are incapacitated. Some state laws require you to record in writing your wish to have life support withheld. In these states, life support is always initiated unless you have written documents requesting otherwise, and even your designated agent cannot change this.

If you want life support to be withheld or withdrawn after a certain period, it is imperative that you complete an advance directive and/or POLST/MOLST. A doctor’s order may also serve this purpose. See DNR below.

ARTIFICIAL VENTILATION

Artificial ventilation is often used while treating the underlying problem that causes the patient to be unable to breathe. A tube is inserted through the mouth into the windpipe, and a machine pushes a precise combination of oxygen and air into the lungs, at a controlled speed and pressure. Sometimes the tube is inserted into the windpipe (trachea) through a hole made in the throat. Also called mechanical ventilation, artificial ventilation brings oxygen and air to the lungs of a person who cannot breathe on their own.

Some patients are given artificial ventilation, and are then slowly weaned off it. But many patients are unlikely to recover the ability to breathe alone. The longer a patient uses artificial ventilation, the less likely recovery becomes.

DNR ORDER AS A TOOL

A DNR order instructs health care providers not to attempt to resuscitate you if your heart stops in a medical facility. This option is sometimes selected by people who, for medical reasons, would not benefit from CPR. Discuss with your doctor whether a DNR is appropriate for you.

Some states allow you to include DNR instructions in your advance directive. If yours does not, you will need to complete a separate document. Also keep in mind that instructions in your advance directive may not apply if you receive emergency care, such as in the event of a sudden collapse. If you do not want resuscitation attempted in any circumstance, you need a DNR form that is separate from your advance directive, sometimes called an “out-of-hospital DNR.” This form requires a physician’s signature.

Paramedics are required to initiate rescue and resuscitation measures. If you have an out-of-hospital DNR order, it is important to display it prominently. Prepare family members and neighbors in case they should find you without heartbeat and not breathing.

Out-of-hospital DNR orders can be difficult to enforce. Emergency personnel rarely withhold resuscitation and they are not required to search for out-of-hospital DNR documentation in an emergency. If you want to reject all emergency efforts, you must persuade your family and neighbors, far ahead of time, not to call 911 if they should find you without signs of breathing or heartbeat. To learn about local practices and ask what you need to do to enable paramedics to comply with your out-of-hospital DNR, call your local ambulance service or fire department.

- Your advance directive is key to making your wishes known if you should be unable to communicate.
- Death shouldn’t have to include fear, pain or suffering, and planning is one of the best ways to avoid it.
- Create your advance directive now.

ARTIFICIAL FOOD AND WATER

An adult may forgo or terminate active treatment such as chemotherapy, radiation therapy, antibiotics or other medications. Similarly, the choice of whether to take food or water, by mouth or through a tube, is the patient’s. But if you have situations in which you do not wish to receive this treatment, you need to record your wishes in your advance directive. Some states require you to receive artificial nutrition and hydration unless you have stated otherwise in writing.

Nutrition and hydration are provided for patients who cannot swallow, cannot swallow sufficient amounts, or cannot absorb nutrition through the stomach. In the case of a person who cannot swallow, this can be provided through a tube. This can be a nasogastric tube, a tube that is inserted through the nose, or a percutaneous endoscopic gastrostomy (PEG) tube, a tube that is surgically inserted directly into the stomach. If you are terminally ill and do not wish to be fed artificially, you can still receive artificial hydration, usually through an intravenous tube.

YOUR WISHES

Your life-support preferences should be recorded in your advance directive and discussed with your health care agent, doctors, family and loved ones. Be sure you have all the information you need, and make your decisions carefully. Discuss these situations with your primary physician and take your general health and other health conditions into account.

As part of your advance directive, we recommend including two supplements developed by Compassion & Choices: “My Particular Wishes” and “The Dementia Provision,” which are available through Compassion & Choices. If you have additional questions as you determine, record and communicate your wishes, please contact our End-Of-Life Consultation team at 800.247.7421. Our staff counselors can provide individual information and support as you complete your documents.

Myth and Fact

Myth: *You always have to use your state's statutory form for your advance directive to be valid.*

Fact: Many states do not require a particular form but require witnessing or other specific signing formalities. Other states specify a particular form. Contact Compassion & Choices for your state's correct forms.

Myth: *An advance directive means "do not treat."*

Fact: An advance directive can express both what you want and don't want.

Myth: *If I name a health care agent, I give up the right to make my own decisions.*

Fact: Naming a health care agent does not take away any of your authority. You always have the right while you are still competent to make your own health-care decisions or revoke a directive.

Myth: *Once I give my doctor a signed copy of my directive, my task is done.*

Fact: Advance-care planning is an ongoing process. Review your wishes annually or anytime your health or family status changes. Make the appropriate changes. We recommend you initial and sign your advance directives annually. Communicate those changes as needed and give copies of revised documents to those who need them.

Myth: *You must have an advance directive to stop treatment near the end of life.*

Fact: Treatment may be stopped without an advance directive if everyone involved agrees. However, without some kind of advance directive, decisions may be more difficult and disputes more likely.

Myth: *Advance directives are only for old people.*

Fact: It is true that, on average, older people are more likely to have advance directives, but every adult should have one. Some of the best-known choice-in-dying cases arose from the experiences of young people (e.g. Terri Schiavo, Nancy Cruzan, Karen Ann Quinlan) incapacitated by tragic illness or car accidents and maintained on life support.

(Adapted from documents produced by the American Bar Association)

All in the Circle of Life

Jan Corey Arnett

Compassion & Choices recently invited submission. Jan Corey Arnett, of Battle Creek, Michigan, had with her dad in his final days of life will also be a farm in the Upper Peninsula. She's passionate a

My father was a hard-working farmer who worked the cows, helping neighbors, or caring for what he could. He taught me to drive a tractor and to share stories of Bobby, his favorite horse.

Dad was in his early 70s when his prostate cancer was diagnosed. After the many times he'd come within inches of death in the face without looking away. When he was in the hospital, conversations about the death of someone were not doing the talking. But at the same time, it was that dreaded time.

He hoped he could die at home with his ordinary work pants. He didn't want to be in a farm in life to want any near him in death. He had his ashes scattered under the stars.

If anyone had told me that as my father lay in bed, bend low to his ear, and recite his wishes, it could be. Not me. The thought of loss kept him as comfortable as possible. He lay above his bed, and calm reassurances were okay, because we would take care of him.

One afternoon, when I was alone with him, he lay in bed as if stroking the fur of an animal. His smile creased his lips. Later, he opened his eyes. Then, in a clear strong voice he said, "I want to go home."

"Is Charlie here, Dad?" I asked, knowing he had nodded. His friend Charlie had been with him when he came in spirit form to accompany him on his journey.

Dad set off for that journey just as I was knowing that his time was very near. Instead she said quietly, "Dad died."

Sue is gone now too, taken by breast cancer with dignity, similar to Dad's in many ways. I dream her voice was on my telephone when I called you."

Sue's ashes, like Dad's, nurture the soil of the Michigan river. And her spirit, like his, lives in their lives is joy. Trusting that

ons for its first annual Storytelling Contest, designed to help us share the stories of people from across the an was our first-place winner in 2009. Jan's beautifully written and touching account of the conversations she be published on our Web site at www.compassionandchoices.org. Jan, a lifelong Michigan resident, was born on about life and nature and writing is her love.

who did everything to the best of his ability whether it was tending crops, milking or his family. The youngest of five daughters, I spent as much time with Dad as I or, ride a horse, and recite poems like, "Simon Slick's Mule" and "My Pa." He loved ate childhood pet; and to enjoy good visits with Charlie, a longtime friend.

ostate cancer was found and near 80 when we learned it had spread to his spine. n a breath of death as a farmer, he didn't fear it even when death was staring him at bothered Dad the most was leaving the family he loved.

eeone you love aren't comfortable, especially when it is the someone you love who is ime, there was a certain rightness and relief when Dad conveyed his desires about

amily around him and then be whisked away wearing his favorite blue sweater and a chunk of granite marking his grave. He said he'd picked too many stones on the death. In fact, he didn't want to be buried at all. He wanted to be cremated and shade of a grove of fragrant cedar trees he and Mom had long admired.

ther approached death, I would have the strength and calm to sit at his bedside, favorite poems in a steady voice, I would have told them they were wrong as wrong sing him was incomprehensible. But Mom, my sisters and I, with his hospice team, . Medications eased the suffering, movement with our hands massaged the energy field s - that when he chose to move on to the next step in his circle of life it would be one another - eased the anguish. For him most of all, we prayed.

h Dad, he rested with his eyes closed but began to caress the air beside him on the visible pet. "Daddy, is Bobby with you?" I asked, to which he nodded, "Yes," as a pened his eyes, raised a weary arm, and looking toward the door, waved slightly. id, "I'm ready!"

owing the words had come from intelligence far greater than my own. Again, he a gone for years, but had visited Dad in a dream to say he was waiting for him. Now, y my father on a journey to a new beginning.

days later. The night he left, my sister Sue had to return to her job in Virginia, r. When she called from an airport between flights, she didn't ask how he was doing, d just a little while ago, didn't he? I felt his spirit."

st cancer little more than a year ago. She too made her wishes known about death with ways. As she departed in the night, she sent a message by way of a dream. In the e answering machine. "Jan," the message said, "I just called to tell you that I love

he Earth at places she loved - a children's garden, the cedar grove, a place along a ke Dad's, knows life anew. Losing them was sorrow. Treasuring having been a part of I will be with them again is anticipation.

- Jan Cory Arnett



Jan with her Dad.

The Conversation



My girlfriend asked me, “If you could know how and when you were going to die, would you want to know?” I told her no. And so she said, “Forget it then.”

~Steven Wright

We can’t control everything about our death. But if we communicate effectively, we make it more likely that our wishes for the end of life will be known and respected. Simply completing an advance directive does not ensure it will be respected. Recent studies indicate the single most powerful thing a person can do to improve the chance for gentle dying is --- simply and courageously --- to talk about it.

Effective communication with those who will be called upon to make decisions on our behalf is key to the likelihood that our wishes are carried out. Compassion & Choices offers a *Good to Go Toolkit* and other resources that can help you define priorities, understand who you need to talk with and come up with ideas on how to get the conversation rolling. It is never too early to get started.

What to talk about

Your discussions should include feelings about how you would want to be treated in a variety of situations. Identify your main concerns, worries and fears. Those close to you need to know what you would prioritize if you were living with physical pain, disability, terminal illness, dementia and debilitating chronic illness. Consider who you want to make choices if you can no longer make your own decisions and let people know who that person will be. Talk to your doctor about specific treatments that

could come up, particularly given your current medical condition.

The *Good to Go Toolkit* includes a Values and Priorities Worksheet to help you set priorities.

Clarifying what you do and do not want and where you are unsure is an important step in the ongoing process of determining wishes for your end-of-life care.

Before talking with your physician, you will want to prepare questions about what they can and will do based on your advance directive. For example, if you specify that you do not want a specific treatment, would this doctor ensure that you were kept comfortable? Will the doctor do his/her best to fully explain all procedures/treatments, alternatives and risks to you and/or your family/representative(s)? Are there religious affiliations and/or policies at the local hospitals that would limit your provider or the facility from complying with specific parts of your directive?

Who to talk to

First and foremost, talk to your personal physician and family, who have the greatest impact on your care choices. The other people who need to know about your end-of-life concerns and wishes could include your health care representative, estate attorney, caregivers and friends.

It is possible in conversation with your physician or others that you may realize they do not support your wishes. You have the right to change physicians and to name a health care representative who supports your desires. If you anticipate that other family members may strongly disagree, communicate directly (verbally and in writing) with those you anticipate will not support your wishes and be clear that you do not want them involved in decision making and why.

When to have the conversation

Death is like having an elephant in the room: even if no one mentions it, everyone knows it’s there. How do you begin?

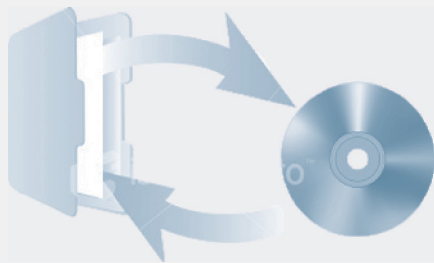
One approach is to consciously create time to initiate the conversation. You might choose a family gathering for holidays or special events or when illness and doctor's visits provide an opening.

Another approach is to stay alert to spontaneous opportunities. You might prepare to introduce the topic of end-of-life wishes when a particular subject arises, such as concerns about losing various aspects of your independence.

Decide if it would work better to have individual conversations with specific family members first or a group discussion. You might begin by giving family members a copy of your advance directive.

Conclusion

It is important to think through your concerns and how they affect your wishes for end-of-life care, and to communicate those wishes to your physician and your loved ones. If ever they have to make decisions on your behalf, that difficult task is made easier by being confident that they know your wishes. You relieve them of the burden of guessing what you would choose when you make your preferences clear to everyone well ahead of a medical crisis.



Did You Know?

Your membership card from Compassion & Choices has space on the back for the name and phone number of your agent(s) for health care.

As a benefit of membership at the Benefactor level and above, Compassion & Choices can put your advance directive on a wallet-size CD rom that you can carry with you. To learn more about this level of membership, call us at 800.247.7421.

For starters . . .

Conversations about your wishes for end-of-life care can be difficult, but there are sensitive ways to broach the conversation.



With loved ones:

"It's important to me to be able to talk honestly with you about my concerns and wishes if I ever become seriously ill or unable to speak for myself..."

"My doctor/ attorney, _____, says I need to go over my advance directive ..."

"I want to make sure that I get the best care possible and the type of care that I want, so there are things we should talk about..."

"I want to make it as easy as possible for my family to make medical decisions on my behalf if I ever become incapable of communicating my wishes..."

"If you are ever in a position where you need to make health care decisions for me, it will be most helpful to you if you know what I really want..."

With your physician:

"I just read about a study that found all that high technology at the end of life doesn't work and just causes suffering. Do you know I wouldn't want that?"

"I love so much about my life – being active, loving my family. If none of that were possible anymore, I'd like to go out peacefully, without a lot of heroics. Does that fit with your medical philosophy?"



You can also download a sample "letter to my doctor" at www.compassionandchoices.org/LetterToMyDoctor.pdf

LGBTQ End-of-Life Advice

Even though some states have enacted domestic partnership (DP) laws that provide certain rights, only married couples have all the rights associated with marriage. Additionally, other states may not honor your state's DP laws.

Every LGBTQ adult, whether legally partnered or not, should consider making these essential life-planning documents, also known as advance directives.

Documents protecting choices in medical care:

- Directive to Physicians (a.k.a. Living Will)
- Durable Power of Attorney for Health Care
- Physician/Medical Orders for Life-Sustaining Treatment (POLST or MOLST)
Note: This form is recommended only after diagnosis with a serious health condition and must be signed by a physician.
- Hospital Visitation Authorization
- Documents protecting financial assets
- Power of Attorney
- Last Will and Testament

Talk to your partner, family (immediate and self-identified), and primary care physician about your decisions, and give them copies of all your documents. Tell your primary care physician to make them part of your medical record.

Make clear to other family members that the healthcare agent named in your DPOA for Health Care who may or may not be your partner is the person you have chosen to make your healthcare decisions, if you become unable to do so.

Additionally, if you can complete your own paperwork upon entering a medical facility, list your partner or loved one as “next of kin” or as the “emergency contact,” and provide a copy of your Directive to Physicians, DPOA for Health Care, and your Hospital Visitation Authorization.

End-of-Life Planning for the Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ) Community

Coming to terms with one's own impending death or that of a loved one is difficult in even the best of circumstances. But homophobia and invisibility within society can add tragic complications to life's culminating moment. Our counselors have too many stories to tell of same-sex couples, even ones who have planned for the end of life, whose preferences are ignored by family and the medical establishment.

Discrimination on the part of health care professionals, hospitals and hospices who may refuse to respect the reality of same-sex relationships can be horrible when people are denied their final wishes.

In the absence of a legal marriage option for same-sex couples in most states, end-of-life planning is especially burdensome to these couples. At almost every moment in the continuum of care from diagnosis to death, same-sex couples must take proactive steps to protect their basic health care rights.

In issues of health insurance, interactions with doctors and other providers, treatment preferences, home care, hospice, relationships with family, end-of-life choices, death, burial, and bereavement – none of the norms that apply to heterosexual partnerships can be assumed to apply in the same way. It is essential that lesbians and gay men understand their legal rights and take assertive steps to enforce them.

Few states recognize same-sex life partners, although this is beginning to change. Even where there is legal recognition of same-sex relationships, including marriage, couples often suffer greater hurdles around end-of-life decision making. Many health care providers and insurance companies are not required to recognize a marriage between same-sex couples.

Decision-making authority that would be automatic in heterosexual relationships may be actively denied when a lesbian or gay relationship is involved. Life partners may be prevented access to one another at the deathbed, and end-of-life

treatment choices may be ignored. Partners should make advance directives expressing their wishes, with appropriate power of attorney relationships expressed in writing and kept on file with all health care providers.

Although the LGBTQ community developed a variety of excellent end-of-life care programs for people with AIDS during the worst years of the epidemic, there are few resources available if they are dying from some other disease or condition. One of the unfortunate consequences of improved drug therapy for HIV is that AIDS programs have de-emphasized their focus on end-of-life care. As the boomer generation continues to age, the numbers of gays and lesbians facing end-of-life issues are growing.

While same-sex couples coming to terms with loss may be prepared for disenfranchised grief, they might not appreciate the struggles they may face in dealing with institutional prejudice within the health care profession.

Compassion & Choices provides information and guidance to meet the very real and specific needs of individuals in the LGBTQ community to ensure that their end-of-life choices are honored and respected.

Learn more at www.CompassionAndChoices.org/lgbtq.

New for 2011

The ***Sectarian Health Care Directive*** is an optional addendum to your advance directive. The language in this addendum clarifies that admission to a religiously-affiliated facility does not imply consent to particular care mandated by the institution's religious policies, and directs a transfer if the facility declines to follow the wishes outlined in an advance directive.

Find the Sectarian Health Care Directive at www.CompassionAndChoices.org/g2g

The Good to Go Toolkit



Compassion & Choices is your resource for end-of-life planning documents.

- State-Specific Advance Directives
- The Dementia Provision
- My Particular Wishes
- **NEW: Sectarian Health Care Directive**
- Hospital Visitation Authorization
- Finding a Health Care Representative

The Good to Go Toolkit includes all these and more, along with helpful instructions for filling out these forms.

To download the ***Good to Go Toolkit***, please visit us online. You may also to have your Toolkit mailed for a postage and handling fee of \$5 (free for members and donors).

The Web site also includes a variety of other helpful information. Our End-of-Life Consultation Program can provide support and help you with questions.

Visit our Web site at www.CompassionAndChoices.org or call us at 800.247.7421.

Who. What. Where.

Already have your documents in order?
You have taken the first step, answering the **WHAT**. You still need the **WHO** to make sure you have spoken to your agent and loved ones about your wishes. The final step is the **WHERE**. Make sure copies of your advance directive are in the right places: your agent, your home or obvious place for your agent or loved one to find it, and your doctor.

Now That You're "Good to Go," Think About Leaving Some "Good" Behind

Now that you've gotten your advance directives in order

Now that your kids are grown and out of the house

Now that you're more settled, and your family needs less from you

Your needs change as your family changes

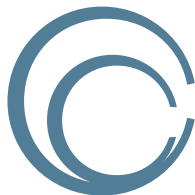
Now's the time to review your will and other estate plans, and make sure that your plans adequately address your wishes and goals for the distribution of your estate. Perhaps there's room for a deferred gift to Compassion & Choices.

We can provide you with complimentary brochures on estate planning and charitable giving that can help you think through this important subject.

Call us at 800.247.7421 or visit our website at www.CompassionAndChoices.org to get more information to assist you in your estate planning.

Or let us know if you've included Compassion & Choices in your plans already.

We want you to be "Good to Go."



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Support. Educate. Advocate. Choice & Care at the End of Life

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