Deciding Together
End of Life Care

How to start a conversation that matters.

Reid
There are a million reasons to avoid having the conversation.

But it’s critically important. And you can do it. Consider the facts:

- More than 90% of the people think it’s important to talk about their loved ones’ and their own wishes for end-of-life care.
- Less than 30% of people have discussed what they or their family wants when it comes to end-of-life care.

  National Survey by The Conversation Project 2013.

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- 56% have not communicated their end-of-life wishes

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- 80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care
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- 82% of people say it’s important to put their wishes in writing; only 23% have done it

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One conversation can make all the difference.

“What a conversation can do is provide a shared understanding of what matters most to you and your loved ones. This can make it easier to make decisions when the time comes.”
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Glossary

**Advance care planning (ACP)**
An ongoing process of discussing and clarifying the current state of a person’s goals, values and preferences for future medical care. The discussion often, but not always, leads to the signing of documents known as Advance Directives. A health care proxy is the only Advance Directive authorized by Massachusetts statute.

**Advance Directive (AD)**
General term referring to a written document for future medical care in the event that a person loses capacity to make health care decisions (i.e. becomes “incapacitated”). It sometimes results from the process known as advance care planning. A health care proxy or a Living Will is considered to be an Advance Directive.

**Aggressive medical care**
Care and treatments meant to prolong life when a person is close to death.

**Artificial hydration and nutrition (AHN)**
Medical treatment that supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and/or fluids through a tube placed directly into the digestive tract (enteral); or through a tube directly into a vein (parenteral).

**Brain autopsy**
Scientific examination of brain tissue after death that often allows doctors or researchers to confirm if a person had Alzheimer’s or another type of dementia.

**Cardio-pulmonary resuscitation (CPR)**
A set of medical procedures that attempt to restart the heartbeat and breathing of a person who has no heartbeat and has stopped breathing. Such procedures may include pressing on the chest to mimic the heart’s functions and cause blood to circulate; insertion of an airway into the mouth and throat, or insertion of a tube into the windpipe; artificial ventilation such as mouth-to-mouth or other mechanically assisted breathing; the use of drugs to stimulate the heart; and/or electric shock (defibrillation) to stimulate the heart. CPR can be life-saving in certain cases for otherwise healthy people but is much less effective when a person has a serious chronic illness.

**Comfort Care/Do-Not-Resuscitate Verification protocol (CC/DNR)**
Followed by emergency medical service (EMS) personnel when encountering an authorized CC/DNR Verification Form outside of a hospital setting. The CC/DNR protocol directs that a patient in respiratory or cardiac distress be made as comfortable as possible, but that no resuscitative measures be attempted.
**Decision-making capacity**
The ability to make and communicate meaningful decisions based upon an understanding of the relevant information about options and consideration of the risks, benefits, and consequences of the decision. The ability to understand other unrelated concepts is not relevant. Capacity can vary according to the task: it may be possible for an individual to appoint a health care agent, for example, yet not make a decision about a medical procedure. Capacity should be assessed routinely, and it is not the same as competence, which is a legal determination made in court. In Massachusetts the determination of a patient’s lack of capacity must be made by a physician in writing before a health care proxy can be put into effect.

**Dialysis**
The process of filtering the blood through a machine via two small tubes inserted into the body in order to remove waste products from the body in the way that the kidneys normally do. Dialysis can be done temporarily in order to allow the kidneys time to heal or it can be done on a longer term basis in order to prolong life.

**Do Not Hospitalize orders (DNH)**
Medical orders signed by a physician that instruct health care providers not to transfer a patient from a setting such as a nursing facility (or one’s home) to the hospital unless needed for comfort.

**Do Not Intubate orders (DNI)**
Medical orders signed by a physician that instruct health care providers not to attempt intubation or artificial ventilation in the event of respiratory distress.

**Do-Not-Resuscitate orders (DNR)**
Medical orders signed by a physician that instruct health care providers not to attempt cardio-pulmonary resuscitation (CPR) in the event of cardiac and respiratory arrest.

**Durable Power of Attorney for Health Care**
See Health Care Proxy (HCP).

**Feeding tube**
A tube that provides artificial nutrition when a person is unable to eat. The most common type of feeding tube is inserted through an incision in the stomach.

**Guardian**
A court-appointed individual granted authority to make certain decisions regarding the rights of a person with a clinically diagnosed condition that results in an inability to meet essential requirements for physical health, safety or self-care. In Massachusetts not every guardian has authority to make health care decisions. If a health care proxy is in effect, a health care decision of the agent takes precedence over that of the guardian.
(absent an order of the court to the contrary). Further, guardians who do have authority to make health care decisions may be subject to limitations on their authority to make decisions regarding life-sustaining treatments.

**Health care agent**
A trusted person, officially appointed, who speaks on behalf of a person 18 years of age or older who is unable to make or communicate health care decisions. The agent is called upon only if the doctor determines in writing that a patient lacks capacity to make health care decisions. Unless otherwise limited by the person, the agent has all the rights that the patient has with regard to medical decision-making, including the rights to refuse treatment, to agree to treatment, or to have treatment withdrawn. Decisions should first be made based on the patient’s stated wishes, if known; or if unknown, an interpretation of what the patient would have wanted; or finally, an assessment of the patient’s best interest.

**Health care proxy (HCP)**
A document in which a person appoints a health care agent to make future medical decisions in the event that the person becomes incapacitated. This may be an outcome of the advance care planning process.

**Hospice**
Care designed to give supportive care to people in the final phase of a terminal illness and focus on comfort and quality of life, rather than cure. The goal is to enable patients to be comfortable and free of pain, so that they live each day as fully as possible. Aggressive methods of pain control may be used. Hospice programs generally are home-based, but they sometimes provide services away from home -- in freestanding facilities, in nursing homes, or within hospitals. The philosophy of hospice is to provide support for the patient's emotional, social, and spiritual needs as well as medical symptoms as part of treating the whole person.

**IV hydration**
Providing liquids through a needle into a person’s vein when he or she can no longer drink independently.

**Life-sustaining treatment**
Refers to medical procedures such as cardio-pulmonary resuscitation, artificial hydration and nutrition, and other medical treatments intended to prolong life by supporting an essential function of the body in order to keep a person alive when the body is not able to function on its own.
**Living Will**
A document in which a person specifies future medical treatments in the event of incapacity, usually at end of life or if one becomes permanently unconscious, in a persistent vegetative state or “beyond reasonable hope of recovery.”

**Medical (or Physician’s) Orders for Life-Sustaining Treatment (MOLST /POLST)**
A document intended for seriously ill patients that stipulates wishes for life-sustaining treatment based on the patient’s current condition. A MOLST form becomes effective immediately upon signing and is not dependent upon a person’s loss of capacity. It does not take the place of a health care proxy. Consideration of MOLST may be an outcome of the advance care planning process.

**Palliative care**
A comprehensive approach to treating serious illness that focuses on the physical, psychosocial and spiritual needs of the patient. The goal of palliative care is to prevent and relieve suffering and to support the best quality of life for patients and their families through such interventions as managing pain and other uncomfortable symptoms, assisting with difficult decision-making, and providing support regardless of whether or not a patient chooses to continue curative, aggressive medical treatment.

**Persistent vegetative**
A condition caused by brain injury. The victim is unable to respond to his or her surroundings and is not aware of anything, even though the eyes may be open periodically. It is similar to a coma in that the person is unresponsive, but in a permanent condition. A head injury, stroke or other events may result in this condition and a person may be kept alive indefinitely in this condition by artificial means.

**Surrogate decision-making**
Allows an individual or group of individuals (usually family members) to make decisions about medical treatments for a patient who has lost decision-making capacity and did not prepare an Advance Directive. A majority of states have passed statutes that permit surrogate decision making for patients without Advance Directives.

**Withholding or withdrawing treatment**
Forgoing life-sustaining measures or discounting them after they have been used for a certain period of time.

*Information retrieved from:*
- Massachusetts Medical Orders for Life-Sustaining Treatment
  - [http://molst-ma.org/](http://molst-ma.org/)
- MedicineNet
- Ohio Department of Aging
  - [http://www.goldenbuckeye.com](http://www.goldenbuckeye.com)
Your Conversation Starter Kit

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We know that no guide and no single conversation can cover all the decisions that you and your family may face. What a conversation can do is provide a shared understanding of what matters most to you and your loved ones. This can make it easier to make decisions when the time comes.

Name: ______________________________________________

Date: _________________________________________________

Created by The Conversation Project and the Institute for Health care Improvement
This Starter Kit doesn't answer every question, but it will help you get your thoughts together, and then have the conversation with your loved ones.

You can use it whether you are getting ready to tell someone else what you want, or you want to help someone else get ready to share their wishes.

Take your time. This kit is not meant to be completed in one sitting. It’s meant to be completed as you need it, throughout many conversations.

Step 1: Get Ready
Step 2: Get Set
Step 3: Go
Step 4: Keep Going

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Step 1: Get Ready

There are a million reasons to avoid having the conversation. But it’s critically important. And you can do it.

Consider the facts.

- More than 90% of the people think it’s important to talk about their loved ones’ and their own wishes for end-of-life care.
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*Source: Survey of Californians by the California Health Care Foundation (2012)*

One conversation can make all the difference.
Remember:

- You don’t need to talk about it just yet. Just think about it.
- You can start out by writing a letter—to yourself, a loved one, or a friend. Think about having a practice conversation with a friend.
- These conversations may reveal that you and your loved ones disagree. That’s okay.
- It’s important to simply know this, and to continue talking about it now—not during a medical crisis.

What do you need to think about or do before you feel ready to have the conversation?
Step 2: Get Set

Now, think about what you want for end-of-life care.

Start by thinking about what’s most important to you. What do you value most? What can you not imagine living without?

Now finish this sentence:

What matters to me at the end of life is…

Sharing your “What matters to me” statement with your loved ones could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what’s worth pursuing treatment for, and what isn’t.
Where I Stand scales

Use the scales below to figure out how you want your end-of-life care to be. Select the number that best represents your feelings on the given scenario. As a patient...

<table>
<thead>
<tr>
<th>I only want to know the basics</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>I want to know as much as I can</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ignorance is bliss</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>I want to know how long I have to live</td>
</tr>
<tr>
<td>I want my doctors to do what they think is best</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>I want to have a say in every decision</td>
</tr>
</tbody>
</table>

Look at your answers.

What kind of role do you want to play in the decision-making process?
### How long do you want to receive medical care?

| I want to live as long as possible no matter what | 1 | 2 | 3 | 4 | 5 | Quality of life is more important to me than quantity |
| I’m worried that I won’t get enough care | 1 | 2 | 3 | 4 | 5 | I’m worried that I’ll get overly aggressive care |
| I wouldn’t mind being cared for in a nursing facility | 1 | 2 | 3 | 4 | 5 | Living independently is a huge priority for me |

### Look at your answers.

What do you notice about the kind of care you want to receive?
How involved do you want your loved ones to be?

<table>
<thead>
<tr>
<th>I want my loved ones to do exactly what I’ve said. Even if it makes them a little uncomfortable at first</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>When the time comes, I want to be alone</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I don’t want my loved ones to know everything about my health</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

I want my loved ones to do what brings them peace even if it goes against what I’ve said

I want to be surrounded by my loved ones

I am comfortable with those close to me knowing everything about my health

What role do you want your loved ones to play? Do you think that your loved ones know what you want or do you think they have no idea?
What do you feel are the three most important things that you want your friends, family and/or doctors to understand about your wishes for end-of-life care?

1.

2.

3.
**Step 3: Go**

When you’re ready to have the conversation, think about the basics.

Mark all that apply:

- ✔️ **Who do you want to talk to? Who do you trust to speak for you?**

<table>
<thead>
<tr>
<th></th>
<th>Mom</th>
<th>Child/Children</th>
<th>Friend</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dad</td>
<td>Partner/Spouse</td>
<td>Doctor/Caregiver</td>
</tr>
<tr>
<td></td>
<td>Sibling</td>
<td>Minister/Priest/Rabbi</td>
<td>Other:______________</td>
</tr>
</tbody>
</table>

- ✔️ **When would be a good time to talk?**

<table>
<thead>
<tr>
<th></th>
<th>The next big holiday</th>
<th>Before my next big trip</th>
<th>Before I get sick again</th>
<th>Other:___________</th>
</tr>
</thead>
<tbody>
<tr>
<td>At Sunday diner</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before my kid goes to college</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before the baby arrives</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- ✔️ **Where would you feel comfortable talking?**

<table>
<thead>
<tr>
<th></th>
<th>At the kitchen table</th>
<th>On a walk or hike</th>
<th>Other:___________</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>At a cozy café or restaurant</td>
<td>Sitting in a garden or park</td>
<td></td>
</tr>
<tr>
<td></td>
<td>On a long drive</td>
<td>At my place of worship</td>
<td></td>
</tr>
</tbody>
</table>

What do you want to be sure to say? If you wrote down your three most important things at the end of Step 2, you can use those here.
**How to start**

Here are some ways you could break the ice:

- “I need your help with something.”
- Remember how someone in the family died—was it a “good” death or a “hard” death? How will yours be different?
- “I was thinking about what happened to (Uncle Joe), and it made me realize...”
- “Even though I’m okay right now, I’m worried that (I’ll get sick), and I want to be prepared.”
- “I need to think about the future. Will you help me?”
- “I just answered some questions about how I want the end of my life to be. I want you to see my answers. And I’m wondering what your answers would be.”

**What to talk about**

- When you think about the last phase of your life, what’s most important to you? How would you like this phase to be?
- Do you have any particular concerns about your health? About the last phase of your life? Who do you want (or not want) to be involved in your care? Who would you like to make decisions on your behalf if you’re not able to? (This person is your health care proxy.)
- Would you prefer to be actively involved in decisions about your care? Or would you rather have your doctors do what they think is best?
- Are there any disagreements or family tensions that you’re concerned about?
- Are there circumstances that you would consider worse than death? (Long-term need of a breathing machine or feeding tube, not being able to recognize your loved ones)
- Are there important milestones you’d like to meet if possible? (The birth of your grandchild, your 80th birthday)
- Where do you want (or not want) to receive care? (Home, nursing facility, hospital)
- What kinds of aggressive treatment would you want (or not want)? (Resuscitation if your heart stops, breathing machine, feeding tube) When would it be okay to shift from a focus on curative care to a focus on comfort care alone?
- What affairs do you need to get in order, or talk to your loved ones about? (Personal finances, property, relationships)
This list doesn’t cover everything you may need to think about, but it’s a good place to start. Talk to your doctor or nurse if you’re looking for more end-of-life care questions.

**Remember:**

- Be patient. Some people may need a little more time to think. You don’t have to steer the conversation; just let it happen.
- Don’t judge. A “good” death means different things to different people.
- Nothing is set in stone. You and your loved ones can always change your minds as circumstances shift.
- Every attempt at the conversation is valuable.
- This is the first of many conversations—you don’t have to cover everyone or everything right now.

**Now, just go for it!**

Each conversation will empower you and your loved ones. You are getting ready to help each other live and die in a way that you choose.
Step 4: Keep Going

Congratulations!

Now that you have had the conversation, here are some legal and medical documents you should know about. Use them to record your wishes so they can be honored when the time comes.

- **Advance Care Planning (ACP):** the process of thinking about your wishes—exactly what you have been working on here.

- **Advance Directive (AD):** a document that describes your wishes.

- **Health Care Proxy (HCP):** identifies your health care agent (often called a "proxy"), the person you trust to act on your behalf if you are unable to make health care decisions or communicate your wishes. In some states, this is called the Durable Power of Attorney for Health Care. This is probably the most important document. Make sure you have many conversations with your proxy.

- **Living Will:** specifies which medical treatments you want or don’t want at the end of your life, or if you are no longer able to make decisions on your own (e.g. in a coma).

You can find more information about these documents from the link in the "Keep Going" section of the website Starter Kit at www.TheConversationProject.org.

Remember, this was the first of many conversations. You can use the questions below to collect your thoughts about how your first talk went, and then look back to them when you prepare for future conversations.

Is there something you need to clarify that you feel was misunderstood or misinterpreted?
Who do you want to talk to next time? Are there people who should hear things?

At the same time (like siblings who disagree about everything)?
How did this conversation make you feel? What do you want to remember? What do you want your loved ones to remember?

What do you want to make sure to ask or talk about next time?

We hope you will share this Starter Kit with others.
You have helped us get one conversation closer to our goal: that everyone’s end-of-life wishes are expressed and respected.
How To Talk To Your Doctor
(Or any member of your health care team)

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

Talking with your loved ones openly and honestly, before a medical crisis happens, gives everyone a shared understanding about what matters most to you at the end of life. (See the Conversation Starter Kit for help taking that first step. It’s available for free at theconversationproject.org.)

After you’ve had the conversation with your loved ones, the next step is talking to your doctor or nurse about your wishes. Again, don’t wait for a medical crisis; talking with your doctor or nurse now makes it easier to make medical decisions when the time comes.
You can use this guide as a workbook to make notes of what to tell the health care team—whether you’re getting ready to discuss your own wishes, or you’re helping someone else get ready to discuss theirs.

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Step 1: Get Ready

Okay—so you’ve had the conversation with your loved ones. Congratulations! You’ve already taken the most important step.

(Note: If you haven’t yet had the conversation with your loved ones, see the Conversation Starter Kit for help taking that first step. It’s available for free at theconversationproject.org.)

The next step is to have a conversation with your health care team to make sure that they know your preferences regarding end-of-life care.

Remember: You’re the expert about what matters most to you. Your health care team’s role is to listen carefully to your wishes, and then help you make the most appropriate decisions about your care.

That means explaining the available treatment options and helping you decide which ones are right for you—especially if you or your loved one experience a dramatic change in health.
Step 2: Get Set

When you’re ready to talk to your doctor (or help someone else talk to their doctor), start by thinking about the basics.

Mark all that apply:

Who do you want to talk to?

- [ ] Your primary care doctor
- [ ] Your nurse, nurse practitioner, or physician’s assistant
- [ ] Your specialist provider, if you have a chronic condition (heart doctor, lung doctor, etc.)
- [ ] Your therapist, social worker, psychologist, or psychiatrist
- [ ] Your case manager
- [ ] Your admitting team, if you are hospitalized
- [ ] The staff physician or nurse at your nursing home or assisted living facility
- [ ] Other __________________________

Choose someone you’re comfortable talking to—if possible, someone who knows you and your health status.

When would be a good time to talk?

- [ ] At your next annual physical
- [ ] At your next routine follow-up visit
- [ ] During an urgent visit
- [ ] After a visit to the emergency room
- [ ] When you’re admitted to the hospital
- [ ] If you have a new diagnosis (for example, cancer, chronic heart or lung disease)
- [ ] Other __________________________
Even if you’re in good health, it’s still important to make sure your health care team knows your wishes, since anyone’s health status can change suddenly. It’s particularly important to have this conversation if you or a loved one has a chronic illness.

You’ll probably have several conversations with your doctor over time, and each one will be a little different depending on the context. But every conversation will help your health care team understand what matters to you.

Most importantly—don’t wait until there’s a crisis. And don’t wait for your doctor to bring it up. It always seems too early… until it’s too late.

How else can you prepare yourself for the conversation with your doctor?

Learn about some common medical terms that might come up.

Your job is not to come up with a list of treatment options; that’s your doctor’s job. Your role is to help your doctor understand what matters most to you. Then your doctor can discuss treatment options in the context of your current health status and your wishes. Then you can make the decision that’s right for you.

Here are a few examples of treatment options that your doctor might mention:

- **CPR (Cardiopulmonary resuscitation):** If your heart stops, attempts are made to restart your heart with chest compressions or electricity.

- **Intubation/mechanical ventilation:** When you can’t breathe on your own, a breathing tube is placed in your throat and into your lungs, connecting you to a machine that can breathe for you. Can be used short-term or long-term, depending on your needs and preferences.

- **Artificial nutrition and hydration:** When you can’t eat or drink on your own, fluid and nutrients are delivered in an IV or through a tube in your nose or stomach. (This is sometimes called a “PEG tube”—an abbreviation for “percutaneous endoscopic gastrostomy.”) Can be used short-term or long-term, depending on your needs and preferences.
- Comfort care: When curative care is no longer likely to help, medication or other non-invasive options are used solely to keep you comfortable.

- A time-limited trial of aggressive care: A short-term trial (usually days) of all possible life-saving medical care, with the understanding that if it is not successful and it appears that your chances of survival are low, or that your quality of life will be inconsistent with your preferences, you would discontinue aggressive care and focus solely on comfort.
Step 3: Go

Sometimes the hardest part is knowing how to begin. When you’re ready to talk to your doctor, here are some ways you could break the ice.

Call your doctor’s office and leave a message before your visit.

- It helps your doctor and health care team if they know in advance that you want to take time during your visit to discuss your end-of-life wishes. That way, they can make sure to set aside time for this important conversation.
  - “Could you please tell Dr. Jones that I want to talk about my end-of-life wishes during my visit on Friday?”

- Write your doctor a letter if it feels easier to start that way.

Prepare your opening line.

- When you meet with your doctor, tell it like it is.
  - “I want to have a conversation about my wishes for end-of-life care.”

- Bring in your Starter Kit and share your “three most important things I’d like people to know about my end-of-life wishes” or your answers to the “Where I Stand” scales (both found in Step 2: Get Set).
  - “Have you heard about The Conversation Project? It’s a campaign to help people talk about their end-of-life wishes. Here’s what I’ve thought about so far.”

- Share your reflections about deaths that you or your loved ones have witnessed.
  - “My friend’s sister recently died in the hospital after weeks of aggressive care. I don’t want that. I think I might prefer to die at home.”
  - “I think I’d feel more comfortable if I died in the hospital. They take such good care of me.”

- Tell your doctor about important milestones you hope to make.
  - “My granddaughter is getting married in a year and I’d really like to be there—can you help me understand what I might need to do to make it to the wedding?”
Bring your health care proxy (the person you’ve chosen to make medical decisions for you if you aren’t able to) and/or a friend or family member to the visit. Ask them to take notes.

- “I brought my sister with me today, because I’d like to talk to you about my end-of-life wishes and she’s my health care proxy.”

Here are some questions you can ask to help you understand your or your loved one’s medical problems. (And in fact, it’s pretty hard to make decisions about end-of-life care without a good understanding of the answers to these questions.)

- “Can you tell me what I can expect from this illness? What is my life likely to look like 6 months from now, 1 year from now, and 5 years from now?”
- “What can I expect about my ability to function independently?”
- “What are some possible big changes in my health that my family and I should be prepared for?”
- “What can I expect to improve (or not improve) if I choose this course of treatment, or another course of treatment?”
- “What can I expect if I decide to do nothing?”

Make sure to ask your doctor or health care team to document your discussion, and your wishes, in your medical record.

**Things to remember and other things it’s okay to say:**

- Ask a lot of questions.
  - “I don’t understand—can you explain it in a different way?”

- You don’t have to decide about anything right away.
  - “I’d like to talk this over with a friend—can we have another conversation in a couple of weeks?”
  - “Would you write this down for me?”
• Ask for numbers and statistics if it helps you, but also realize that in many cases, there is simply just a lot of uncertainty.

• You may want to have a private conversation with your doctor. It can be hard to do this, especially if your loved one always accompanies you. Leave your doctor a message prior to the appointment. They are accustomed to facilitating this in a way that will not make your loved one feel uncomfortable.
  
  o “Could you please tell Dr. Jones that, when I come in for my visit on Friday, I’d like a chance to talk to him alone about my end-of-life wishes?”
Step 4: Keep Going

It’s important to have follow-up conversations to revisit the issues that come up in these conversations. Your preferences may change as time passes. Your health care team may ask you to consider treatment options that you’d like some time to think about.

And sometimes, these conversations don’t go as planned.

Here are some scenarios that may require you to have the conversation again with your health care team, or to revisit the conversation with your loved ones.

- **My health care provider doesn’t want to talk about it.**
  - It is your right to talk about this—you can insist on it. (“Yes, I am doing well now, but things can change at any moment and I want us both to be prepared.”)
  - If there isn’t enough time, suggest scheduling another appointment specifically to focus on this conversation.
  - If you continue to feel resistance, you may need to consider seeking another health care provider.

- **My loved one has dementia and it’s not possible to discuss what matters.**
  - Can you remember a conversation with your loved one about the death of someone close? Did she or he ever comment on the experience someone else had at the hospital? Use these observations to guide the conversation with the care team and the decisions that are made.
  - **I am a health care proxy for a loved one, and I disagree with his or her wishes.**
    - A health care proxy should act on a loved one’s behalf using “substituted judgment”—in other words, making the decision your loved one would make if he or she could. If you feel that you cannot carry out your loved one’s wishes, then it’s a good idea to say so. They might want to choose an alternate health care proxy. If you have never had a conversation with the person for whom you’re a proxy, then you will need to do your best to act in your loved one’s best interest, guided by their health care team.

  - **I am a health care proxy for my parent, but my siblings disagree with my parent’s expressed wishes.**
    - See the answer above. Your obligation as a health care proxy is to make decisions according to your loved one’s wishes.
• There are teams of people in the medical community (often called ethics committees) that can help clarify these kinds of situations, but sometimes it just takes time for family members to come to terms with their loved one’s expressed wishes.

• My doctor doesn’t agree with my choices and has his/her own strong opinion.
  o First, explore why. Maybe your doctor fears that aggressive therapy will buy you a little time, but little quality of life. Or maybe your doctor believes that a time-limited trial of aggressive therapy may mean that you can be back enjoying your life again. If it’s still challenging to find common ground, you may need to seek a second opinion. Remember, you are the expert on your desired quality of life.

• I got two different opinions from two of my doctors.
  o Get them in same room at the same time and talk! We do this with painters and contractors, and here the stakes are much higher. Sure, it can be logistically difficult—but it is your right.
  o If you’re not comfortable bringing together two of your doctors who disagree, tell one of your doctors (or another member of your team) that you’ve received two different opinions and you’d like help understanding the difference.

We invite you to talk back:

Was your health care team “Conversation Ready”? Were they ready to listen? We invite you to share your experience talking to your doctor by visiting theconversationproject.org and clicking on “Your Stories.”

We hope you will share this document with others.
Every time people talk to their doctors (or any member of their care team) about their end-of-life wishes, it helps ensure that their wishes will be properly respected.
Questions for Your Return Visit

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**Physician Orders for Scope of Treatment (POST)**

**What Is a POST Form?**
A POST form is a doctor’s order that helps you control medical care at the end of life. Like a Do-Not-Resuscitate (DNR) order, the form tells emergency medical services (EMS) personnel and other health care providers whether or not to administer cardiopulmonary resuscitation (CPR) in the event of a medical emergency. A POST form may be used in addition to -- or instead of -- a DNR order. The POST form may also provide other information about your wishes for end-of-life health care.

**How to Make a POST Form**
A health care professional can help you create a POST form if you have an advanced, progressive medical condition and you enter a medical facility or health care setting -- such as a hospital, nursing home, or hospice care in a facility or at home. To be legally valid, a POST form must be dated and signed by a doctor (Indiana Code § 16-36-6-8). If a member of the medical staff does not ask you whether you want to create a POST form, you may ask for one. A POST form is usually printed on brightly colored paper so it will easily stand out in your medical records. The form travels with you if you move from one health care setting to another. You can change it or cancel it at any time.

**How Does a POST Form Differ From Other Health Care Directives?**
A POST form differs from a DNR order in one important way: A POST form also includes directions about life-sustaining measures in addition to CPR, such as intubation, antibiotic use, and feeding tubes. The POST form helps medical providers understand your wishes at a glance, but it is not a substitute for a properly prepared Living Will and durable Power of Attorney for health care.

Taken together, a Living Will and durable Power of Attorney for health care provide more information than a POST form, including details about your chosen attorney-in-fact and health care representative, more complete health care wishes, and your preferences for organ donation. Therefore, if you have a POST form, you do not need a DNR order, but you should still complete these two additional health care directives to provide a full set of wishes about your care.

A copy of the Indiana POST form has been provided in the back pocket of this toolkit. While this form is acceptable in most states, please check your state’s regulations by going to http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289.

Please place the enclosed decal on or near your front door so it is visible to EMS personnel. Your POST form should be kept on the refrigerator using the magnet included in your packet. Another option is to keep it with your prescription medications. EMS personnel will take your POST form when they transport you to the hospital.

Indiana’s Physician Orders for Scope of Treatment (POST) Form
Quick Links

Alzheimer’s Association
  - www.alz.org

Caring Connections
  - www.caringinfo.org

Centers for Disease Control
  - http://www.cdc.gov/

Indiana's Physician Orders for Scope of Treatment (POST) Form

MedicineNet

Next Step In Care
  - www.nextstepincare.org

Ohio Department of Aging
  - http://www.goldenbuckeye.com

The Conversation Project
  - theconversationproject.org
    - National Survey by The Conversation Project 2013.
  - California Health Care Foundation
    - Survey of Californians by the California Health Care Foundation
  - Centers for Disease Control
    - http://www.cdc.gov/