



# How To Talk To Your Doctor

Discussing end-of-life care with your doctor, nurse, or other health care provider.



CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

**Generously distributed by:** Kokua Mau - A Movement to Improve Care

**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](http://theconversationproject.org).)

After you've had the conversation with your loved ones, the next step is talking to your health care team 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.

NAME \_\_\_\_\_

DATE \_\_\_\_\_

**HOW TO USE THIS GUIDE**

You can use this guide as a workbook to make notes of what to tell your health care team — whether you're getting ready to discuss your own wishes, or you're helping someone else get ready to discuss theirs.

**TABLE OF CONTENTS**

**Step 1: Get Ready** . . . . . 2

**Step 2: Get Set** . . . . . 3

**Step 3: Go** . . . . . 6

**Step 4: Keep Going** . . . . . 9

This document does not seek to provide legal advice. ©2017 The Conversation Project. All rights reserved.

# 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](http://theconversationproject.org).*

The next step is to have a conversation with your health care team:

- **Ask your care team to explain where things stand with your health today, and what the future may hold.** Your care team can explain the available treatment options — and the chances of certain treatment options working. Be sure to ask questions if anything is unclear. (Note: It's important to understand that even for the care team there is often a lot of uncertainty — both about the course of your illness, and about how different treatment options will work.)
- **Also, let your care team know your goals and preferences, especially regarding end-of-life care.** You're the expert about what matters most to you.

Then together, you and your care team can decide which treatment options are right for you — especially if you or your loved one experience a dramatic change in health.

*Note: Medicare Part B (Medical Insurance) covers voluntary Advance Care Planning as part of your Yearly "Wellness" visit. This is planning for care you'd want to get if you become unable to speak for yourself.*

# Step 2 Get Set

When you're ready to talk to your health care team (or help someone else get ready to talk to theirs), **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, 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
- Your palliative care specialist
- 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
- After an urgent care 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 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. As we say in The Conversation Project, "It's always too soon... until it's too late."

---

## How else can you prepare yourself for the conversation?

### Here are some common medical terms that might come up:

- **Advance Care Planning:** Making plans now for the care you want when you have a serious illness. Part of planning could include giving guidance about decisions regarding end-of-life care and choosing a representative ("proxy" or "agent") to make decisions if you are unable to do so (Note: See [\*How To Choose a Health Care Proxy & How to Be a Health Care Proxy.\*](#))
- **Hospice Care:** Focuses on providing the person with serious illness and their family with comfort, pain relief, support services, and spiritual care when they are expected to live six months or less.
- **Palliative Care:** Care to help people get relief from pain, distress, psycho-social and spiritual distress, and other symptoms that can occur during an illness. A person can receive palliative care at any stage of a serious illness, including when getting treatment.
- **Shared Decision-Making:** A process in which clinicians and patients work together to make decisions and select tests, treatments, and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values.

Remember, your job is not to come up with a list of treatment options; that's your care team's job. Your role is to help your doctor or nurse understand what matters most to you. Then they can explain and 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.

**And here are brief explanations of some of the treatment options your care team might mention:**

- **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.
- **CPR (Cardiopulmonary Resuscitation):** If your heart stops, attempts are made to restart your heart with chest compressions or electricity.
- **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 (or any member of your health care team), **here are some ways you could break the ice.**

---

## Call or email your doctor's office 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 wishes regarding end-of-life care. 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 care wishes during my visit on Friday?"*

## 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 wishes for end-of-life care. 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 want to talk to you about my health care wishes and she’s my proxy. I want her to be part of this.”*

## **Here are some questions you can ask to help you understand your or your loved one’s medical problems.**

- In fact, it’s pretty hard to make decisions about the care you want to receive 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 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.

*"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 wishes for end-of-life care?"*

# 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. (Note: See our [\*Conversation Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia.\*](#))

## **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. (Note: See [How to Choose a Health Care Proxy & How to Be a Health Care Proxy](#).)

## **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.**

- 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.**

- 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.
- 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](http://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.

**For additional information about advance care planning in your area, please contact:**

#### Kokua Mau

PO Box 62155,  
Honolulu, HI 96839  
808-585-9977

[info@kokuamau.org](mailto:info@kokuamau.org)  
[www.kokuamau.org](http://www.kokuamau.org)



**KŌKUA MAU**  
***Continuous Care***

**A Movement to Improve Care**

## Contact Us

---

#### VISIT US

[www.theconversationproject.org](http://www.theconversationproject.org)

#### E-MAIL US

[conversationproject@ihi.org](mailto:conversationproject@ihi.org)

#### FOLLOW US ON FACEBOOK AND TWITTER

 @convoproject

 TheConversationProject