the conversation project
in central florida

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I HAVE TOO MANY PROJECTS. I'M FREAKING OUT.

EXPERTS SAY YOU SHOULD TACKLE THE MOST UNPLEASANT TASKS FIRST, SO YOU HAVE A FEELING OF ACCOMPLISHMENT AND CONTROL.

NOW I HAVE TOO MANY PROJECTS AND SOME EXTRA ANXIETY THAT I'M DOING THEM IN THE WRONG ORDER.

OFF YOU GO.
The Conversation Project

A national public engagement campaign dedicated to assure that everyone’s wishes for end of life are expressed and respected.
History of TCP

- Ellen Goodman
- Author, columnist, Pulitzer Prize winner 1980
- Experience with Mother’s illness
- Convened with friends and colleagues
- Founded TCP in 2010
- Collaboration with IHI in 2011
Institute of Medicine
“Dying in America”

Key Recommendations

- Person-centered/family-oriented care
- *Clinician-patient communication and advance care planning*
- Professional education and development
- Policies and payment solutions
- Meaningful dialogue about values, care goals, and preferences related to advanced serious illness
The Challenge

90% of Americans believe it is important to have end-of-life care discussions with their families, yet less than 30% have done so.

- Most people don’t want to think about one’s own death
- Family members might feel uncomfortable raising the subject of an older person's death
Failure to Act

60% of people say that making sure their family is not burdened by tough decisions is "extremely important" but 56% have not communicated their end-of-life wishes.

- Decisions are made on patient’s behalf by uncertain family members while they are under duress
- Decision makers are at a higher risk for mental health issues such as depression and anxiety
Patient-Provider Communication

80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care but just 7% report having had such a conversation with their doctor.

- 7/10 causes of death in 2010 were chronic diseases
- Conversations with provider
  - more likely to receive care consistent with preferences
  - less death in an ICU, fewer hospital days
  - better quality of life, lived 25% longer
My Story

It’s about family.
“You should always go to other people’s funerals, otherwise, they won’t come to yours.” Yogi Berra
Before I die

I want to...
swim the English Channel

LOVE GOD

LOVE and be loved unconditionally

I want to be

LOVE

WE SHOULD LEARN TO LOVE

AND JUST SIMPLY -

BE

GO TO SPACE

WANT TO SEE equality all over the world

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The Starter Kit
A Tool for Having the Conversation
Your Conversation Starter Kit
When it comes to end-of-life care, talking matters.

Su Guía de Iniciación a La Conversación

El Proyecto La Conversación tiene como objetivo el ayudar a las personas a reflexionar para que puedan expresar sus deseos relacionados con la etapa final de la vida.

Siempre hay conversaciones que son difíciles de afrontar, y sobre todo aquellas relacionadas con el final de la vida. Sin embargo, es una de las conversaciones más importantes que podemos tener con nuestras personas queridas.

Aquí nos referimos a ello como "La Conversación."

El presente documento es una herramienta que tiene como objetivo el ayudarte a reflexionar, para que después puedas tomar decisiones.

No se trata de una encuesta, ni de un formulario, sino de una guía para que nos sienten quienes sean la que usted desea. Y también para que pueda ayudarles a expresar sus deseos y de hablar sobre cómo deseasen ser cuidados durante la etapa final de la vida.

Lo que nos gustaría es que usasen fuerza en sus deseos y los de sus seres queridos. No los médicos, ni las enfermeras, ni los expertos en cuidados paliativos. Usted.
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.

Taking 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.

Your Conversation Starter Kit:
Having the Conversation with Your Child

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

We developed the original Conversation Starter Kit as a useful tool to help people have conversations with their family members or other loved ones about their wishes regarding end-of-life care. We know these conversations can be difficult. Even though people say it’s important to have the conversation, we all find lots of reasons to avoid actually doing it.

After we posted the Conversation Starter Kit on our website a few years ago, parents contacted us about the need for an additional resource: a Starter Kit specifically designed to help parents of seriously ill children who want guidance about “having the conversation” with their children.

We are not experts in this area, but we are parents, and it is with a lot of humility that we offer this new Starter Kit as a resource to help parents and loved ones begin a conversation with seriously ill children.

the conversation project
Institute for Healthcare Improvement
Created by The Conversation Project and the Institute for Healthcare Improvement
Get Ready

- What do you need to think about or do before you feel ready to have the conversation?
- Do you have any particular concerns that you want to be sure to talk about?
  - finances, family members who need special care
- Write a letter to yourself, family, or friend.
- Have a practice conversation with a friend.
Questions to Consider

- When you think about the last phase of your life, what’s most important to you?
- How would you like this phase to be?
- Are there circumstances that you would consider worse than death?
- Are there important milestones you would like to meet if possible?
Get Set

- What’s most important to you as you think about how you want to live at the end of your life?
- What do you value most?
- What matters to me at the end of life is...
What Matters to Me

- I want to say goodbye to everyone I love, have one last look at the ocean, listen to some 90’s music, and go.”
- “A tingling sensation of sadness combined with gratitude and overflowing love for what I leave behind.”
- “Paced (and with enough space and comfort so that I can make it a ‘quality chapter’ in my life.) I want time and help to finish things.”
- “Having my sheets untucked around my feet!”
- “Peaceful, pain-free, with nothing left unsaid.”
- “In the hospital, with excellent nursing care.”
Get Set
Where I Stand Scales
As a patient, I’d like to know...

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<td>Only the basics about my condition and my treatment</td>
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<td>All the details about my condition and my treatment</td>
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How long do I want to receive medical care? What are my concerns about treatment?

1. Indefinitely, no matter how uncomfortable treatments are

2. I’m worried that I won’t get enough care.

3. Quality of life is more important to me than quantity

4. I’m worried that I’ll get overly aggressive care.
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<td></td>
<td>I want my loved ones to do exactly what I’ve said, even if it makes them a little uncomfortable</td>
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<td>I want my loved ones to do what brings them peace, even if it goes against what I’ve said</td>
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What are my preferences about where I want to be?

1. I wouldn’t mind spending my last days in a healthcare facility.
2. 
3. 
4. 
5. I want to spend my last days at home.
Three most important things

What do you feel are the three most important things that you want your friends, family and doctors to understand about your wishes and preferences for end of life care?

1. ____________________________
2. ____________________________
3. ____________________________
Go

Who do you want to talk to?

☐ Mom  ☐ Sister/Brother  ☐ Caregiver
☐ Dad  ☐ Minister/Priest/Rabbi  ☐ Other: ____________
☐ Child/Children  ☐ Friend  ☐
☐ Partner/Spouse  ☐ Doctor

When would be a good time to talk?

☐ The next big holiday  ☐ Before I get sick again  ☐ At the next family gathering
☐ Before my kid goes to college  ☐ Before the baby arrives  ☐ Other: ____________
☐ Before my next trip  ☐ The next time I visit my parents/adult children
Icebreakers

- “I need your help with something.”
- “I was thinking about what happened to ____, and it made me realize…”
- “Even though I’m okay right now, I’m worried that ____ and I want to be prepared.”
- “I need to think about the future. Will you help me?”
“A few conclusions become clear when we understand this: that our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one’s story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone’s lives.”

Atul Gawande

*Being Mortal: Medicine and What Matters in the End*
Recommended Reading/Viewing

  http://www.newyorker.com/magazine/2010/08/02/letting-go-2
- http://www.pbs.org/wgbh/pages/frontline/being-mortal/
References

- Besmartbewell.com
  https://www.youtube.com/watch?v=VTBtHTyKUwo
- http://www.cdc.gov/chronicdisease/overview/
References