

the conversation project



Introductions

- Name
- Organization
- Share a time when you experienced a “good” or “hard” death - either personally or professionally

5 minutes

TCP Founder Ellen Goodman







A public engagement campaign dedicated to assure
that everyone's wishes for end-of-life care are
expressed and respected.

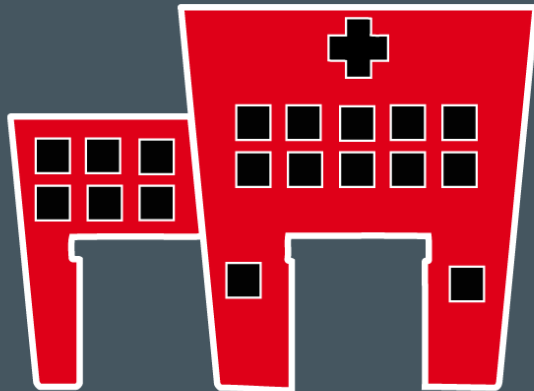
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70%



WANT TO DIE AT HOME.

70%



ACTUALLY DIE IN THE HOSPITAL

80%



WANT TO TALK WITH THEIR DOCTORS.



17%



HAVE HAD A CONVERSATION WITH THEIR DOCTORS



7%



HAVE HAD A CONVERSATION WITH THEIR DOCTORS

90%



**THINK IT'S IMPORTANT
TO HAVE THESE CONVERSATIONS**

30%



HAVE ACTUALLY DONE SO

“Maybe stories are just data with a soul.”

~ Brené Brown

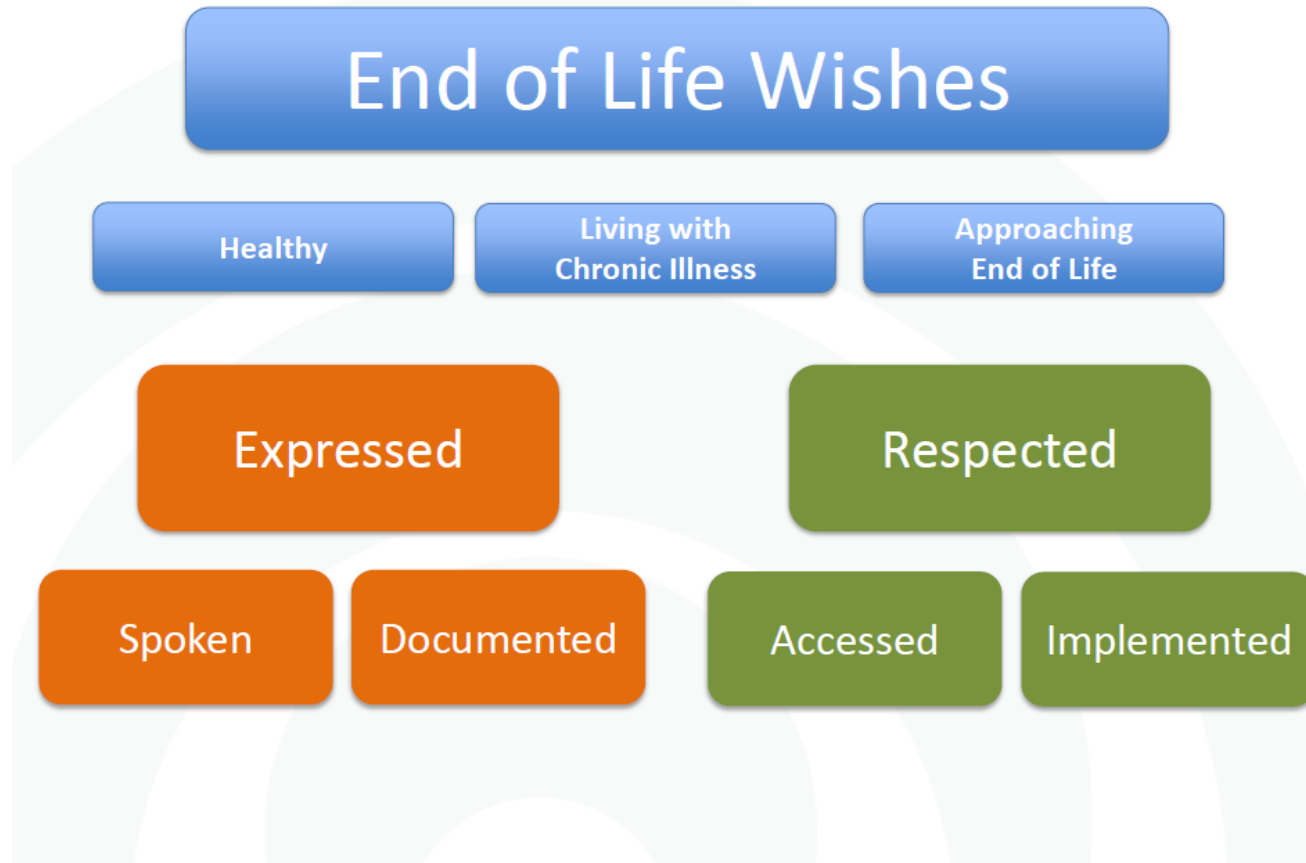
Signs of Cultural Change

- Mainstream
 - Dr. Atul Gawande's book "Being Mortal" and Dr. Paul Kalanithi's "When Breath Becomes Air" hit the best seller list
 - Opening weekend success of "The Fault in Our Stars"
 - The Writers Guilds East and West
 - Brittany Maynard's illness and death provokes national debate
 - Bi-partisan support for new legislation
- Medicine
 - The Institute of Medicine releases its report, "Dying in America"
 - Massachusetts rules that doctors must have a conversation about advance planning with terminally ill patients
 - **CMS now reimburses for End-of-Life Care Conversations**

Strategy for Creating Cultural Change

- **Awareness:** National media campaign and community engagement events
- **Accessible:** Tools to help people get started
- **Available:** Bringing TCP to people where they work, where they live, where they pray and where they receive care

The Conversation Continuum



Awareness: Media Engagement



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



*When it comes to
end-of-life care,
one
conversation can
make
all the difference.*

Let's Talk.

Begin Your Conversation Today.

[starter kit »](#)



We've Had the Conversation. **Have You?**

Accessible: Our Tools

- Conversation Starter Kit (translations + EMR summary)
- How to Talk to Your Doctor Starter Kit
- Starter Kit for Parents of Seriously Ill Children
- Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia





Your Conversation Starter Kit

For Families and Loved Ones of People
with Alzheimer's Disease or Other
Forms of Dementia



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CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

Available: Where People Live, Work, and Pray

- Conversation Ready Communities: 400+ organizations in 40+ states
- Conversation Ready Companies: Tufts Health Plan, Goodyear Tire and Rubber Company, Fidelity and Dow Chemical bringing TCP to their employees
- Conversation Ready Health Systems: 40 systems
- Conversation Sabbath: an interfaith initiative started in Boston - engaging many faiths in November

The Conversation Starts with You



Setting the Table

- Literally – please set your table! Tablecloths out!
- How it works
 - Give current answers!
 - Personal, table, report out
- Ground rules

Example Ground Rules

- Privacy. Please do not share others' personal stories.
- Listen quietly. This is not a time to offer advice or solve problems.
- Turn off cell phones.
- Everyone is here as a person, not a "role" or "title."
- What else is important to people in the group?

The Starter Kit

Step 2 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? **Thinking about this will help you get ready to have the conversation.**

- ?** Now finish this sentence: **What matters to me at the end of life is...**
(For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)

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.”*
- *“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.”*

The Starter Kit: Get Set

How long do you want to receive medical care?

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

Indefinitely, no matter
how uncomfortable
treatments are

Quality of life is
more important to
me than quantity

.....

What are your concerns about treatment?

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

I'm worried that I won't
get enough care

I'm worried that I'll get
overly aggressive care

The Starter Kit: Go

MARK ALL THAT APPLY:

? WHO do you want to talk to?

- | | |
|---|---|
| <input type="checkbox"/> Mom | <input type="checkbox"/> Faith leader (Minister, Priest, Rabbi, Imam, etc.) |
| <input type="checkbox"/> Dad | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Child/Children | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> Caregiver |
| <input type="checkbox"/> Sister/Brother | <input type="checkbox"/> Other: <input type="text"/> |

? WHEN would be a good time to talk?

- | | |
|--|---|
| <input type="checkbox"/> The next holiday | <input type="checkbox"/> Before the baby arrives |
| <input type="checkbox"/> Before my child goes to college | <input type="checkbox"/> The next time I visit my parents/ adult children |
| <input type="checkbox"/> Before my next trip | <input type="checkbox"/> At the next family gathering |
| <input type="checkbox"/> Before I get sick again | <input type="checkbox"/> Other: <input type="text"/> |

When to Have “The Conversation”

- Early
 - Coming of Age – 18 & 21
- Often
 - Before a Medical Crisis – 30, 40, 50, 60, 70
- Major Life Event
 - College, Marriage, Children, Divorce, Medicare, Death in the Family
- Major Trip
- Newly Diagnosed with a Serious Illness

Icebreakers

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 , 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?"

"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."

The Starter Kit: Go

- Health Care Planning (HCP)
- Advance Directive (AD)
- Health Care Proxy
- Living Will
- MOLST/POLST

What Did You Learn?

- What plans did you make?
- Questions
- Concerns
- Surprises
- Trends

Leaving in Action

- Complete the Conversation Starter Kit
- Have the conversation
- Share the Conversation Starter Kit and other tools with friends and family
- Appoint a proxy, talk to your doctor, complete and Advance Directive
- Share your stories on our website
- Team up with local efforts in your region
- Join our monthly webinar for those interested in community efforts

Don't Panic – It's OK: A Letter to my Family

If you are faced with a decision that you're not ready for,

It's ok

I'll try to let you know what I would want for various circumstances,

But if you come to something we haven't anticipated,

It's ok

And if you come to a decision point and what you decide results in my death,

It's ok.

You don't need to worry that you've caused my death – you haven't –

I will die because of my illness or my body failing or whatever.

You don't need to feel responsible.

Forgiveness is not required,

But if you feel bad / responsible / guilty,

First of all don't and second of all,

You are loved and forgiven.

If you're faced with a snap decision, don't panic --

Choose comfort,

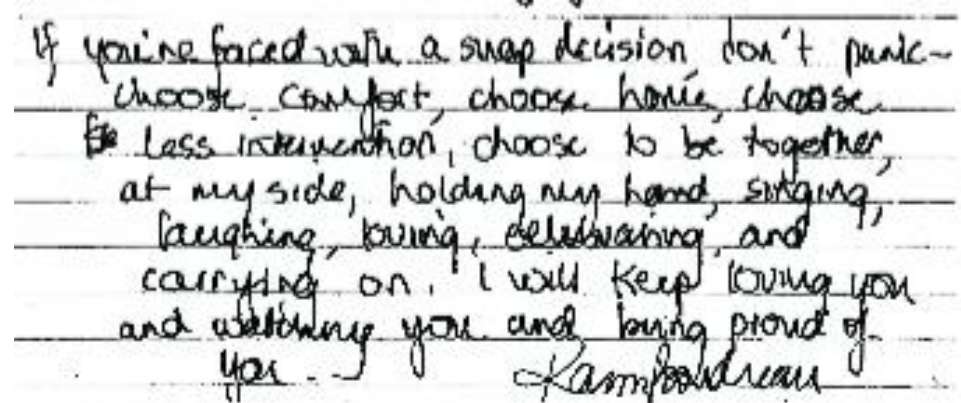
Choose home,

Choose less intervention,

Choose to be together, at my side, holding my hand,

Singing, laughing, loving, celebrating, and carrying on.

I will keep loving you and watching you and being proud of you.



If you're faced with a snap decision, don't panic --
choose comfort, choose home, choose
less intervention, choose to be together,
at my side, holding my hand, singing,
laughing, loving, celebrating, and
carrying on. I will keep loving you
and watching you and being proud of
you. - Kamryn

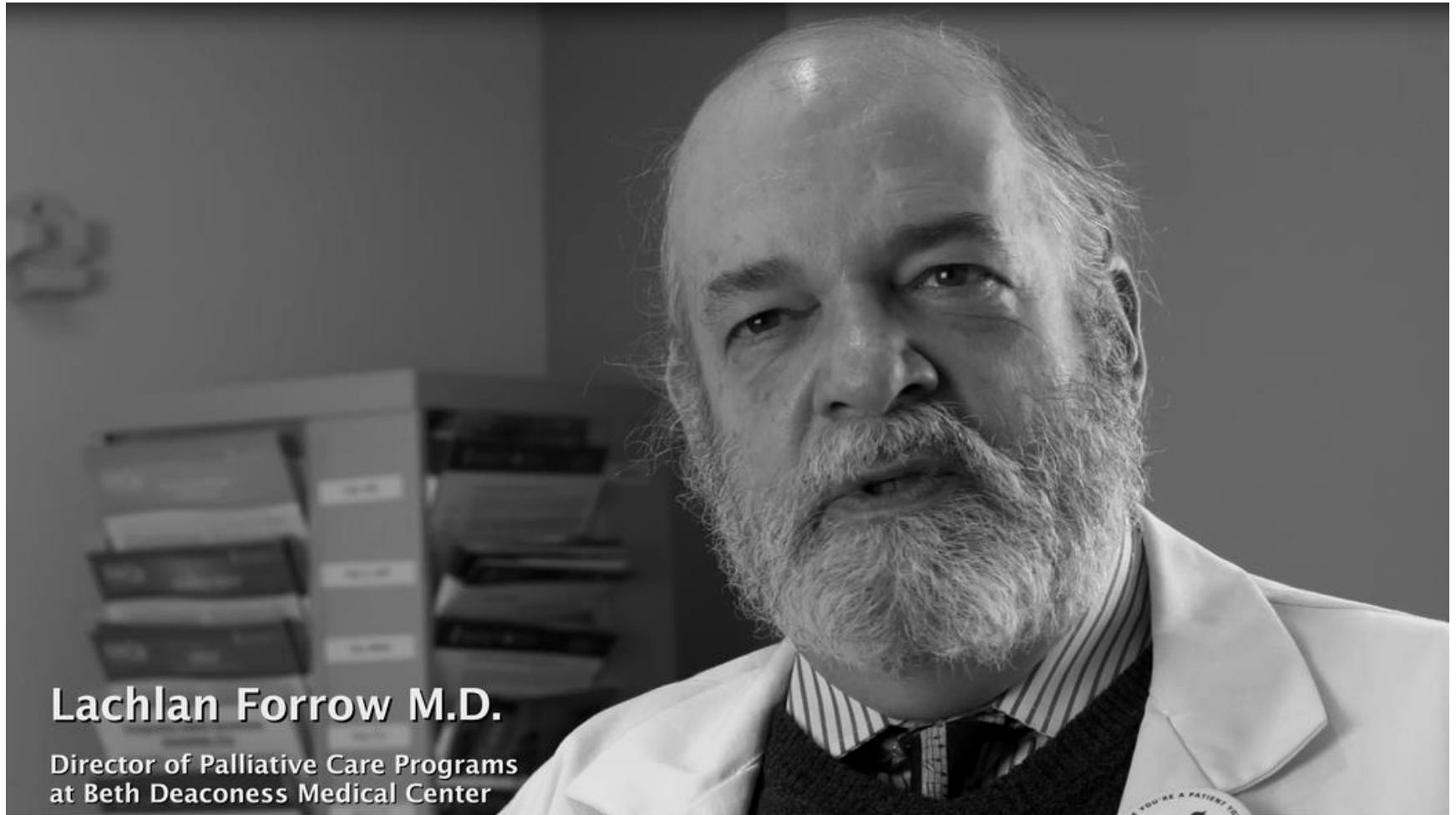
Questions?

Your name and organization

Your email address/phone number

www.theconversationproject.org

A Soul Doctor and a Jazz Singer



Lachlan Forrow M.D.

Director of Palliative Care Programs
at Beth Deaconess Medical Center