The Conversation Project
New Resources and Updates at TCP to Help Support “What Matters to Me” Conversations

September 16, 2020

Dr. Erik Fromme
Kate DeBartolo
Intros/Chat Warm Up

Type into the chat box:

Your location, organization and type of organization? (faith-based, healthcare, community, government, individual volunteer, etc.)

Make sure you send your message to “All Participants.”
On Today’s Call

Dr. Erik Fromme
Ariadne Labs

Kate DeBartolo
Senior Project Director

Krissy Cronin
Project Coordinator
Agenda

• Updates from TCP
• Introduction of our new patient guide to serious illness conversations with Ariadne Labs
• Time for Q&A
New at TCP

Helping people share their wishes for care through the end of life.

Get Started

What's New

Get Involved

Whether you're a health care professional, community volunteer, or faith leader, help us spread The Conversation Project to people where they work, live, and pray.
My Health

1. What is your understanding of your current health situation?

2. How much information about what might be ahead with your illness would you like from your health care team?

About Me

1. MY GOOD DAYS • What does a good day look like for you?
   Here are some things I like to do on a good day:
   EXAMPLES
   Have coffee with a friend • Sit in the garden • Go for a walk • Play the piano

2. MY HARD DAYS • What does a hard day look like for you?
   These are the toughest things for me to deal with on a hard day:
   EXAMPLES
   Can't get out of bed • In a lot of discomfort • No appetite • Don't feel like talking to anyone

3. MY GOALS • What are your most important goals if your health situation worsens?
   These are some things I would like to be able to do in the future:
   EXAMPLES
   Take my dog for a walk • Attend my son's wedding next September • Go to church services • Talk to my grandchildren when they come to visit
My Care

Everyone has their own preferences about the kind of care they do and don’t want to receive. Use the scales below to think about what you want at this time.

Note: These scales represent a range of feelings; there are no right or wrong answers.

1. What are your biggest fears and worries about the future with your health?

These are the main things I worry about:

- [ ]

EXAMPRESS
- I don’t want to become dependent
- I don’t want to be in pain
- I don’t want other people to see me in pain
- I don’t want to be a burden on my loved ones
- I’m worried that I won’t be able to get the care I want
- I don’t want to get stuck in a facility where no one will visit me

2. My strength • As you think about the future with your illness, what gives you strength?

These are my main sources of strength in difficult times:

- [ ]

EXAMPRESS
- My friends
- My family
- My faith
- My garden
- Myself ("I just do it")

3. My abilities • What abilities are so critical to your life that you can’t imagine living without them?

I want to keep going as long as I can

- [ ]

EXAMPRESS
- As long as I can sit up on the bed and occasionally talk to my grandchildren
- As long as I can eat ice cream and watch the football game on TV
- As long as I can recognize my loved ones
- As long as my heart is beating, even though I’m not conscious

When it comes to sharing information about my illness with others...

- [ ] I don’t want those close to me to know all the details about my illness
- [ ] I am comfortable with those close to me knowing all the details about my illness

If I become sicker, which matters more to me: Pursuing the possibility of a longer life, or pursuing the possibility of a good quality of life?
MY WISHES AND PREFERENCES • What wishes and preferences do you have for your care?

If my health situation worsens, here’s what I want to make sure DOES happen:

EXCEPTIONS
I want to stay as independent as possible • I want to get back home • I want my doctors to do absolutely everything they can to keep me alive • I want everybody to respect my wishes when I say I want to switch to comfort care only

And here’s what I want to make sure DOES NOT happen:

EXCEPTIONS
I don’t want to become a burden on my family • I don’t want to be alone • I don’t want to end up in the ICU on a lot of machines • I don’t want to be in pain

What else do you want to make sure your family, friends, and clinicians know about you and your wishes and preferences for care if you get sicker?

My People

Are there key people (family, friends, others) who will be involved in your care going forward?

Who would you want to make medical decisions on your behalf if you’re not able to? This person is often called your health care proxy, agent, or surrogate.

Name, contact info, relationship to me

Yes No I have talked with this person about what matters most to me.

Yes No I have filled out an official form naming this person as my health care proxy.

Yes No I have checked to make sure my health care team has a copy of the official proxy form.

Who are the main people who will be involved in your care (family members, friends, faith leaders)? For each person you list, be sure to include their phone number and relationship to you.

How much do they know about your wishes and preferences? What role do you want them to have in decision-making? When might you be able to talk to them about your wishes?

My Health Care Team

Who are the key clinicians involved in your care?

My primary care provider

Name

Phone number

My social worker

Name

Phone number

My main specialist

Name

Phone number

Other

Name

Phone number

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Two Approaches to Advance Care Planning

**Your Conversation Starter Kit**

When it comes to end-of-life care, talking matters.

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**Serious Illness Conversation Guide**

**Understanding**
- What is your understanding now of where you are with your illness?

**Information preferences**
- How much information about what is likely to be ahead with your illness would you like from me?
  - None required
  - Patient prefers to know about time, where to know what to expect, when to know what to expect, when to know what to expect.

**Propose**
- Share prognosis, tailored to information preferences

**Back**
- If your health situation worsens, what are your most important goals?

**Fears**
- What are your biggest fears and worries about the future with your health?

**Ewments**
- What abilities are so critical to your life that you can't imagine living without them?

**Sickies**
- If you become sicker, how much are you willing to go through for the possibility of gaining more time?

**Family**
- How much does your family know about your priorities and wishes?
  - (Support bringing family and/or health care team to next visit to discuss together)
Two Approaches to Advance Care Planning

- **The Conversation Starter Kit**
  - For any adult
  - To plan for and talk about end-of-life wishes
  - No experts needed

- **The Serious Illness Conversation Guide**
  - For seriously ill
  - To discuss values and goals if health situation worsens
  - Initiated by clinician
The What Matters to Me Workbook

- To help seriously ill patients and their important people prepare to talk to clinicians
  - Follows the questions and order of the Serious Illness Conv Guide
  - Uses simple language and structure similar to The Conversation Starter Kit

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Potential Use Cases

• Daughter downloads Workbook to complete with elderly mother, then brings to doctor’s appointment
  - Connects to “How to talk to your doctor”
• Clinician at health system that has implemented the Serious Illness Care Program gives the Workbook to a patient to complete and bring back next visit so they can discuss
• Others...what do you think?
Evaluation

- Using in-depth interviews and surveys of people (patients and caregiver dyads)
- Will ask them to actually complete the guide
- Trying to get as diverse a sample as we can — race, ethnicity, LGBTQ, disabled, etc.
- 4 questions: Utility, safety, acceptability, usefulness.
Interested in Being in the Research Study?

✓ If you have a serious illness, or
✓ If you are a friend or family member of someone with serious illness who would like to participate.

✓ 3 steps:
   1) Complete the Workbook
   2) Talk about it with someone (patient, family, clinician)
   3) Participate in an interview by phone or Zoom (~1 hour) and complete a questionnaire

To join – complete survey at the end of this call or reach out to Kate DeBartolo at kdebartolo@ihi.org
Q&A

• What do you think of the new workbook?
• How might you use this? (personally/professionally)
• Thoughts on getting the word out – who might be interested?
Ways to Engage with TCP’s Network

- Tweet us, tag us on social media
  - Twitter: @convopproject
  - Facebook: The Conversation Project
  - Instagram: convopproject
Ways to Engage with TCP’s Network

- Facebook discussion group

https://bit.ly/2ukc7B0
Ways to Engage with TCP’s Network

- Search, connect/network and learn together

https://theconversationproject.org/get-involved
Ways to Engage with TCP’s Network

• Monthly **Newsletters**
  – General Newsletter
  – Community Engagement Newsletter

• Sign up and share your events

https://theconversationproject.org/get-involved
Next Community Call: October

Reaching and harnessing the power of students

Stay tuned for date/time!

https://theconversationproject.org/get-involved
Thanks and Appreciation

The John A. Hartford Foundation
Dedicated to Improving the Care of Older Adults

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Additional Feedback?

- After this call you will be redirected to a survey form

Please take a few moments to answer if you have further feedback that you didn’t get to share today