The Conversation Project

ACP Messaging and Repurposing NHDD during COVID-19

April 9, 2020

Kate DeBartolo
Patty Webster
Christopher Joshi
Katie Nerney
The Conversation Project Field Team

Kate DeBartolo
Director

Patty Webster
Advisor, Community Engagement

Christopher Joshi
Project Coordinator

Katie Nerney
Project Assistant
Ice Breaker Question

Type into the chat box the following:

What is **one word** that causes you concern about the COVID-19 pandemic?

Make sure you send your message to “All Participants.”
Ice Breaker Question

Type into the chat box the following:

What is one word that causes you hope about the COVID-19 pandemic?

Make sure you send your message to “All Participants.”
On the call

Anna Gosline
Senior Director of Health Policy and Strategic Initiatives
Blue Cross Blue Shield of Massachusetts

Marisette Hasan, RN, BSN
President & CEO, The Carolinas Center
Co-Chair, CSI Advance Care Planning Workgroup

Nathan A. Kottkamp
Founder
National Healthcare Decisions Day
On the call:
Where are you located on the map?
Agenda

- New resources available
- Messaging in current climate and repurposing
  NHDD
- Open Discussion
- Q&A
New resources for general public


Being Prepared in the Time of COVID-19
Three Things You Can Do Now

This is a challenging time. There are many things that are out of our control. But there are some things we can do to help us be prepared – both for ourselves and the people we care about. Here are three important things each of us can do, right now, to be prepared.

1. Pick your person to be your health care decision maker
   Choose a health care decision maker (often known as a proxy, agent, or health care power of attorney) – a person who will make medical decisions for you if you become too sick to make them for yourself.
   - Here’s a simple guide to help you choose a health care decision maker.
   - Have a talk with your health care decision maker to make sure they know what matters most to you.
   - Make a plan to talk with your decision maker as soon as possible.
   - Phone calls or video chats are great if you don’t live with that person.
   - Fill out an official form naming your health care decision maker. Give one copy of the filled in form to your decision maker and one copy to your health care team.
   - Get a free health care power of attorney form here or download a form here from your state attorney general’s website.
   - In some states, you may not be able to create an official legal document. That’s okay! Writing it down is still better than nothing!

2. Talk about what matters most to you
   Talk with your important people and decision maker about what matters most.
   - The Conversation Starter Kit can help you get ready to talk to others about what matters most.
   - If you’ve already completed the Conversation Starter kit or have an Advance directive, review it with your loved ones to see if you want to make any changes or updates.
   - After you talk to your loved ones about what matters, talk to your health care team.
   - Call your primary care provider or specialist to set up a time to talk about this. Knowing what matters to you helps your care team provide better care that’s right for you.

YOU SHOULD KNOW
- First and foremost, do everything you can to stay healthy and safe: shelter at home, practice social distancing. Stay home. Clean your hands often. Avoid close contact. Cover coughs and sneezes.
- Most people who get COVID-19 get a mild or moderate illness and don’t need to go to the hospital.
- Those who get a severe case of COVID-19 are mostly people who are older or have other medical problems.
- Some people, especially those who are weak and healthy, will get better with routine hospital care. But many, especially those who are older and older, are not likely to survive even with a ventilator breathing machine.
- Some care may be held at home or in a long-term care facility in your community. This is known as hospice care. Some people may have to stay in a nursing facility, someone who may not have enough strength to function on their own.
- People who do not want intensive care should review care options. Intensive care may be possible at home in a nursing facility, especially with the care and support of your health care team.

3. Think about what you would want if you became seriously ill with COVID-19
   People who are older or have chronic medical conditions are more likely to become very sick if they get COVID-19. Some will recover with hospital care, but even with ventilator support many will die.
   Think about what you would want if you became very sick at this time:

   What would be most important to you? (Examples: Being comfortable. Poking all possible treatments.)

   What are you most worried about? (Examples: Being alone. Being in pain. Being a burden.)

   What is helping you through this difficult time? (Examples: My friends. My faith. My cat.)

   If you became very sick with COVID-19, would you prefer to stay where you live or go to the hospital?

   If you chose to go to the hospital, would you want to receive intensive care in the hospital?

   When you speak with your health care provider, ask if completing an HOSPITAL form would be appropriate or discuss what treatments you want to avoid if you become very sick.

   List any other questions or concerns you want to bring up with your friend/family provider:

   [Blank space for additional notes]
New resources for general public

18 Helpful Resources to Help You Navigate COVID-19

Posted on 04/04/2020

There’s a saying we often use on The Conversation Project team: “never worry alone.” This idiom is meant to encourage one another to express our concerns, if any, and to let our peers know how they can best support one another during challenging times. When we act on this sentiment, our team grows closer and our anxieties often subside. In the wake of COVID-19, we know there are many people who are experiencing different levels of anxiety. Well, we’re here to tell you that you don’t have to worry alone. We’ve compiled a sampling of resources to help you take care of yourself and others during this time. And, as you keep socially connected, we hope these resources will help you think through what matters most to you when it comes to medical care and help you talk about this with those that matter most to you. We hope these resources put your heart at ease.

NEW GUIDE!

Click here to download your Conversation Starter Kit!
Facebook Group: TCP Community Champions

https://bit.ly/2ukc7B0
Messaging in Current Climate & Repurposing NHDD
Five Consumer Segments

**Worried Action Takers** 10%
Younger, diverse, most educated. Nearly half identified as having a disability.

Highest trust and regard for the health care system. ~80% have been a caregiver for an incapacitated loved one.

**Self-Assured Action Takers** 24%
Oldest by far; most likely to be white and least likely to be low-income.

Confident about managing their health and navigating the health care system with fewer worries about a future serious illness.

**Disengaged Worriers** 34%
Youngest, most diverse, lowest education and income; poorest health and health care navigation and management skills.

Seen loved one’s wishes not honored. Many worries about their health and future serious illness.

**Confident Independents** 18%
Older (mostly 45+), average education and racial composition.

Fewer experiences with dying loved ones. Confident about managing their health and navigating the health care system with fewer worries about a future serious illness.

**Self-Reliant Skeptics** 14%
Middle-aged, lower income and education.

Lowest trust of doctors and regard for the health care system. Poorer health care self-management and navigation skills.
COVID-19 and Advance Care Planning

With funding from the Cambia Health Foundation, the Massachusetts Coalition for Serious Illness Care is working with local and national partners to provide public messaging guidance to support appropriate advance care planning at this time and create a consistent set of language for organizations to draw from.

Public Messaging Resource: Communicating with the Public About COVID-19 and Advance Care Planning

The Communicating with the Public About COVID-19 and Advance Care Planning Resource is derived from the Coalition's 2019 extensive and in-depth advance care planning communication research with members of the public, highlighting language and concepts that resonated with all segments of the population. In this resource, you will find messaging and social media posts that you can use in your work, adapt as needed and share with others in your network.

Download Resource
What are you seeing, what messages are resonating with folks now?

------

What are you doing/how are you reformatting NHDD?
Teeshla—If you’re going to be quarantined, you might as well take part in Health Care Decisions Month! Here’s how to get started.

A Way To Connect

Next month is South Carolina Health Care Decisions Month. In the time of “social distancing” we encourage you to use this month as a way to virtually connect with others.

What matters most to you? What are your wishes for the future, and what you would want if you became seriously ill?

Use our ACP Bubble Map to answer these questions, and then pick up the phone, start a video chat or send an email—have an open, honest conversation with someone important about #WhatMattersMost.

There is perhaps no more appropriate time for us to think and talk about these questions than while confronting the realities of a global pandemic.
Virtual opportunities

National Healthcare Decisions Day
April 16, 2020

National Healthcare Decisions Day (NHDD) aims to inspire, educate, and empower the public and providers around the importance of advance care planning. Just a third of adults in the U.S. have spoken with loved ones about their end-of-life preferences. We want to change that.

Join us April 15 for a live Zoom presentation covering COVID-19-specific advance care planning. On April 16, trained conversation coaches will be available via Zoom and by phone throughout the day to answer questions and provide the documents to ensure your wishes are respected, including specific coronavirus care preferences.

Advance Care Planning in the Era of COVID-19
Zoom Presentation
April 15, 2020 1-2pm
Join: trucare.zoom.us/j/757269831

Advance Directive Open House
Online or phone appointments available every 20 minutes.
April 16, 2020 8 a.m. - 6 p.m
Sign up: bit.ly/nhddsignup

If you are unable to attend, contact Amanda Moier at amanda.moier@trucare.org or (303) 250-4510 to schedule an advance directives coaching session. Online and telephone options are available.

Your Decisions Matter
8 hrs

Check out our interview with Rev. Emilie Boggis. She explains why having end-of-life conversations are especially important now, during COVID-19, and gives some great tips on how to do this when we’re social distancing.

Watch together with friends or with a group

Start

3 Shares

Like
Comment
Share
Virtual opportunities

CIVHC hosts activities for National Health Decisions Day (NHDD) • Thursday, April 16th, 2020

Center for Improving Value in Health Care (CIVHC) is an objective, not-for-profit organization. Through services, health data, and analytics, we partner with Colorado's health care systems to drive improvements in the delivery of care. A key initiative we have is to help providers educate and resources for Advance Care Planning (ACP) and host a bi-monthly ACP stakeholder meeting.

This is the second year that CIVHC has helped to lead the efforts here in Colorado. For more information about CIVHC or the ACP work, please reach out to Karin Degens and kdegens@chc.org.

Join us for any of the virtual opportunities to learn more and ask questions of experts about making your wishes known and documented. There is no cost associated with these events.

National Healthcare Decisions Day exists to inspire, educate and empower the public and providers about the importance of advance care planning. www.nhdd.org

CU Anschutz Multidisciplinary Center on Aging • Hillary Lum, MD, PhD

Thursday, April 16th from 3:00 p.m. to 4:00 p.m.

Dr. Lum will provide an overview of Advance Care Planning, why it is important for everyone and how to get started, or continue, on your Advance Care Planning journey. There is no cost to attend, it will be recorded and publicly available following the webinar.

- To register, please go to: https://uwinyuw.zoom.us/j/93665585000?pwd=WWZKdzZ3Y25Hb1ZQbV9QaDhTRm5XQT09
- Dr. Lum is a primary care geriatrician and palliative medicine physician. Her clinical practice helps inform her research on advance care planning (ACP) for older adults and their family members. Dr. Lum has done extensive research on Advance Care Planning and finding best practices for documenting patient preferences through Advance Care Planning. As part of this work, she and her team of colleagues at the University of Colorado School Of Medicine with stakeholder engagement, created a website for Advance Care Planning resources.

For more information on Dr. Lum and ACP resources, please visit www.medscape.org and https://coloradoareaplanner.org/

The Conversation Project in Boulder County • Amanda Meier

TRU Community Care • Thursday, April 16th from 8:00 a.m. - 10:00 a.m.

Volunteers available to answer questions about Advance Care Planning and provide planning documents. Appointments in 20 minute blocks are required to ensure privacy. There is no cost to these resources.

- To schedule your time please go to: https://www.medscape.org/viewarticle/956656
- If you are not comfortable using zoom, please call 303-395-6516.
- English and Spanish-speaking volunteers will be available

For more information, including Advance Care Planning starter kit please visit: http://theconversationprojectinboulder.org/

The Denver Hospice • Melissa Davis

The Colorado Cancer Coalition (CCC) will have a special presentation at 1:00 pm focusing on Advance Care Planning (ACP). Please feel free to register for the full event or just to join at 1:00. The Colorado Cancer Coalition is a statewide collaborative working to address the burden of cancer in Colorado. We provide providers, patients, survivors, and caregivers with essential resources.

In addition to ACP, the meeting will feature updates on COVID-19 and implications for Cancer Patients and Survivors.

There is no cost to attend.

- Registration: https://denver.zoom.us/meeting/register/tNJwquezqz5lEw44Z7ErMRY5Fls54WxKrGZw
- Melissa Davis is a Licensed Social Worker with The Denver Hospice and Optio Palliative Care. After earning her BA in Psychology from the University of Northern Colorado, she moved to Scotland and attended the University of Edinburgh to pursue her Master’s Degree in Social Work. She worked as a case manager there until 2011, at which time she moved back to her home state of Colorado. She has continued her social work career, focused on working with people with chronic and terminal illnesses. Melissa is highly experienced in hospice client and their loved ones negotiate difficult transitions and losses. Melissa is deeply passionate about end-of-life care, grief support and educating social workers and healthcare professionals about these topics.

To learn more about The Colorado Cancer Coalition, please go to: https://www.coloradocancercoalition.org/
To learn more about The Denver Hospice, please go to: https://thedenverhospice.org/
CHAT/RAISE HAND

What are you seeing, what messages are resonating with folks now?

-------

What are you doing/how are you reformatting NHDD?
Questions?
Jump Starters

Pairing articles in the news with planning guides

Continue to Share

- Tweet us, tag us on social media
  - Twitter: @convopproject
  - Facebook: The Conversation Project
  - Instagram: convopproject

- Join our Facebook Discussion Group for Community Champions
Other ways to Engage with TCP’s network

- Sign up and share: Monthly **Newsletters**
  - General Newsletter
  - Community Engagement Newsletter
  - NHDD

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

- Search, connect/network and learn together

Conversation Champions Map

- Connect with others doing similar work in your area.
- You can search by location, organization, name, and filter by setting, faith, health care, or community. Feel free to reach out directly to members on the map via their listed contact information.
- **Apply here** to be listed on the map if you are actively sharing TCP resources and/or messaging.

The Conversation Project (TCP) relies on the Conversation Champions, like the ones listed on the map below, to help spread the importance of end-of-life care conversations in their communities. These groups plan their own programming using TCP resources or messaging (in addition to their own). As a reminder, TCP has no position on what someone’s wishes for end-of-life care should be — we just want folks to start talking about it. Please read more about our principles [here](https://theconversationproject.org/get-involved).
Ways to engage with TCP

Quarterly **Community Activity Survey** is open

https://www.surveymonkey.com/r/5TNFK3F

THANK YOU to all participants so far
Opportunity: COVID-19 and Equity Call

Wednesday, April 15 from 1:00-2:00 PM ET
To enroll: click here
Hosted by IHI Pursuing Equity Team

Call Objectives:
- Increase our knowledge on how equity plays a role in the current COVID-19 crisis
- Share promising practices on leveraging an equity lens to improve care during this time

More info/link will be shared in post-call follow-up!
Thanks and appreciation

The John A. Hartford Foundation
Dedicated to Improving the Care of Older Adults
We want your feedback!

After this call you will be redirected to a Survey Monkey form

Please take a few moments to answer the following questions:

- How useful was this session on a scale from 1-5?
- Given today’s topic, what would you like to learn more about?
- Any other comments on today's session?