Welcome to the COVID-19 and Cancer ECHO Series

Use the Q&A portal throughout today’s session to submit your questions! Our expert faculty will be answering your questions live.

All ECHOs take place on the Zoom platform. Review Zoom’s privacy policy at zoom.us/privacy.

This ECHO will be recorded.
Erin Kent, PhD, MS
Associate Professor
University of North Carolina at Chapel Hill
## Today’s agenda

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<th>Didactic presentations</th>
<th>J. Nicholas Dionne-Odom, PhD, APRN, ACHPN, FPCN</th>
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<td>Matthew Loscalzo, L.C.S.W., APOS Fellow</td>
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<th>Question and answer session</th>
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<th>Wrap-up</th>
<th>Kristen Wehling, MPH</th>
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Introductions
INTRODUCTIONS

Expert faculty panel

Durado Brooks, MD, MPH
Vice President, Prevention and Early Detection
American Cancer Society

Rachel Cannady
Strategic Director, Cancer Caregiver Support
American Cancer Society

J. Nicholas Dionne-Odom, PhD, APRN, ACHPN, FPCN
Assistant Professor, School of Nursing, University of Alabama at Birmingham
Co-Director, Caregiver and Bereavement Support Services, UAB Center for Palliative and Supportive Care

Matthew Loscalzo, L.C.S.W., APOS Fellow
Liliane Elkins Professor in Supportive Care Programs (NPI 1437690500)
City of Hope
Didactic presentation
J. Nicholas Dionne-Odom, PhD, APRN, ACHPN, FPCN
Assistant Professor, School of Nursing
University of Alabama at Birmingham
Co-Director, Caregiver and Bereavement Support Services, UAB
Center for Palliative and Supportive Care
Planning for the Unexpected in the Time of COVID-19

J. Nicholas Dionne-Odom, PhD, RN, ACHPN
Assistant Professor | UAB School of Nursing
Co-Director | Caregiver and Bereavement Support Services
UAB Center for Palliative and Supportive Care
Email: dionneod@uab.edu
Twitter: @N_DionneOdomPhD
Key questions to consider

- What should I know about COVID-19 as family supporting family with cancer?
- What are some realities about COVID-19 that I need to be aware of?
- How do I have conversations that help me and my loved ones prepare for the future?
COVID-19: What are the initial signs and symptoms?

1. Cough (50%)
2. Fever (43%)
3. Muscle pain or achiness (36%)
4. Shortness of breath (29%)
5. Sore throat (20%)
6. Diarrhea (19%)
7. Nausea/vomiting (12%)
8. Loss of taste/smell, runny nose, abdominal pain (<10%)

Sources: Stokes et al., 2020, doi: 10.15585/mmwr.mm6924e2; Raymond et al., 2020, doi: 10.1007/s11523-020-00721-1
What can I do to protect myself and my loved one?

1. Avoid physical contact with others (physical distancing)
2. Avoid crowds, maintain 6 feet of distance from people when in public
3. Wear masks when out in public
4. Wash hands diligently (20 seconds) and frequently
5. Use hand sanitizer that is ≥60% alcohol
6. Avoid touching your face
7. Clean and disinfect objects that are frequently touched
8. Cover coughs and sneezes with a tissue or your elbow
9. Ensure adequate ventilation of indoor spaces

What do I do if myself and/or my loved one have COVID-19?

1. Notify patient’s oncologist

2. Stay home except to get medical care

3. Separate yourself from other people in the home as much as possible

4. Wear masks in the home if there is a mix of people in the home with and without the virus

5. Monitor your symptoms

6. Seek emergency care if: trouble breathing, pain/pressure in the chest, new confusion, inability to waken or stay awake, bluish lips or face (Call 911 or call ahead to your local emergency facility to let them know you are seeking care for someone who has COVID-19)

COVID-19 Realities

1. Those who have a severe case of COVID-19 are mostly people who are older and who have other medical problems (i.e., possibly the very individuals you may be caring for)

2. Individuals who are older and sicker with a severe case of COVID-19 are not likely to survive even with a ventilator

3. Those who survive may be left with disabilities and may not be regain enough strength and function to return home.

Sources: Raymond et al., 2020; Yang et al., 2020; Mo et al., 2020; Ahmed et al., 2020; Richardson et al., 2020; Grasselli et al., 2020
4. There are alternatives for people who do not want intensive care in a hospital, such as hospice.

5. Most hospitals have restrictions on family being present with patients, especially those with COVID-19.

6. Access to hospitals and intensive care may become limited over the coming weeks and months.

Sources: Hui et al., 2020
Talking about the future matters.

92% talking to others about end of life care is important.

21% haven’t had these conversations because they don’t want to upset their loved one.

32% have actually had these conversations.

53% say they’d be relieved if their loved one started a conversation.

95% say they are willing or want to talk about their wishes for end of life care.

Sources: The Conversation Project, 2020, www.theconversationproject.org
1. What do you need to think about or do before you feel ready to have a conversation?

2. Do you have any particular concerns that you want to be sure to talk about?

3. Consider some basics: When and where is a good time to talk? What do you want to be sure and say?

Remember:
• It’s okay to think about it.
• Consider practicing
• If you and your loved disagree, that’s okay
• Doesn’t have to be a single conversation, can be the first in a series
“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.”

“With everything happening with COVID-19, I’ve been thinking about this Fall/this next year. Can you help me?”
Step 3
What to talk about

“Let’s say you get really sick from COVID-19...”

What would be most important to you?
What would you be most worried about?
Would you prefer to stay home if you got really sick or go to the hospital?
If you went to the hospital, would you want to receive intensive care?
Are there any medical treatments you DO NOT want?
Who would you like to make decisions on your behalf if you’re not able to?
What other affairs do we need to have in order for you/us?
Step 4
Complete important documents

1. Health care proxy
2. Advance directive/living will

Every state has its own advance directive forms: https://www.nhpco.org/patients-and-caregivers/advance-care-planning/advance-directives/

Important to remember:
• You DO NOT need a lawyer
• Can be changed anytime
• Make sure others, including healthcare team, are aware of/have a copy of these documents
1. **Be patient.** Most of us need time to think.

2. **No need to steer** these conversations. Just let them happen.

3. **Don’t judge.** A “good death” looks different to different people.

4. **Nothing is set in stone.** You and your loved one can always change your minds.

5. Every attempt at conversation is valuable. **Keep trying!**

6. You **don’t have to cover everything** in one sitting.
Thank you!

J. Nicholas Dionne-Odom, PhD, RN, ACHPN
Email: dionneod@uab.edu  Twitter: @N_DionneOdomPhD

Key resources on have conversations that matter:

- The Conversation Project
- American Cancer Society: How to Communicate as a Family Member
Matthew Loscalzo, L.C.S.W., APOS Fellow
Liliane Elkins Professor in Supportive Care Programs (NPI 1437690500)
City of Hope
Partners: Taking Care of Each Other

Matthew J. Loscalzo, L.C.S.W., APOS Fellow
Liliane Elkins Professor in Supportive Care Programs (NPI 1437690500)
Executive Director, Department of Supportive Care Medicine
Professor, Department of Population Sciences
City of Hope
Partners Matter, A Lot

- Illness is a problem, life threatening, a crisis
- Partners are often the primary support for each other
- Families are smaller so inter-dependence is greater
- Less social support for women from other women
- Families may be more isolated due to physical distances
- High expectations on same sex or heterosexual partners
- Unlike in the past, women seek emotional support from fewer others, partners struggle to know what to do, the health care setting makes no meaningful space for partners to support their partners, partners can be a life raft or a millstone
- Who else is going to teach the next generation how to care
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<th>For him (and him)</th>
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<tr>
<td>• Reflect before Reacting</td>
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<td>• Wise &amp; courageous</td>
<td>• Avoid the natural inclination to protect</td>
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<td>• Do not try to fix their problems</td>
<td>• No testing-say what you need</td>
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<td>• Listen without giving advice (unless asked)</td>
<td>• No mind reading, ask do not tell</td>
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<td>• Be open to them expressing their concerns as often as they need</td>
<td>• Stay in the present, no past hurts</td>
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<td>• Be physically and emotionally present</td>
<td>• Tell your partner what you really want</td>
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COVID-19 Stressed-out couples at home, doing what works!

- Healthy relationships take time and effort
- Beware. When one partner wins over the other, the relationship loses!

- Commit to learn about and respect each other’s perspectives
- Ask how to meet each other’s needs-specifics
- Generously recognize partners efforts
- Be flexible
- Request and give space as needed
- Triangulate challenges of the pandemic
  - There is you and your partner against COVID-19
- Choose one specific challenge to problem-solve together
- Plan for the large and small definable problems
  - Beginning --- middle --- end
- Decide to be proud of how you rise to the challenge
- Love gently
Resiliency means both bouncing back and moving forward, together!

1. We are objectively living in the safest time in human history
2. It is not possible to take the risk out of living
3. Give the benefit of the doubt to others, we are all stressed
4. Going back to normal is not good enough
5. It is absolutely possible to better manage our emotional responses
   - Be highly selective what/who you allow to access your invaluable attention
   - Be informed but not infirmed
   - Go on a Low Bad Information Diet
   - Avoid multiple sources of information, choose one
   - Quickly tell others who spread emotional contagion that they are upsetting you
   - Consciously seek out upbeat people and experiences
   - Be physically active

We are objectively living in the safest time in human history. Give the benefit of the doubt to others, we are all stressed. Going back to normal is not good enough. It is absolutely possible to better manage our emotional responses.
Let Us be Afraid, Courageous and Compassionate Together!

- Do not get entangled about the meaning and endless minutia of the crisis, but rather, focus on what you will personally do now to be proud of yourself.

  Accept and not waste energy either ignoring or becoming obsessed with the pandemic

  Feel and talk about your emotions when appropriate but not cause “emotion contagion” to others

  Be courageous in reaching out to professionals for guidance and support

  Be grateful for all that you have (index card)

  Decide you are going to look back and be proud of how you act during this challenging time.
Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom.

— Viktor E. Frankl —
Question and answer session
Use the Q&A portal to submit your questions
What are some out-of-the box or creative ways that caregivers and care recipients can support one another during COVID-19?
How do I keep my husband safe from infection? He has a blood cancer and is immune compromised.
What can I do to help when someone is “cancer free?”
What are the latest statistics on caregivers who get sick or depressed during or after their loved one’s experience with cancer?
What are some of the barriers that are preventing minority communities from seeking cancer services/supports for COVID-19?
What steps can we take to motivate our community to return to cancer screening?
Use the Q&A portal to submit your questions
For more information and COVID-19 resources, visit:

cancer.org
nccn.org/covid-19
cdc.gov

For more about what Project ECHO is doing to respond to COVID-19, visit echo.unm.edu/covid-19
Complete the **post-session evaluation** to help us improve future ECHO series.

Email [echo@cancer.org](mailto:echo@cancer.org) with questions.