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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Introductions
INTRODUCTIONS
Expert faculty panel

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

Laura Makaroff, DO
Senior Vice President, Prevention and Early Detection
American Cancer Society

Matthew Loscalzo, L.C.S.W., APOS Fellow
Liliane Elkins Professor in Supportive Care Programs (NPI 1437690500)
City of Hope
Didactic presentation
Today’s presenter

Rachel Cannady
Strategic Director, Cancer Caregiver Support
American Cancer Society
Cancer Information
Coping with a Cancer Diagnosis

• **Learn as much as you can about the type of cancer and its treatment**; it gives you a sense of control.

• **Express your feelings.** It may help to talk to trusted friends or relatives, or keep a journal. Some people emote through music or art.

• **Take care of yourself.** Take time to do something you enjoy every day.

• **Reach out to others who have provided care.** Having someone to relate to when feeling overwhelmed can help ease the stress of care.

• **Try to focus on what you can control, not what you can’t.** Finding ways to be hopeful can improve the quality of your life, which will allow for you to provide better care.

• **Seek help.** Talk to a doctor about any feelings of depression or anxiety.
Communication with the Cancer Care Team: cancer.org/questions

- **Find the right doctor(s).** Both you and your loved one should feel at ease with the doctor. In choosing a doctor as your main contact, some things you may want to ask are:
  - Will you be the one to coordinate care?
  - Will you keep the other doctors updated on what’s going on?

- **Deciding whether to go to all medical appointments.** Going to see the doctor with your loved one can also help your loved one if they forget to mention problems come home without the information you need.

- **Making the most of the time with the doctor.** The average doctor’s appointment is about 10 to 15 minutes or even less, so it helps to be ready with questions.
What is the exact name and location of the cancer?

What’s the stage of the cancer?

What treatments are recommended? How are they done, and how long do they take?

Will my loved one need to be in the hospital? When and for how long?
Talking Through Feelings

- **Anger and Frustration.** We often vent our worst feelings onto those close to us. Sometimes it can be hard to put into words the losses cancer brings and we rely on our emotions with anger and frustration being the most popular.

- **Acting Passive.** Acting childlike and looking for direction from others is one way of expressing helplessness.

- **Fear and Anxiety.** Uncertainty can create major emotional swings from time-to-time. Being scared and/or harsh to the ones we’re most comfortable with is common.

- **The Blame Game.** Sometimes people think they got cancer because of something they did or didn’t do; encouraging your loved one is the only way to move forward.
Caregiver Resource Guide

Caring for a Loved One with Cancer

What is a Cancer Caregiver? .................................................. 1
What Does a Caregiver Do? .................................................. 5
What Does It Feel Like to Be a Caregiver? ......................... 8
What If You Don’t Want to Be the Caregiver? ................. 8
You’ve Decided to Take Care of Yourself, Too .............. 9
Take a Break or Time For Yourself................................. 7
Know Your Limitations..................................................... 8
Finding Support for Yourself.............................................. 8
Ask Others to Help............................................................ 9
Caring for Your Children during This Time ................. 10
Being a Caregiver, and Keeping Your Job ................. 10
Keeping Your Health Insurance If You Have to Quit Your Job ................................................................. 11
If You Have Nicotine ................................................... 12
Making Health Insurance Decisions as a Cancer Caregiver ................................................................. 12
Caregiver Resource Guide: cancer.org/caregiverguide

- Cancer Caregiving
- Caregiver Self-Care
- Communication
- Cancer Information

- Cancer Treatment
- Patient Nutrition
- Coping
- Caregiver Resources

Online, interactive Guide
Free copy at 1-800-227-2345
DIDACTIC PRESENTATION

Caregiver Support Video Series: cancer.org/caregivervideos

**CAREGIVER SELF-CARE**
- Healthy Eating
- Physical Activity
- Stress Management
- Fear of Recurrence
- Relaxation

**PHYSICAL CARE TRAINING**
- Drain Care
- Pain Management
- Management of Side Effects
- Medication Management
- Signs of Infection
- Lifting

**ADVOCACY**
- How to effectively communicate the patient’s needs to the cancer care team
Today’s presenter

Matthew Loscalzo, L.C.S.W., APOS Fellow
Liliane Elkins Professor in Supportive Care Programs (NPI 1437690500)
City of Hope
Just Another Pandemic

a Strengths-based Approach to

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
Social and Physical Distancing is Against Human Nature/Instinct

Loss of connection is a loss, grief, vulnerability, exhaustion

Instinct is to be close when under threat but

- No touching, hugging and especially kissing
- Physical comforting tied to soothing life-long memories

- Cannot circle the wagons (tend and befriend)
- Isolated from family, elderly parents (to protect them)

- Cannot physically strike out (fight/flight/freeze)
Resiliency Means **Both** Bouncing Back and Moving Forward, Together!

- **Practical and realistic strengths-based behaviors**
- **Mutual Support**
- **Honest and Courageous Discussions**
- **Personal accountability, courage and compassion**
- **Maximize wellness and mental health for ourselves and our loved ones**
Sometimes, even if I stand in the middle of the room, no one acknowledges me.
What are Common Unspoken Fears in Caregivers and Families?

- Fear about contagion to me and/or my loved ones?
- Dying?
- Relationship disintegration?
- Anxiety about the future?
- Impact on children?
- Fatigue?
- Losing job?
- Finances?
- Not knowing how to cope?
- Feeling isolated?
- Lack of productivity?
Fear of Contagion

• The basics first...

• Quality mask, gloves, physical distance, fastidious personal cleanliness, avoid crowds of all kinds

• Avoid bodily fluids of others, including pets (sorry)

• Go on family outings during low population volume times

• Avoid groups, especially low inhibition/high risk settings

• Clearly and consistently communicate your need for high need for distance and safety:
  • Let’s make some space to keep us safe
  • Cover your face and keep 6 feet of space

• Be social, but at a distance

• Be creative!

• Others!

• The more complex the problem the more opportunities there are for change

• In the darkest of spaces you only need a little light to guide you and to know which way to go
COVID-19 Pandemic is New (Only) to Us

- There have been many other pandemics*
- Never before so many competing sources of *distressing* information
- Multiple levels of emotional contagion to a public health pandemic, economic collapse, politically charged environment, racial conflict

Normal Responses to the Threat of COVID-19 or Serious Illness

- Physical vulnerability
  - Brain has “negative bias”
  - Hot state (reflex)
- Control & Predictability
  - Confrontation with reality of only mitigating risk
- Connection
  - Threat to link with valued others
- Meaning
  - Question firmly held core beliefs
“Please, Lord, enough already.”
Undeniable Adaptive Realities

• The only reality we can be sure of is what we know right now

• No one really knows when (and if) the pandemic will be over

• “Waiting out” the pandemic is not an effective coping strategy
  ▪ Holding our breath is not a strategy, *it is abdication or a temper tantrum*

• Although we are all vulnerable
  ▪ We are also prolific problem-solvers
Re-Connect with your body
Breathing abdomen (low/slow)
Feel & remember this body experience

My Core Values
My thoughts /feelings are wind in the tops of the tree, passing cars on a highway, waves in the ocean
I own my value-driven behaviors
I am a work in progress

I am connected to something much bigger than myself
I grow best by getting/giving ongoing compassionate feedback
I am committed to being there for others
All interactions as opportunities to practice my core values
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
QUESTION AND ANSWER SESSION

Question 1

How is the pandemic impacting the care and/or treatment of cancer patients?
What are the key steps to consider when taking care of a spouse or loved one with cancer during the pandemic?
How can healthcare providers expand their reach to cancer caregivers during this pandemic?
How can we keep spirits positive for patients and caregivers when everyone is housebound?
What materials do you have available for depression and coping with cancer during this pandemic (English and Spanish)?
How should I respond to people with good intentions who bring food but the food is not what the patient likes or has no appetite for?
What are the latest statistics on caregivers who get sick or depressed during or after their loved one’s experience with cancer?
Use the Q&A portal to submit your questions
Wrap up
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
Join us Wednesday, September 16 at 2:00 ET

W R A P  U P

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

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• Discussion will focus on advanced symptom management and hard conversations about advanced disease.
Complete the **post-session evaluation** to submit your questions for our expert faculty panel!

Email **echo@cancer.org** with questions.