LGBTQIA+ Inclusive Care Near the End of Life: A Professional and Personal Perspective

with Kimberly Acquaviva
April 13, 2022
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Today’s Presenter

Kimberly Acquaviva, PhD, MSW, CSE, FNAP
Betty Norman Norris Endowed Professor
University of Virginia School of Nursing
LGBTQIA+ Inclusive Care Near the End of Life: A Professional and Personal Perspective

Kimberly D. Acquaviva, PhD, MSW, CSE, FNAP
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University of Virginia School of Nursing

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Learning Objectives

After attending this webinar, the participant will be able to:

• Describe ways in which health care professionals and institutions can be inclusive of LGBTQIA+ persons near the end of life;

• Explain why LGBTQIA+ patients near the end of life may hesitate to seek and/or receive support; and

• List one specific step they can take in the next 30 days to foster LGBTQIA+ inclusive end-of-life care.
A bit of background....
May 2017

Book Signing/book launch party
1453 EY | Langston Room | May 1, 2017
7:00 pm - 9:00 pm

Anchored in the evidence, extensively referenced, and written in plain language, LGBTQ-Inclusive Hospice & Palliative Care: A Practical Guide to Transforming Professional Practice will change the way readers approach their work with all patients and families, not just with those who are lesbian, gay, bisexual, transgender, gender non-conforming, queer, and/or questioning (LGBTQ). The book is published by Harrington Park Press and distributed by Columbia University Press.

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Please tag your pictures of today to compete with
#LGBTQinclusivecare

UVA NURSING
May 10, 2018

2018 LGBTQ+ Health Care Symposium: Embracing Inclusion & Diversity in Caring for the Whole Person.

May 10, 2018
7:00 - 5:00
Boar’s Head Inn, Charlottesville, VA

Provided by the office of Continuing Medical Education, University of Virginia School of Medicine and the School of Nursing, Continuing Education
January 29, 2019
We made some decisions that day:

- Forego futile treatment;
- Seek aggressive palliative care;
- Use our situation to educate others and advocate for LGBTQ-inclusive care;
- Share everything on social media; and
- Communicate clearly with friends and family about what would and wouldn’t be helpful.
The next 30 days....
February 3
February 6
February 6

Kim Acquaviva  
February 6 •

Dear family and friends,

One of the wonderful things about Facebook is the ability to stay in touch with so many people from various facets of our lives. While the following may seem like an impersonal way to communicate, when you read it we hope you understand that Kathy and I have limited energy to reach out to our many dear friends to communicate this directly.

Next Tuesday Kathy will undergo surgery for ovarian cancer. She’s had a cluster of seemingly unrelated symptoms for the past six months and while she’s seen several doctors, the diagnosis wasn’t made until last week (on my birthday -that’s why I’ve been so quiet on FB).

As you know our family has had a difficult six months with the death of Kathy’s mother and my grandmother. Kathy, Greyson, and I are eternally grateful for the support we’ve received during this time. We know that many of you will want to continue to be helpful during this time and we so appreciate it.

At this point we are all okay. Greyson is receiving amazing support from friends at Emerson, and Kathy and I have had many wonderful offers of help already.

I’ll post an update after the surgery sometime next Tuesday. Until then thank you for the prayers, best wishes, etc. that we know you will send our way.

I put together these FAQ’s based on actual questions I’ve already been asked. 😊

FAQ’s

Q: OMG - why didn’t the doctor catch this sooner? She had all the classic symptoms of ovarian cancer. How did they miss this? Didn’t she go to the doctor?

A: Kathy was first seen by several clinicians for her symptoms in late August of last year. At that time, they thought she had a kidney infection. Since then, she’s been seen by a number of fantastic physicians, nurse practitioners, and physician assistants. No one put the pieces of her history together until Kathy self-referred to a gastroenterologist who did bloodwork and then sent Kathy to the emergency room for a CT scan and ultrasound. There’s no one to blame – every healthcare professional who saw Kathy over the 6 months she’s been symptomatic did the best they could given the limitations of our disjointed healthcare system. Imagine a machine lobbing baseballs at someone rapid-fire. No matter how good a player they are, they’re only going to hit a handful of those balls. Blaming the player isn’t fair: It’s the machine that’s broken.

Q: Is there a history of ovarian cancer in Kathy’s family?

A: No, Kathy’s relatives live to be a gazillion years old and then get Alzheimer’s. My mom died of ovarian cancer at age 52. Out of every 100 women diagnosed with ovarian cancer, only 20-25 of them have a genetic mutation associated with ovarian cancer.

Q: Didn’t you realize Kathy was showing all the classic symptoms of ovarian cancer? It’s a textbook case. How did you miss this?

A: Everything seems obvious in hindsight. For example, I just realized you have the emotional intelligence of a gym sock. 😅
February 10
February 12
February 13

Kathy went into surgery last night (Tuesday) at 9:15pm. The surgery was over around 1:00am. The surgeon spent almost 45 minutes with me discussing the results of Kathy's surgery. From 1am until 4:30am, Kathy was in the ICU for post-surgical recovery. A little before 5am, they brought her to her room (room 512).

Here's what the surgeon found: Kathy's cancer is a high-grade serous carcinoma involving both ovaries and fallopian tubes, with metastases to the peritoneum and a spot in the abdomen. There was around 100 cc of ascites. It is either Stage IIIa or Stage IIIb, depending on what the pathologist finds in the omentum. The surgeon was able to remove all visible evidence of the cancer but at this stage, the disease is not curable.
February 14

I'm pretty sure I have the cutest Valentine ever. ❤️
February 15

The staff at Sibley Memorial Hospital really know how to make Kathy and I feel #queerandcaredfor. The care is LGBTQ-inclusive, clinically excellent, and welcoming of us as a couple. We're so grateful. 😊

When you strip away talk of chemo or “battling” cancer, people who care about you are left to deal with the gaping rawness of truth without the conversational balm provided by the futile pursuit of a cure.

ATTENTION VISITORS

PLEASE KEEP VISITS TO 15 MINUTES OR LESS.

THIS IS SCIENTIFICALLY PROVEN TO BE THE OPTIMAL LOVE DOSE PER VISIT.

THANK YOU!
February 18

Kim Acquaviva is with Kathy Brandt.
February 18

Kathy: Can you order me some sherbet?
Me: Honey, I love you but you don’t have hand cancer. Pick up the phone and order it.
Nurse we just met 1 minute ago: 😶
Me: We’ve been married for 18 years.
Nurse: Ahhhhh....

Jennifer Bass
Wait...the stairs lead to a window??? That's not very palliative. 😅

53m Like Reply
Update:

Kathy's oncologist called today with the results of the pathology report. The cancer is a Stage IIIb, which we expected, but we were surprised to learn (as was the oncologist) that Kathy's cancer was ovarian clear cell carcinoma, not a high-grade serous carcinoma as originally thought. Ovarian clear cell carcinomas are rare -- comprising only around 5% of ovarian cancer cases -- and have a much worse prognosis than high-grade serous carcinomas because they are aggressive and generally resistant to chemotherapy. The pathology report confirmed that there was cancer in both ovaries, both fallopian tubes, the omentum, the peritoneum, the surface of the rectum, and the abdomen. In addition, the pathology report indicated that Kathy has malignant ascites, generally considered to be a poor prognostic sign. Kathy's oncologist said it's difficult to know what the disease course will look like but we're definitely looking at a time frame of less than 9 months. The oncologist said we should expect to see the tumors grow back and potentially begin causing bowel obstructions in 3-4 months.
February 22

Kim Acquaviva
February 22 · 📌

Things I never thought I'd be doing at age 47:
1. Installing grab bars on our toilet.
2. Decarboxylating medical marijuana.
3. Contemplating a future without my wife in it.

Live your life today like it really counts. Because it does. 💖
February 24

Making medicinal olive oil for Kathy. (Add this to my list of things I never thought I’d be doing). I spilled some so now I smell like a mix of a vinaigrette and a frat house.
February 25

8:31

Kimberly Acquaviva 🇺🇸 @ki... · 30m

Death is this awkward elephant in the room that’s clearly sitting on my wife’s lap while the people around the two of us who are uncomfortable with dying pretend not to see it.

Don’t be afraid to look at the elephant. It won’t crawl into your lap. Not today, anyway.
February 27
February 28
I am so tired that anything could trigger tears. I’m tired in a way I have never been tired before. Moving my body takes more effort and I need more time to recover after doing something.

And that’s fine. I have time to rest between working to get the house ready to sell (Kim works, I rest). The problem is Kim is exhausted from everything she has been doing. So when I randomly start crying it disrupts her ability to get stuff done and she feels bad she can’t comfort me.

But here’s the thing, I’m not sad. My filter is just gone. Obliterated by exhaustion (and cancer) the loss of my filter means I might start crying while thinking about the nice lunch Kim and I had on Monday, or how proud I am of Greyson for all his hard work this semester.

I guess the good thing is, I’m right there feeling whatever I’m feeling, not trying to hide my tears. And Kim, dear patient Kim, is getting used to the instant waterworks.

Yesterday we put in an offer on a house in Charlottesville and it was accepted -- an exciting day but at the same time, bittersweet. It’s our dream house in a beautiful neighborhood in Charlottesville - it has literally every feature we were looking for. We were SO ecstatic the seller accepted our offer. But nothing dampens one’s home-buying enthusiasm quite like realizing this is the house in which your spouse is going to die over the summer. Or worse - the house your spouse will never live in if they die before move-in day mid-June. I want to host Thanksgiving with Kathy and have a house full of family and a basket full of crescent rolls I burned because I was too busy laughing to pay attention to the oven timer. I want to sit next to Kathy on Christmas morning wearing dorky matching pajamas and opening stockings with Greyson. I want the house to be an envelope Kathy, Grey, and I stuff full of memories over the next twenty years. Knowing Kathy won’t be with us a few months from now to stuff that envelope makes my heart hurt.

Stuff your envelope with memories today. That’s what we’ll be doing today.
May 9, 2019 by Kim Acquaviva, Beneficiary

An update from Kathy:

The disease is progressing. I knew it was, but I couldn’t tell. Now I can.

Cancer is growing in my abdomen. Fluid is building up and causing my belly to swell and even though we have the tube to drain the fluid, because the fluid is loculated, the drain can’t access all the fluid. Which is a bummer.

Right now my stomach doesn’t hurt much, but I can feel the pressure and know that it will just continue to grow over time.

I’m not scared of the pain. We have a meeting with palliative care to come up with a plan to address it. And I know that Kim and the team will keep me comfortable. It’s what the plan represents, the ticking clock.

May 29, 2019 by Kim Acquaviva, Beneficiary

Taco Tuesdays - an update from kb

There is a saying going around Facebook “It’s okay if you fall apart sometimes. Tacos fall apart and we still love them.” It’s a really great thing that Kim and Grey like tacos.

Between the depressants (medical marijuana), steroids, emotional goodbyes we’re saying to DC folks before the move, and navigating the depths of sadness I feel about leaving my family - I fall apart on a regular (multiple times a day) basis. It’s gotten to the point where it’s funny (sort of).
I am not a patient person. That's been true my entire life. I have so many memories of sitting by the door as a child, so annoyed that once again I was having to wait for my mother. I've never been a patient driver, I seek opportunities to pass someone, speed up, or quickly turn right on red.

So, it shouldn't surprise me that I'm still impatient. Pretty much every hospice person I know abides by the saying that people “die how they lived.” Meaning if someone is sweet and kind in life, they will likely act the same way until they die and if someone was mean and ornery, they'll continue to be that way until they die.

The cancer is spreading in my abdomen. It's been growing for a while but now I can actually feel the tumors.

The masses in my liver are causing increasing pain and discomfort. Fortunately, I've only had a few days with bad pain but when they happen, I'm pretty much glued to the couch all day, relying on my MMJ and the other tools in my pain control toolbox. I've decided I don't want to be completely “out of it,” so I'll take a little pain if it means I can be fully present with my family.

No matter what I do to control my symptoms, though, the underlying cause of those symptoms is increasingly evident: I'm dying. I'm jaundiced (yellow) from the masses in my liver, I get out of breath easily and need a hand as I climb steps or curb cuts. I have trouble getting up from a low sofa. I walk with my hands behind my back now in an attempt to counterbalance the big belly I'm hauling around. I can't walk around for more than 10 minutes without being completely exhausted and winded.

Sometimes I lose my balance because the weight of my abdomen is throwing off my center of gravity. My legs are skinny and my butt has disappeared and I'm rarely hungry and food doesn't taste the same anymore. I know it's a matter of weeks, not months. My family knows it too. I'm hoping to make it to late July, but I know that's a long shot.
An update from kb:

I’m ready.

Over the past few days I’ve decided I’m ready to die. That may sound like I’ve given up or want to die. That isn’t the case. I’ll try to describe it.

For me I think the transition started last week. We went to dinner and when we got home, I struggled mightily to get up the 5 steps to our front door. And to do so, I had to pull myself up using the banister, which was painful. I told Kim a few days later that I didn’t think I’d leave the house again.

Then I had another episode of having to drink Magnesium Citrate, reminding me that my bowels are still capable of bringing me down.

My pain is worse. My side hurts all the time and when I cough sometimes it hurts a lot. It’s taking much higher doses of MMJ to keep my pain under control. I want to be awake enough to enjoy time with my family so I know I’m under-treating my pain. I started a new medicine on Friday - olanzapine - that’s helped a lot with my nausea, anxiety, and emotionality. But weird new symptoms keep popping up. The latest one: genital lymphedema. (Kim has decided my drag queen name is “Puffy Pudenda”). Is this TMI? Probably. But I want people to know that dying isn’t like a Lifetime movie. It’s weird and your body betrays you and you’re constantly having to adjust.
A few minutes ago @Kathy_Brandt looked up and said with amazement in her voice, “I think I’ve slept through our entire marriage.”

My super-cute wife just asked me if my husband has a good job with the government.

I gave @Kathy_Brandt a bed bath and used dry shampoo to freshen up her hair. She woke up, smiled, and said “you’re kind of a bitch.” Then she asked me if I could get her “better advertising equipment.” And then she fell back asleep. #magic #hpm
Kathy: [crying] I'm going to DIE. I'm going to LEAVE you and Grey.

Me: I know, honey. We love you. We're going to miss you but we're going to be ok.

Me: A little piece of you will live on inside of us.

Kathy: [eyes fly open] What?! Is that why they took that piece of my arm?

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An update from Kim:

I haven't posted an update in awhile because I've only had the time and energy to post "micro" updates via social media (Twitter, Facebook, and Instagram). Kathy hasn't been able to get out of bed for almost a week and she's sleeping 99% of the time now. When she's awake, she's very confused but there are brief flickers of lucidity. In those moments when her head is clear, she tells Greyson and me that she loves us. I read cards, texts, emails, and social media messages to her and she cries happy tears.

Kathy's sleeping as I type this on my phone. It's 4am and I'm laying awake next to her, listening to her breathe. Thinking about the moment when my nighttime sound machine of 18 years will fall silent makes my heart hurt.
For the last 4-5 days, @Kathy_Brandt's short-term memory has been limited to about 15 seconds.

Last night and again this morning, she woke up confused and desperately wanting to get up to go to the bathroom.

Kathy went to the bathroom first this morning and fell back asleep, so it was a good time for me to hike.

While I was gone, @greyacquaviva laid in bed next to @Kathy_Brandt working on screenplay edits for his class.

This is the sweetness I saw when I got home.❤️
Kimberly Acquaviva @kmacquaviva · Jul 31
This morning @Kathy_Brandt wanted a t-shirt so I put one of her favorites on.

It's a t-shirt of mine with the Scout sign on the front and "OMHIDMB" on the back. It's a motto I've always tried to live by:

On
My
Honor
I
Will
Do
My
Best

❤️
Kimberly Acquaviva 🇩🇪 @kimacquaviva • Aug 1

It’s been a week since @Kathy_Brandt was last able to get out of bed.

I’m sitting next to her prepping lesson plans for my Health Policy class. ❤️

Kimberly Acquaviva 🇩🇪 @kimacquaviva • Aug 3

Greyson has been a kick-ass caregiver and I’m so proud of him!! ❤️❤️❤️

Greyson Acquaviva @greyacquaviva • Aug 3

It feels good to know that maybe other people will learn not to be scared of death and dying after reading my mom’s tweets.

I’ve learned so much this summer helping care for my mom. It’s sucked but I wouldn’t trade it for anything. ❤️ twitter.com/kimacquaviva/s...
I’m sharing this for non-medical people who have never heard the beginnings of a “death rattle.” (The death rattle is @Kathy_Brandt’s - the periodic snoring snorts are from Mitzi). The video is dark and jumpy but the sound is decent.

#hapc #hpm
An update from Kim:

Kathy died at 4:51 this morning. I had fallen asleep with my hand on her arm — both dogs were in the bedroom with us. I woke up around 3:30 am when I noticed her breathing change. I could tell she was close so I talked softly to her about her favorite beach and ocean waves and cobalt blue sea glass. She sighed deeply and that was it - she was gone. I washed her and contemplated putting a different outfit on her but then remembered how pragmatic she was. Instead, I pulled the covers up to tuck her in one last time, and then I brushed my teeth and took a shower. No idea why...maybe I just wanted the day to have something normal in it. I don’t know.

Mitzi was still laying in the bed watching over Kathy when I was done showering. I took both dogs out, brought them back inside, then went upstairs to wake up Greyson. Grey came downstairs and kissed Kathy goodbye. Then I turned on the oven and made cinnamon rolls. Kathy always made Greyson cinnamon rolls on the first day of school. It seemed like the right thing to do so I did it.
Barriers to LGBTQ-Inclusive Care Near the End of Life

1. Perceptual barriers to care
2. Financial barriers to care
3. Institutional barriers to care
Facilitators of LGBTQ-Inclusive Care Near the End of Life

- Nondiscrimination statement
- Employee benefits, orientation, and training
- Intake forms and processes
- Marketing and community engagement
What will you do in the next 30 days make care inclusive for LGBTQIA+ patients and families like mine?
Contact Info:

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Questions?

Post your questions in the Q&A box.
Ways to Engage

Organizations
- Become a Sustaining Supporter
- Become an Organizational Member
- Purchase our World Class Materials
- Sponsor the Premier Palliative Care Summit in CA, May 4 & 5
- Hire CCCC to Provide Training for your Staff

Individuals
- Attend the Annual Summit, May 4 & 5, 2022
- Participate in Palliative Care Webinars
- Make a donation! *Support the Movement!*
Wednesday, June 15

"Can We Still Have a Child After You're Gone?" Navigating the Challenges of Reproductive Planning with Terminally Ill Patients

Joanna Sharpless, MD
Assistant Professor, Division of Palliative Medicine
University of California, San Francisco (UCSF)