

Social Workers and LMHCs: How to Obtain Your Continuing Education Contact Hour for this Webinar

- ▶ Create a Username & Password at the NYU Silver CE Online Portal :
 - <https://sswforms.es.its.nyu.edu/>
- ▶ Log on to the “Continuing Education Online Portal for the NYU Silver School of Social Work” page, click on “All Events & Programs” tab
- ▶ Scroll down & select today’s webinar under “Online Learning”
- ▶ Click “Register”
- ▶ Fill in the billing information, click register, and pay the CE registration fee

Social Workers and LMHCs: How to Obtain Your Continuing Education Contact Hour for this Webinar, cont.

- ▶ After registering, you will receive a confirmation email with a link to complete an evaluation
- ▶ Once the evaluation is submitted, within 24 - 48 hours, log back on to NYU Silver CE Online Portal, go to “Your Registrations” and you will see “Take Assessment” in red next to the name of the program
- ▶ Complete assessment
- ▶ Once done, you will be directed how to download your CE certificate
- ▶ For Questions: Call us at 212-998-5973 or email us at silver.continuingeducation@nyu.edu

The New Grief

THE TRANSFORMATION OF DEATH AND
MOURNING

JOSEPH NOWINSKI, PH.D.



ctac

THE COMMUNITY TECHNICAL
ASSISTANCE CENTER OF NEW YORK

December 6,
2017

Discussion Question

- ▶ What are some of the challenges you face when working with families who face terminal illness?

▶ “Bereavement is a universal and integral part of our experience of love. It follows marriage as normally as marriage follows courtship or as autumn follows summer. It is not a truncation of the process but one of its phases; not the interruption of the dance, but the next figure.”

▶ **-C.S. Lewis**

-
- ▶ “If the dead be truly dead, why should they still be walking in my heart?”
 - ▶ **-Winnenap, Shoshone Medicine Man**

Death and Grief: The Way it Was

- ▶ **“Terminal” illness 50 years ago:**
 - ▶ Expected longevity often weeks to months
- ▶ Sudden death (e.g. from heart attack) not uncommon
 - ▶ Death as an “event”
 - ▶ Mourning as an individual matter

Elisabeth Kübler-Ross

- ▶ “On Death and Dying” (1970)
- ▶ Described a process that individuals experience when confronted with a terminal diagnosis
- ▶ Has been extended to describe what loved ones also experience
- ▶ 5 Stages: Denial, Anger, Bargaining, Depression, Acceptance

Joan Didion

- ▶ “The Year of Magical Thinking”
- ▶ Describes the response to sudden, unexpected death:
- ▶ ...not reading obituaries
- ▶ ...expecting husband to come home
- ▶ ...not looking in his closet

“Traditional” Grief

- ▶ = our response to the relatively sudden loss of an attachment
- ▶ Attachments define who we are: why we matter, why we are here
- ▶ Mourning is not the same for everyone: The stronger the attachment, the more profound our subsequent mourning will be

The New Grief

- ▶ = a process that begins with a diagnosis and go on for years (Elizabeth Edwards; Steve Jobs).
- ▶ Can lead to remission, control, and/or recurrence
- ▶ Involves the entire family
- ▶ Includes the patient

Dr. Peter Bach

- ▶ “Oh, Ruth, I think this is a cancer.”--Dr. Hiram Cody, a breast cancer surgeon, after an initial physical examination of Dr. Bach’s wife
- ▶ “And with that simple statement, down into the tunnel Ruth and I stumbled, into the strange, dehumanizing, aching, opaque and misunderstood world of cancer doctors and cancer care”

Ellen

- ▶ *“My initial diagnosis was in 1992. I was 47 years old, and it was 2 months after getting a clean mammogram. There was a puckering in the breast, and it turned out to be Stage 2 breast cancer.*
- ▶ *I did all the right things: mastectomy, chemo , Tamoxifen for 5 years. I wore a pink ribbon, I did the cancer walks. And I thought I was safe.... until September 2001, a day or two before the World Trade Center collapsed.*

Ellen's Story

- ▶ *On a routine mammogram, the radiologist said the words that send chills up your spine: "Let's take a few more pictures". It turned out to be stage I breast cancer in the other breast. A lumpectomy was recommended. I wanted to be done with cancer--not waiting for the other shoe to fall. So I decided on a mastectomy with all the accompanying treatments.*

Ellen's Story (con't)

- ▶ *One year later, in another routine scan, I learned the cancer was back and had spread. Neither the scan report nor my oncologist ever used the word metastatic—both used the term Stage 4. And would you believe, it took me several months to connect in my head that Stage 4 was metastatic! I was in shock. I'd had a bi-lateral mastectomy and still I got breast cancer - with no breasts!"*

The New Grief: *A Road Map*

- ▶ *Five Stages or Phases:*
 - ▶ **Crisis**
 - ▶ **Unity**
 - ▶ **Upheaval**
 - ▶ **Resolution**
 - ▶ **Renewal**

- ▶ *Stages are NOT separated by sharp lines*

The New Grief: *CRISIS*

- ▶ The new grief begins with a diagnosis: sometimes after a period of testing and consultation...
- ▶ Sometimes by surprise
- ▶ Most common initial reaction is **anxiety**, but...

Crisis

- ▶ ***Expect the unexpected:*** Although anxiety is the most typical first response to learning that we or a loved one has cancer, some people report feeling angry or resentful, or even terrified. Such reactions are normal. You may indeed experience anxiety, but don't be surprised if you also experience other emotions.

Factors Affecting *Crises* Reactions

- ▶ The role of the diagnosed loved one in the family:
- ▶ Financial
- ▶ Social
- ▶ The relationship between the loved one and other family members

John

- ▶ Father diagnosed with lung cancer
- ▶ Initial reaction: **Anger**
- ▶ “Now everyone will expect me to feel sorry for him!”
- ▶ Unresolved, avoided family issues can trigger unexpected initial reactions

Martin

- ▶ Age 42, bright but diagnosed with severe Asperger's disorder
- ▶ Lived with parents all his life
- ▶ Father died two years ago
- ▶ Two older sisters with families
- ▶ Mother recently diagnosed with brain cancer
- ▶ Martin's reaction: **Unconsolable Panic**

Crisis

- ▶ Typically, uncomfortable emotions and unresolved grievances are put “on the shelf” as...
- ▶ Loved ones unite around the patient
- ▶ One person usually emerges as the primary caretaker and “point person”

Crisis (con't)

- ▶ **Therapeutic Goals in the Crisis stage:**
 - ▶ *Listen*
 - ▶ *Normalize the diversity of reactions*
 - ▶ *Support the primary caretaker*
 - ▶ *Promote resilience*

Psychological Resilience

- ▶ Mediates the effects of trauma and crisis
- ▶ Resilience is associated with...
- ▶ Reduced depression and anxiety
- ▶ Better physical health

Resilience: *Life Has Meaning*

- ▶ As it pertains to life crises--including terminal illness--this belief promotes psychological resilience because it encourages people to believe that the crisis itself may have meaning for them, if only they are open to finding that meaning.
- ▶ In contrast, psychologically fragile persons are inclined to seek no meaning in crisis. They are much more likely to view themselves as victims of bad luck or, worse, of others' intentional efforts to make them miserable.

Resilience: *Crises Should be Expected*

- ▶ Some people believe that life is a smooth road. They are shocked to encounter a wall or an impasse or an unexpected ditch. These people are apt to react to problems as if they were more significant than they really are--and to draw false conclusions about their own fitness and abilities. They are more likely to throw up their hands and feel helpless.
- ▶ Resilient people approach life with no such expectations. They allow that there will be bumps in the road of life, and they are not overly put off when they hit one. They more or less keep their hands on the steering wheel.

Resilience: *We Create Our Own Luck*

- ▶ This is the opposite of believing that what happens to us in life is either the result of luck--good or bad--or of forces that are beyond our control. That is what psychologically fragile people are inclined to believe.
- ▶ The resilient person rejects the role of victim. Resilient people are inclined to believe that they can overcome adversity through determination, flexibility, and versatility and that it can build character and make a person stronger in the long run.

Resilience: *We Can Survive*

- ▶ While fragile people harbor inner doubts about whether they can survive a crisis, resilient men and women are confident in their ability to survive. Applied to the crisis of terminal illness, the resilient patient (and family) will be strong in their conviction that “we can get through this,” in other words, that this will not destroy the family.
- ▶ Some individuals within a family may be more resilient than others.

Resilience: *There are People I Can Turn To*

- ▶ Psychologically fragile people are more apt to be socially isolated. Rather than turning to others—for help, or simply to share their feelings—they stay bottled up
- ▶ Resilient people reach out to others and build a support network

Promoting Resilience

- ▶ Resilience will affect individuals (patient and loved ones) and the family as a whole as it works its way through the new grief
- ▶ Promote resilience through:
- ▶ *Cognitive role-playing* encouraging resilient versus fragile self-talk

The New Grief: *UNITY*

- ▶ Follows the initial, Crisis stage
- ▶ Grievances, negative feelings are typically still suppressed
- ▶ Advice from our interviewees: *“Lots of things to do! Try not to do it all alone!”*

Unity: Create a Team

- ▶ Identify friends, family members, colleagues, and clergy who you believe you can count on for support, for concrete help, or both
- ▶ Let them know about the diagnosis and prognosis and keep them informed as treatment progresses

Unity: Organize and Delegate

- ▶ See if there are a couple of people who would be willing to serve as “point persons” in the months ahead
- ▶ Assignments:
 - ▶ Attend doctors’ meetings and take notes
 - ▶ Research (treatment options, prognoses, side effects)
 - ▶ Facilitate communication among treaters
 - ▶ Helping Hands: babysitting, shopping, transportation
 - ▶ **DON’T WAIT FOR HELP! ASK FOR HELP!**

Unity: Meet the Payers

- ▶ Understand limits of medical coverage
- ▶ Understand the process for specialist consultation
- ▶ Understand the appeals process

Unity: Get Your House in Order

- ▶ If you have no will, have one made up
- ▶ Designate a health care proxy
- ▶ Grant power of attorney for financial matters
- ▶ Organize expenses so loved ones can understand them and assist as needed in paying them.
- ▶ *Do this sooner than later*

Unity: Communicate About Treatment Decisions

- ▶ Although the patient, obviously, has the final word, the team should include one physician who will coordinate the overall treatment plan, along with a small circle of trusted family and friends
- ▶ Do NOT assume that specialists will communicate with one another
- ▶ Communication is essential. Each person on the team should know as much as possible about each alternative that is considered

Tips for Families in the *Unity* Stage

- ▶ Beware of the sole caretaker!
- ▶ Avoid being non-specific: “Let me know if there is anything I can do”
- ▶ Pick something to do and do it
- ▶ Keep communication open—allow people to vent frustration

The New Grief: *UPHEAVAL*

- ▶ The process grinds on...
- ▶ ...*and on, and on, and on.*

Jennifer

- ▶ My parents have been divorced since I was 8 -- almost 27 years ago and I am an only child
- ▶ My dad, age 69, has had prostate cancer since 2000
- ▶ In December 2010 he was diagnosed with completely separate brain cancer, and in April we found out he has separate lung cancer and that his prostate cancer is metastatic

Jennifer (con't)

- ▶ Managing the rest of my life has been so hard. "Numbing exhaustion" is a constant state for me -- emotionally and physically. I feel like I can't even process and grieve because I need to keep going and doing the next thing and there is always some sort of crisis. I work full time as an online editor for a children's book publisher and can hardly focus on work, plus I am constantly on the phone with doctors and taking my dad to appointments. I've been married for three years and this situation has put so much strain on my relationship with my husband in so many ways.

Upheaval: Family Dynamics

- ▶ Lifestyles become skewed and out of balance as a result of added responsibilities
- ▶ Former family roles often re-emerge
- ▶ Unsettled conflicts and grievances resurface
- ▶ Stresses may threaten caregivers' relationships, families, and careers

Ambivalence

- ▶ A normal part of the Upheaval stage
- ▶ Is typically experienced by the patient as well as loved ones and caregivers
- ▶ Also experienced by caregivers' spouses and children
- ▶ Needs to be acknowledged
- ▶ *Therapeutic Goal: Help the patient and family give a voice to ambivalence as well frustration and stress. Help the family problem-solve*

Upheaval and Family Structure

- ▶ Chronic illness can impact family structure in terms of...
- ▶ ...individual roles & responsibilities
- ▶ ..rituals and traditions
- ▶ *Therapeutic Goal: Help the family maintain key traditions; facilitate balance in caregivers' lives*

Upheaval and Burnout

- ▶ Janice Kiecolt-Glaser, Ph.D., a psychologist at Ohio State University, studied the relationship between chronic stress, depression, and the immune system
- ▶ She looked at a sample of 47 men and women who were all caregivers to patients with Alzheimer's and found that all were experiencing moderate levels of depression—not serious enough to prevent them from functioning, but enough to affect their mood and their sleep.

Terminal Illness and Disability

- ▶ UnitedHealth Foundation and the National Alliance for Caregiving 2011 survey:
 - ▶ 96% of disabled veterans' primary caregivers are women
 - ▶ 70% of veterans' caregivers are their spouses
 - ▶ One in four disabled veterans are being cared for by their parents
 - ▶ 30% of veterans' caregivers have been in that role for *10 years* or more

Disability: Impact on Caregivers

- ▶ More than half of the caregivers in this survey who are parents reported that their children were having school and/or emotional problems
- ▶ Nearly two-thirds of these caregivers neglect their own basic health needs, such as scheduling regular physicals or dental visits
- ▶ When they themselves are sick these caregivers often don't go to the doctor

Upheaval: Complementary Treatments

- ▶ Yoga, Tai Chi, Acupuncture, Massage, Reiki, Meditation
- ▶ Have been found to reduce stress; some relieve pain and treatment side-effects
- ▶ Can help caregivers as well as the patient
- ▶ Research suggests: *Pick one and stick with it to achieve the best results*

Upheaval: Reaching Out through the Internet

- ▶ **The Internet offers opportunities for caregivers to:**
 - ▶ ...obtain information on issues ranging from...
 - ▶ ...treatment options to how to access entitlements
 - ▶ ...seek mutual support and advice
 - ▶ ...create a caregiving community e.g., www.LotsaHelpingHands.org.

Upheaval: More “To-do’s”

▶ **Create a “Just In Case” File:**

- ▶ Living will; durable power of attorney; springing power of attorney; advanced medical directives, etc.
- ▶ Letter of intent; desired funeral arrangements; etc.
- ▶ Computer and credit card passwords; important documents, etc.

The New Grief: *RESOLUTION*

- ▶ **Resolution = Opportunity...**
 - ▶ *...to alter one's role in the family*
 - ▶ *...to resolve grievances*
 - ▶ *...to heal wounds*
 - ▶ *...to build a more resilient family*
 - ▶ ***Versus...to leave the family fragmented***

John

- ▶ Perceived older brother to be favored child
- ▶ Harbored longstanding resentment toward father and brother
- ▶ *Identified source of resentment, role-played confrontation with father, and resolved his longstanding grievance*

The Family Inventory

- ▶ **A method for changing your family role:**
 - ▶ 1: Complete a “family role assessment”
 - ▶ 2: Design a new, desired role
 - ▶ 3: Try the new role on for size
- ▶ *Therapeutic Goal: Facilitate role change through coaching and role-playing*

Putting Unresolved Issues to Rest

▶ Guidelines:

- ▶ 1. Choose your issues carefully. Prioritize and don't try to take on too much too soon.
 - ▶ 2. Seek allies if possible
 - ▶ 3. Plan ahead
- ▶ 4. Don't assume bad intentions: Show respect for others while speaking your mind.

The New Grief: *RENEWAL*

- ▶ “If the dead be truly dead, why should they still be walking in my heart?”
 - ▶ – Winnenap, Shoshone Medicine Man

Renewal: Issues

- ▶ Death with Dignity
- ▶ Mourning
- ▶ Bonding and Continuity

Death with Dignity?

- ▶ The Atlas Project: Reported the results of 235,000 patients aged 65 and over who'd been diagnosed with advanced cancer and who'd died between 2003 and 2007
- ▶ Nearly one-third of these men and women had spent their final weeks in a hospital or a hospital intensive care unit, as opposed to at home or in a hospice
- ▶ Despite their nearness to death many of these men and women were the recipients of heroic efforts to extend their lives—even if only for a few days or weeks—such as surgery or chemotherapy

Death with Dignity: Scott Nearing's Funeral Instructions

- ▶ Unless the law requires, I direct that no undertaker, mortician, or other professional manipulator of corpses be consulted, be called in, or participate in any way in the disposal of my body
- ▶ I direct that as soon as convenient after my death my friends place my body in a plain wooden box made of spruce or pine boards; the body to be dressed in working clothes, and to be laid upon my sleeping bag. There is to be nor ornament or decoration of any kind in or on the box.

Death with Dignity

▶ **Take Control:**

- ▶ *Make sure your will and any letter of intent are current and accurate*
- ▶ Make sure your medical proxy and power of attorney is current
 - ▶ *Decide what kind of care you want and at what point*
- ▶ Decide where you want to be, and who should be there
 - ▶ *Plan your funeral*

Helen Nearing

- ▶ **On the loss of her husband, Scott, after 50 years of marriage:**
- ▶ *“Our love affair had lasted half a century and still goes on now, eight years after he died at the honorable age of one hundred. The love continues on my part, and on his side too, I believe. From where else could come the glad certainty every morning, evening, and hour of the day that I live in love and am charged with it—outgoing and incoming.”*

Thank You!



Reference

- ▶ **Saying Goodbye: A Guide to Coping with a Loved One's Terminal Illness**
- ▶ *Berkley, 2012*
- ▶ *Barbara Okun, PhD & Joseph Nowinski, PhD*

Q&A



Social Workers and LMHCs: How to Obtain Your Continuing Education Contact Hour for this Webinar

- ▶ Create a Username & Password at the NYU Silver CE Online Portal :
 - <https://sswforms.es.its.nyu.edu/>
- ▶ Log on to the “Continuing Education Online Portal for the NYU Silver School of Social Work” page, click on “All Events & Programs” tab
- ▶ Scroll down & select today’s webinar under “Online Learning”
- ▶ Click “Register”
- ▶ Fill in the billing information, click register, and pay the CE registration fee

Social Workers and LMHCs: How to Obtain Your Continuing Education Contact Hour for this Webinar, cont.

- ▶ After registering, you will receive a confirmation email with a link to complete an evaluation
- ▶ Once the evaluation is submitted, within 24 - 48 hours, log back on to NYU Silver CE Online Portal, go to “Your Registrations” and you will see “Take Assessment” in red next to the name of the program
- ▶ Complete assessment
- ▶ Once done, you will be directed how to download your CE certificate
- ▶ For Questions: Call us at 212-998-5973 or email us at silver.continuingeducation@nyu.edu

Upcoming Webinar

- ▶ **Part 3: *Beyond Kübler-Ross: New Perspectives in Death, Dying and Grief***

Presenter: Kenneth J. Doka, Ph.D.

Date/Time: December 14, 2017, 12pm-1pm