Navigating Grief with Patients and Their Families

25th Annual Barbara and Alan Echikson Memorial Palliative Care Symposium

What is Reflective of a Robust Palliative Care Program?

April 9, 2024

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Take a Moment to Breathe

Lets just take a minute to breathe. Long slow inhale through our nose and a longer slower exhale through our mouth. Repeat. Check in with yourself 1-10.

“People will forget what you said, people will forget what you did, but people will never forget the way you made them feel.”

-Maya Angelou

How We Will Spend Our Time

- Styles of grieving
- 4 tasks of grieving
- Working with families navigating grief
- Types of grief
- Occupational grief – Coping mechanisms and acknowledgement
- Resources for families and professionals

Dimensions of Loss

Finite Loss

Nonfinite Loss

MANY KINDS Of LOSSES

- A serious or chronic illness, traumatic accident
- Death or impending death of a loved one
- World trauma, disaster, pandemic, natural disasters
- A loved one affected with mental health disorders (depression, anxiety, substance abuse, alcohol dependence, PTSD, panic attacks)
- Divorce, separation, domestic violence, incarceration of loved one, deployment of a loved one
- Homelessness, poverty, food insecurity, community violence,
- Abuse, neglect, and other adverse childhood experiences,
- Loss of stable caregiver (foster care, adoption, custody issues)

Ambiguous Loss Types & Examples

T1: Physical Absence	T2: Psychological Absence
• Missing loved ones from abduction, military, college • Missing from war, terrorism or natural disaster • Abandonment • Adoption • Immigration	• Dementia/Alzheimer's • Mental Illness • Brain injury • Chronic Illness • Autism • Depression • Addiction • Workaholism

Loss in a Hospital

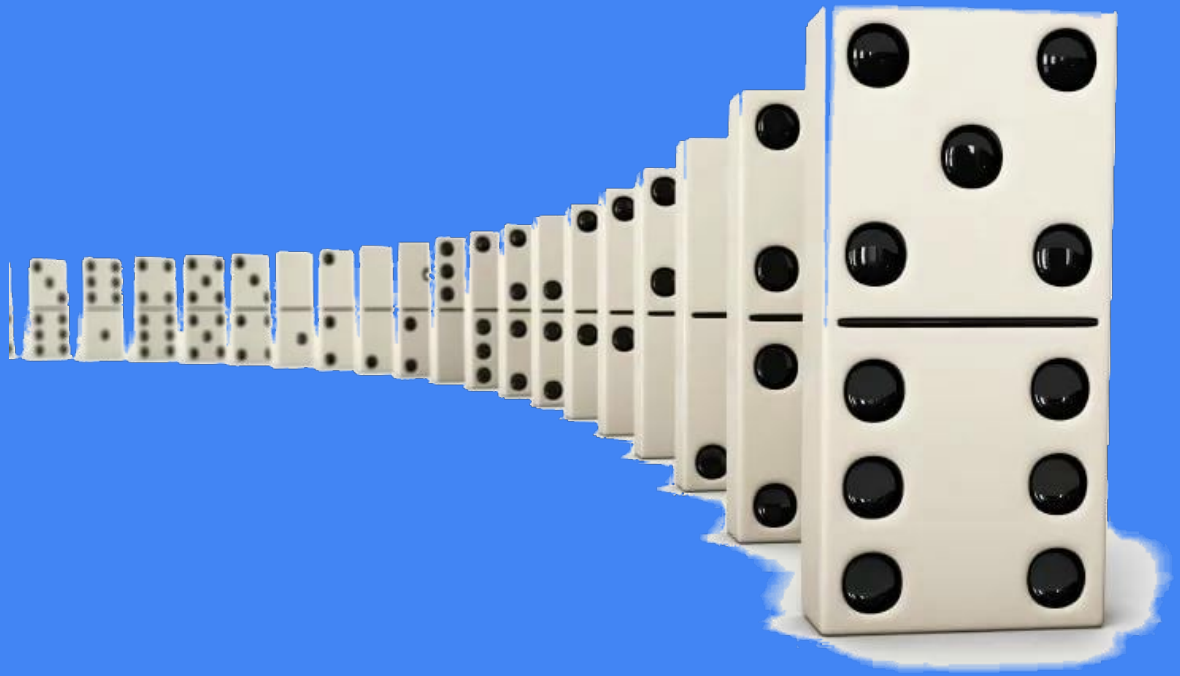
Families:

- Denial, death, or anticipated death of a loved one
- Illness, accident, disease
- Feeling a loss of control
- Pandemic effects and losses
- Loss of connection to medical team members

Health Care Professionals:

- Death of a patients during pandemic
- Limited time to process many losses
- Personal losses too
- Loss of connection to patients & families
- Sharing a life-changing diagnosis

The Dominoes and Loss



Compassionate Care

Supporting Someone After a Loss

- What to say
- What not to say
- What helps, what doesn’t help

Helping Someone in Grief

Do:

- **Say things like:**
  - I can't imagine what you are going through
  - There are no words
  - I don't know what to say but I am here.
  - I am here to listen if you feel like talking.
  - How are you today? *Not how are you?*
  - Is there anything that brings you even a bit of comfort?
- **Listen** to what they are saying and not saying.
- **Acknowledge** the loss and struggle.

Helping Someone in Grief

Don’t:

- Share platitudes
- Start any sentence with “at least”
- Try to fix them
- Talk too much
- Ignore their experience
- **Avoid saying:**
  - I know exactly how you feel
  - You must be feeling incredibly _____
  - I know this must be difficult, but it’s important to remember the good things in life too.
  - Be strong.
  - Move on or Get over it or Put it behind you
  - At least…
  - Don’t think about it, keep busy, be grateful for what you had…

Styles of Grieving

Intuitive	Instrumental	Cognitive
Experience and express grief as deep feeling	Experience and express grief in physical or behavioral ways	Experience and express grief cognitively, privately

Even counselors tend to disenfranchise instrumental and cognitive grievers. Larger community disenfranchises instrumental and cognitive grievers in early grief process; intuitive later in grieving process. Cultural differences.

4 Tasks of Mourning (J. William Worden, Harvard)

Author of Grief Counseling and Grief Therapy

1. **Accept** the reality of the loss
2. **Process** the pain of grief
3. **Adjust** to a world without the deceased
4. **Find** an enduring connection with the deceased while **embarking** on a new life

Supporting Grieving Families

- **Be Simple:** They can't process complicated medical information at this time
- **Be honest and transparent:** Tell the truth and help them understand the situation for themselves
- **Be compassionate:** Death of a loved one may be one of the worst days of the family member's life
- **Give them space:** The family needs space to process, as they can't hear anything beyond the patient's injuries being unsurvivable. They will come to you with their next questions when ready.
- **Offer follow through:** Assure the family that if patient is transferred to another unit you can still answer questions for them (if that's true).

Funny Quote

“A dysfunctional family is any family with more than one person in it.”

~ Mary Carr

Grieving Patients and Families

You can’t “fix it”

- Time (although time alone won’t heal)
- Mourning (rituals, etc.)
- Empathy and compassion
- Allow others to grieve in their own way
- Remember/acknowledge
- Know when to advise professional intervention
- Provide resources

How Grief May Present in Grievers

Common physical reactions:

- Feelings of hollowness in the stomach
- Tightness in the chest, heart palpitations,
- Weakness, lack of energy, sleep changes
- Gastrointestinal disturbances,
- Weight gain or loss

Common cognitive reactions

- Disbelief, Denial, Confusion
- Inability to concentrate
- Preoccupation with dreams of the deceased

Normal emotional reactions:

- Emotional numbness and shock
- Relief, fear, anger, guilt, sadness, loneliness, abandonment, despair, ambivalence
- Need to review the death

Normal social reactions:

- Being on autopilot
- Withdrawal from others or dependence on others
- Fear of being alone

Typical Physical Signs of Grief

Tightness or heaviness in chest or throat	Change in sleep patterns, insomnia, change in dreams	Change in appetite	Somatic Complaints, nausea, dizziness, stomachaches and headaches
Crying, sadness	Listlessness and fatigue	Forgetfulness	Restlessness
Irritability and fighting	Grief hallucinations: when a person feels they can see, touch, hear or sense deceased person	Stress response; fight, flight or freeze, increase in heart rate, fast breathing, sweating	

Cardiovascular Effects of Grief

A study 2014 involving 30K people experiencing partner bereavement suggestions they may have a higher incidence of a fatal or non-fatal heart attack or stroke in the months after the loss. *Ask about loss and grief.*

Another cardiovascular complication with links to grief is Atrial Fibrillation, a serious heart rhythm disturbance.

It is also possible to develop takosubo cardiomyopathy or “broken heart syndrome” following a bereavement. This condition occurs due to severe emotional or physical stress.

All of these conditions may be more likely to occur in people who are already at risk of cardiovascular disease.

Immune System and Grief

A 2019 review found links between bereavement and impaired immunity against infections. Grieving people according to researchers had:

- Higher levels of inflammation
- Lower antibody responses to vaccines
- Maladaptive immune cell gene expression, which is a malfunction in certain genes that influence immunity

TYPICAL VERBAL BEHAVIORS

- Talking a lot about the loss and the grief
- Asking many questions to others or to oneself
- Avoid talking about loss and grief
- Wants to only focus on work
- Wishing to be with the deceased
- Telling the story and details over and over
- Being quiet and withdrawn
- Voicing worries about one's own safety, getting ill and dying (or others)
- Voicing feelings of guilt, regret
- Saying shocking things or joking about loss for attention or diversion of grief

Typical Emotional Behaviors

- Sadness, tears or no tears
- Over-reacting to other situations or under reacting
- Increased feelings of anxiety
- Inability to focus or concentrate
- Lowered self esteem
- Irritability
- Clowning around (may be masking pain)
- Denial, numbness
- Seems to be apathetic
- Not wanting to be alone

Behavioral Changes

- New or increased use or misuse of alcohol or substances
- Keeping busy to avoid feelings
- Irritability and arguments
- Missing work
- Isolation
- Turning to screens, shopping, food, work, keeping busy to avoid feeling

Factors that may affect grief:

- Age
- Development
- Personality
- Existing Coping Skills
- History or Prior Difficulties
- Available Support System
- Type of Death
- Relationship with the Deceased
- Existing Mental Health Issues

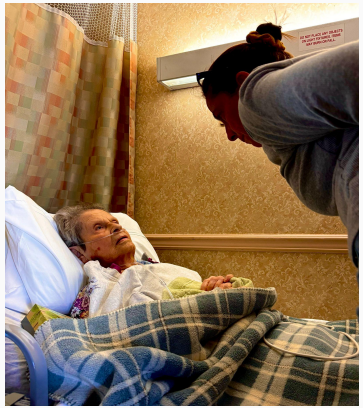
Anticipatory Grief

Reactions experienced in advance of an expected loss, for example, how one might respond to the impending death of a terminally ill loved one

Often includes:

Depression, a heightened concern for the ill loved one, rehearsal of the death.

Time to absorb the reality of the loss. Allows for finishing unfinished business



5 Types of Disenfranchised Grief

(Ken Doka,Ph.D.)

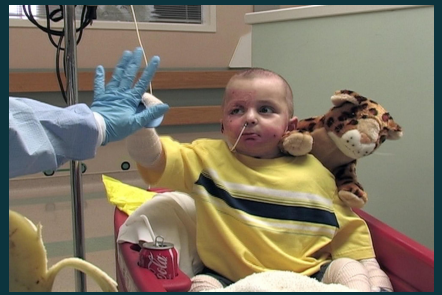
"The grief that people experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported."

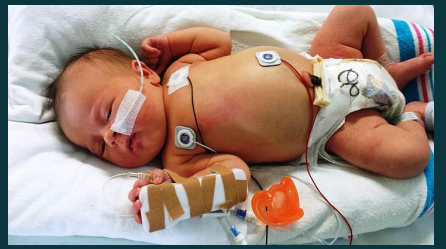
- Relationship is not recognized
- The loss is not acknowledged
- The griever is not recognized and excluded
- Circumstance of the death isn't recognized or stigmatized
- Grief expressions aren't socially accepted

Including Family Members







“Compassion is the #1 Thing”

Peper Howard, burn technician at Arkansas Children’s Hospital for the past 24 years, described compassion as being “caring, loving and understanding, because the patient – they’re hurting and they’re going through different emotions, and you have to go through those emotions with them.”

Fear of the unknown and frustration – common responses of patients in the early stages of burn treatment – are compounded by ongoing pain. Healing hurts. Burn survivors wonder when the pain will end and how the scars from their injury will impact them. In addition to physical wounds, burns often leave mental wounds – a type of post-traumatic stress disorder (PTSD).

Burns can be a lifetime injury. Requires encouragement, hope and resilience.

Talking to Families: Having Difficult Conversations

- Be calm, present, patient and caring.
- Breathe, ground yourself first.
- Most communication is non-verbal.
- Listen, listen and listen more. Clarify what you think you heard.
- Remember you can't "fix" the family. The family wants their loved one to be alive again. You can be present and witness their pain and listen so that you can meet their needs as best as you are able.

What Families Need

Honesty

Compassion

Understanding

Someone who listens

Presence

Not to feel rushed in any way

Your professional care and support

A feeling that you can take care of them and their loved one

To trust what you tell them you will deliver on

You to imagine that this was your own family

Patience and kindness

Tips for Breaking Bad News

- Allow for silence and emotional reactions
- Give time
- Be sensitive to the nonverbal language
- Document and work with the multidisciplinary team
- Use simple language and honest communication
- Ensure privacy and confidentiality
- Listen to what the patient says

Quote

“Critical care nurse here. Having been on both sides of the stethoscope (my husband died 4 months ago after a stroke/arrest, the expectation that a family is going to “let go” is unreasonable unless there has been clear, consistent, continuous communication. Doctors, nurses, social workers, clergy need to sit down and explain, “we’ve done everything we can and despite our best efforts, I think we need to talk about end of life care.” Most families need time to assimilate. They don’t realize that the ventilator/dialysis/mega doses of drugs/tube feedings etc. are the only things keeping their loved one “alive”...temporarily. That transition from hope to no hope takes time.”

Quotes

“It’s simply being compassionate and kind even if overworked. While the staff are working a shift that will end and begin again the next day, some of us are facing goodbyes forever. Interactions that positively impacted us was the nurses and doctors that spent time explaining things, and checking in with us, not just checking off the box of visiting the room.”

“One of the doctors on duty in the ICU spoke very fast so it was difficult for me to process what she was saying. The medical terms were new to me and I was in shock so filling in the gaps what she was saying was impossible.”

When Delivering Bad News, Avoid:

- Making assumptions about the patient’s concerns
- Judgmental comments
- Distorting the truth
- Talking more than listening
- Giving false reassurance
- Information overload
- Withholding information

My Mom and My Son

Calling her oncologist….

Initial Contact with Family for an Emergency Situation

- **If the family is present:**
  - summon to ICU as emergency
  - try to limit the discussion to only one or two members.
- **If the family is not present**:
  - A senior member of health care team should call.
  - Inform them that patient is suddenly ill and prompt treatment is happening.
  - Ask them to come immediately. If patient has died make sure they are not alone.
- **If patient is still alive**:
  - Prepare family for possible death. Foreshadow the bad news. “I am sorry, but I have bad news.”
  - Explain the patient was doing well earlier but suddenly deteriorated.
  - Be patient with family and explain the possible reasons of sudden turn. Allow family to ask questions and express feelings.
  - Family member seeing resuscitation efforts helps them process that everything possible is being done.

Informing Family About Death

- Senior clinician who is responsible for patient sits with family to deliver news with 1 or 2 family members
    - Try to converse with member known already
- **Be clear** - “They died.” or “She is dead.”
- **Avoid euphemisms** - “They passed away” or “He left us”
- Help relatives process the news and grief
- Encourage them to express feelings
- Encourage them to talk about the illness and, if appropriate, share the efforts taken to save their loved one and the outcome

Reactions to News of a Sudden Death

- Often intense, responses are unique and vary by culture, social, and/or ethnic background
- Expressions can vary widely – silence, crying, loud outbursts, wailing.
- Family will often perceive sudden death as “untimely” and “unfair” and may show following grief reactions:
  - Initial shock
  - Denial
  - Anger
  - Guilt

Family After Sudden Death

- When a patient becomes seriously ill, health care team tries to save them which takes place behind closed doors of the ICU
    - **It is vital to brief the family about the efforts being taken to save the relative's life.** Otherwise there may be serious doubts in the minds of the relatives about the circumstances, that led to the death.

- Make use of whatever time is available to prepare the family mentally for the inevitable news. This short communication will give the family some breathing time to cool their nerves and prepare themselves.

Reactions Experienced After a Traumatic Loss

Shock: may be prolonged, persistent memories, flashbacks or dreams about the event may occur for weeks and months. There may be a disbelief that the person has died.

Fear and Anxiety: Normal activities seem overwhelming (driving, sleeping in the dark, speaking on the phone, opening a closed door,...). Not uncommon for people to feel unsafe, worrying that something else is going to happen again, hypervigilant, startle easily

Quote

“Miscarriage is still delivering a baby.

Stillbirth is still birth.

TFMR (termination for medical reasons) is still losing a longed for child.

Whatever name we give to the type of loss, the bottom line is…

They lost their precious baby.”

~Zoe Clark-Coates author of Saying Goodbye, www.sayinggoodbye.org

A Death of a Baby in the NICU or PICU

So important that parents are able to: be at their infant's side during death, given space and privacy with infant when dying, and given time, space and privacy to be with their baby’s body after death.

Families often express needs of: emotional support, nurses and doctors’ proper treatment, financial support, grief care, mental-spiritual, physical support, and support for any guilt after their infant's death.

Proper bereavement care should be prepared in NICUs for families who lose their infants. The need of a family depends on different factors.

Making Memories

Please offer parents time alone with their baby. It is a sad but special time. It allowed them to create memories, acknowledge their baby's existence in the world and recognize their place in the family.

Some grieving parents want to hold baby, take photos, make hand or footprints, dress them and/or wrap them in a special blanket, bathe them, read them a story or sing to them. Some want to sleep with the baby next to them for the night. Encourage them to make a memory box.

Now I Lay Me Down to Sleep: Remembrance portraits of baby
www.nowilaymedowntosleep.org Find a local photographer who will come to hospital

QUOTE

“The things we have to remember Arthur are now some of my most treasured possessions. I wear a locket necklace every day with a photo of him in it and a lock of his hair. We have some beautiful photographs and molds of his footprints. It keeps his memory alive to be surrounded by these mementoes.”

~ Katherine, a mom after losing her baby

Burn and Trauma Injuries

Sudden, life changing events. Victim and family face an acute crisis.

No time to adjust to the trauma. Need time to grieve losses.

Many patients don’t have advanced directives. Many families have not discussed end of life issues with family members.

Patients on the Burn Unit and Grief

In high specialized units, long relationship with patients in deep emotional and physical pain, which cannot be solved or minimized, exposes health care teams to intense emotions, which can boost the stress experience.

Health care team manages: busy work routine, pain and death, uncertainties due to the burn's consequences and to care for patient and family.

Many stress factors, extremely exhausting and can affect the health of the care team members, lead to burnout, compassion fatigue, and vicarious trauma.

Burn unit healthcare staff need to learn how to manage their own emotions as well as the emotions of their patients and families.

Interventions for Families

Maintain hope in patients and their family members. As families pass through the illness trajectory, the nature of their hope changes from hope for cure, to hope for remission, to hope for comfort, to hope for a good death. Offering hope during this time can be as simple as reassuring families that everything will be done to ensure the patient's comfort.

Talking about the past also can help some families by reaffirming the good times spent together and the ongoing connections that will continue among family members. Referring to the future beyond the immediate suffering and emotional pain can also sustain hope. For example, when adult children reassure the ill parent that they will care for the other parent, the patient is hopeful that the surviving spouse will be alright.

Interventions

Involve families in all aspects of care. Include them in decision-making, and encourage active participation in the physical care of the patient. This is their life—they have the right to control it as they will.

Involvement is especially important for children when a family member is very ill. The more children are involved in care during the terminal phase, and in the activities that follow the death, the better able they are to cope with bereavement.

Activity: Strength, Peace and Security

Can be used for care team, family or patient

1. What is your definition of ‘strength’? Where can you go to get it? Who gives it to you? How can you get more?
2. What is your definition of ‘peace’? Where can you go to get it? Who gives it to you? How can you get more?
3. What is your definition of ‘security’? Where can you go to get it? Who gives it to you? How can you get more?

From Douglas C. Smith: It Takes a Village to Say Goodbye

Activity: My Ideal Death (Douglas C Smith)

For care team to design focus of caregiving

A. Where do you die?
B. Who and what is around you?
C. What are you doing?
D. What are the people doing who are around you?
E. What has been happening in the last couple days?
F. What has been happening in the last couple hours?
G. What is the very last thing you do?
H. What is the very last thing you say?

Offer Information

Offer information. Tell families about what is happening in straightforward terms and about what they can expect to happen, particularly about the patient's condition and the process their loved one is to undergo. Doing so also provides families with a sense of control. Initiate the discussion of relevant issues that family members themselves may hesitate to mention. For example, the nurse might say, "Many family members feel as if they are being pulled in two or more directions when a loved one is very ill. They want to spend as much time as possible with the patient, but they also feel the pull of their own daily lives, careers, or families. How does this fit with your experience?"

Activity: Memory Jar (Douglas C Smith)

A grieving person or family would set aside a memory jar (maybe a large Mason jar) someplace in the home. Whenever someone has a memory of the person who died, they write it down on a piece of paper and place in jar. Periodically several people can be invited to sit down with jar and review the memories. Sharing thoughts, feelings and further memories that may arise.

Communicate Openly

Communicate openly. Open and honest communication with nurses and other health professionals is frequently the most important need of families. They need to be informed; they need opportunities to ask questions and to have their questions answered in terms that they can comprehend. Open communication among team members is basic to open communication with the families.

Quote

“The hospital my mom was in, they were so kind. Every person I encountered. Not only to us but to each other. They just radiated a caring nature. They kept us well informed, explained things well and let us ask questions. Checked on us frequently and took the best care they could of my mother. They even brought us drinks and snacks. After she died they offered grief support. I’ve never felt this much care in any other place.”

~ Irene

Supporting Grieving Staff

Joint responsibility and decision making: For staff caring for patients near death, its crucial to use a team approach. One person alone isn't responsible for decisions. Every voice on the team is to be heard and respected.

Recognize Loss: It's important to recognize that experiencing the loss of a patient is difficult. Staff may have cared for the patient long term or gone to extraordinary measures to help the patient and support family members.

Try to debrief a few days after a loss to hear what staff members experienced and talk about coping with loss. Model grieving.

Offer check ins and sessions with group or professional using opt out measure.

Quote by Fred Rogers

“Anything that’s human is mentionable, and anything that is mentionable can be manageable. When we talk about our feelings, they become less overwhelming, less upsetting, and less scary. The people we trust with that important talk can help us know that we are not alone.”

Highly recommend his book, The World According to Mister Rogers

And the film, A Beautiful Day in the Neighborhood with Tom Hanks

Supporting Grieving Staff

Encourage self checks:

- After losing a patient, encourage staff to check with themselves to access how they are doing and to see if they are ready to move to other patients.
- Each staff member should ask themselves: “How do I need to take care of myself to help the next patient and safety care for them?”
- Sometimes a death may hit a staff member particularly hard and they may need to leave for the day.
- Check in with colleagues

Health Care Providers & Self Care

1. Get plenty of rest
2. Eat decent food and drink enough water
3. Connect with loved ones and friends
4. Express yourself (talk to someone, colleagues, counselor, journal)
5. Turn to gratitude; develop a mindfulness practice
6. Care for your mental health
7. Spend time in nature
8. Exercise
9. Self Compassion (science and research based)

Maybe some of us can relate

Grief and Burnout

- Avoid burnout by practicing active grieving and good self care.
- After a death of a patient some attend the funeral services of the person with whom they have been working or write a letter to the family.
- Allow yourself to experience the sadness and other feelings. Don’t feel guilty if you don’t grieve the same for each death.
- Know how to reach out for help and know where support comes from.

Suggestions for Healthcare Professionals

- Explore your own loss history (loss line) and identify unresolved losses.
- Pay attention to how accumulated grief has affected you.
- What are your coping styles? Where do you go to get more strength, peace, security?
- Know your own limitations and pay attention to your own grief, burn out, compassion fatigue, empathy strain.
- Keep in mind your “why” …why you do this work.

Healthcare Professionals Need to Know:

1. Where to get emotional support
2. What your limitations are
3. How to reach out for help when you need it.
4. Regular staff meetings can help.

“With proper training and support we shall find that repeated griefs, far from undermining our humanity and our care, enable us to cope with more confidently, and sensitively with each succeeding loss.”

- C.M. Parkes

Self Care for Front Line Workers

- Remember you are not just your work.
- Let others help. Ask for help when you need help.
- Develop healthy boundaries in relationships.
- Practice time management skills
- Focus on what is in your control.
- Be a wholehearted person.
- Practice self-compassion (Cornell Univ, and Dr. Kristin Neff

How to Support Colleagues After a Tragic Death

Understand that everyone has their own losses outside of work too

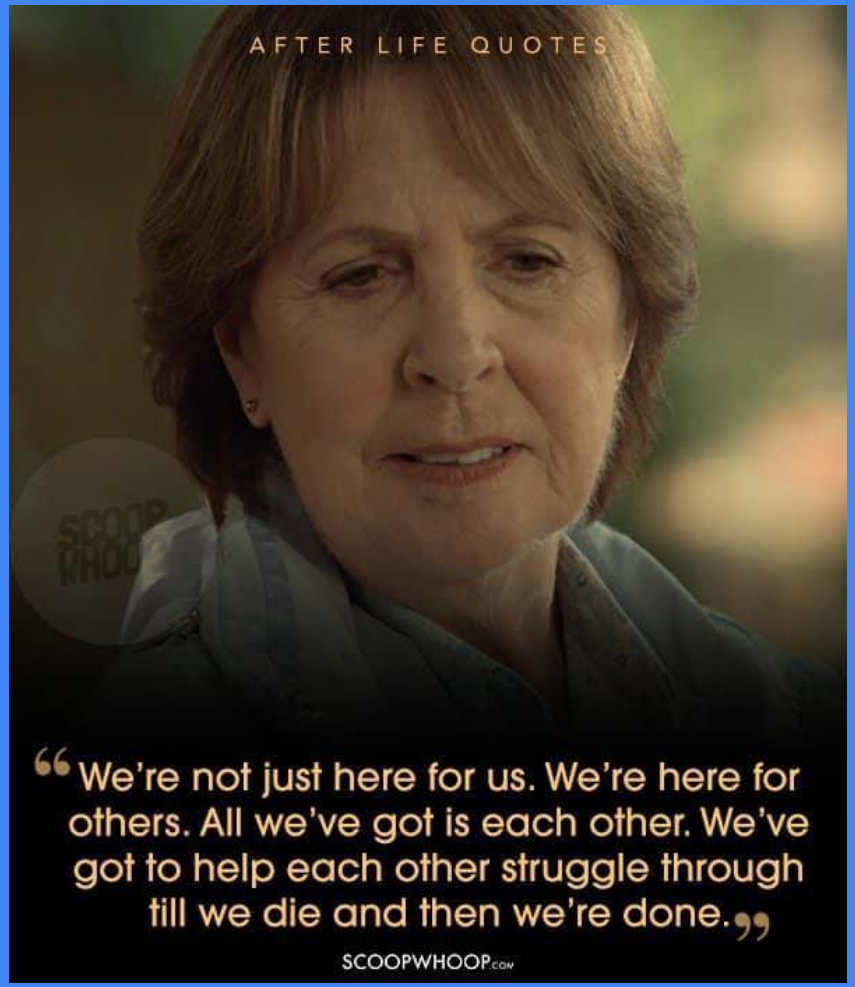
Be patient, compassionate, honest, vulnerable, non-judgmental

Model opening up with newer or younger staff

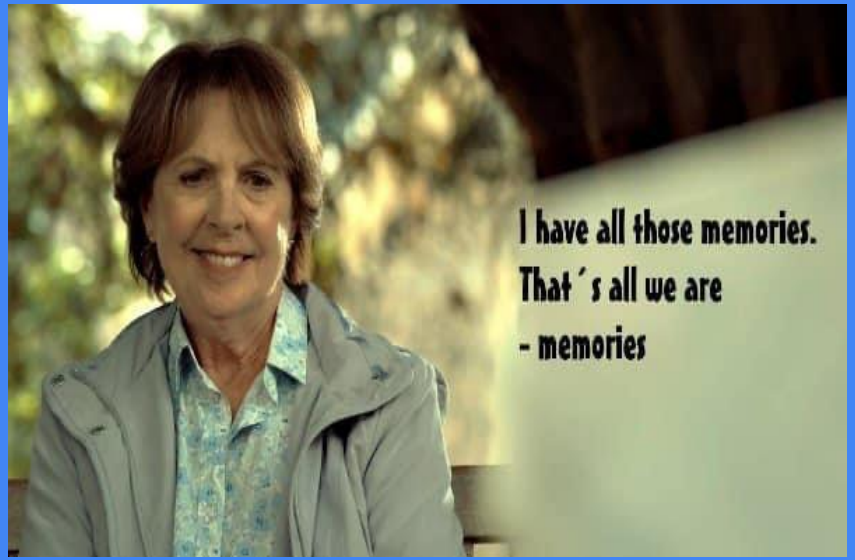
Create a safe and supportive environment for staff (as you do for families)

Pay attention to signs of burnout or compassion fatigue.

Create times to talk with colleagues formally or informally.



After Life on Netflix



Resources for Self Care

Book: Trauma Stewardship: An Everyday Guide to Caring for Self While Caring for Others by Laura van Dernoot Lipsky

Grief on the Frontlines: Reckoning with Trauma, Grief and Humanity in Modern Medicine by Rachel Jones

Article: “I’ll look at your Facebook profile before I tell your mother you’re dead” by Louis M. Profeta, M.D.

Podcasts: The Good Life Project, Terrible, thanks for asking,

Netflix Series: After Life with Ricky Gervais

Favorite Grief Books

Its OK That You're Not OK: Meeting Grief and Loss in a Culture That Doesn't Understand by Megan Devine

The Grief Recovery Handbook by Russell Friedman and John James

Beyond Tears: Living After Losing a Child edited by Ellen Mitchell

I Wasn't Ready to Say Goodbye: Surviving, Coping, and Healing After the Sudden Death of a Loved one, by Brook Noel and Pamela Blair, Ph.D

Online Resources for Grieving Families

Grief Share (www.griefshare.org) Grief Net www.griefnet.org

www.madd.org (support for anyone who has lost someone to drunk driving)

Widownet.org www.pomc.com (parents of murdered children)

MISS Foundation (loss of baby or perinatal loss) www.missfoundation.org

AFSP (American Foundation for Suicide Prevention) www.afsp.org

GRASP (Grief Recovery After Substance Passing)

Additional Resources for Bereaved Families

Compassionate Friends (compassionatefriends.org) For death of a baby, child of any age to any cause.

Now I Lay Me Down to Sleep (nowilaymedowntosleep.org) photographers for infant death

Dougy.org (Dougy Center - find a free year round peer grief support for families)

Grief Speaks.com (website with a lot of information on loss) Facebook page

Open to Hope (www.opentohope.com) podcasts and video clips of interviews with bereaved individuals about their loss.

Thank you

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