

Grief 101 for the Caregiver : Some thoughts on How to Support those Who Grieve



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OBJECTIVE: A BROAD OVERVIEW

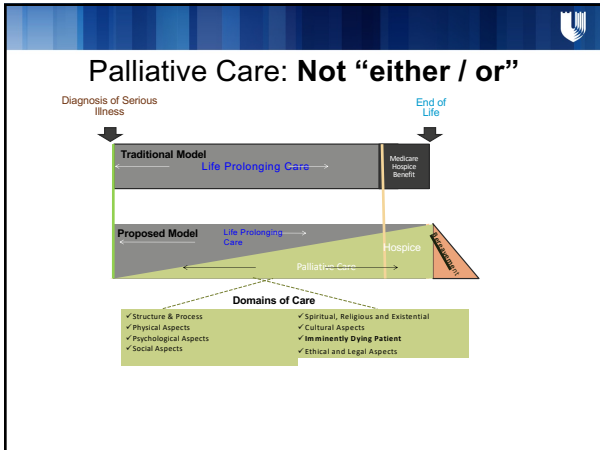
- Address a topic that is often overlooked yet universally affects us all.
- Look at Grief from the Caregiver's Point of View.
- Highlight **"Anticipatory Grief"** and **"Ambiguous Loss"**
- Support from Each Other

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The Caregiver as the "Medical Intern"

- Dr G's definition of an Intern: "all things to all people",eg, doctor, nurse, social worker, Chaplain et al.
- "We rarely register the struggle and sacrifice of the **caregiver** – the thoughts, emotions, and physical effort that go into treatment decisions, dietary restrictions, nursing care, drug administration, physiotherapy, travel, toileting, employment, communication, finances, timetables, and the needs of other dependents".
- George and Mathew: [Pg 1026. JAMA Oncology. August 2024.](#)

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- ### Types of Grief
- Anticipatory
 - Normal
 - Prolonged
 - Ambiguous Loss
 - Disenfranchised Grief

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Ambiguous Loss. Pauline Boss and JR Yeats. Bereavement Care. 2014; vol 33. no 2 : 63-69.

- A loss that remains unclear and without resolution.
- Physical: a loved one is physically absent but psychologically present
- Psychological: a loved one is physically present but psychologically absent
- Can lead to “complicated grief” and “disenfranchised grief”

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Where do clinicians learn about Professional Grief?

- Medical/Nursing/PA Schools?
- Internships and Residencies ?
- *On the job experience*
- From the more Senior Clinicians/Mentors?

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“Our Responsibility for Training Physicians to Understand the Effect Patient Death Has on Them: The Role of the Intensivist.” *Chest. 2014;145:932-34.*

- **“Death Rounds”**: trainees and ICU team review recent deaths *with a focus on the influence of these deaths on the staff.*
- Safe environment to discuss trainee feelings and hear from others how they cope and manage (sounds like G briefs)
- **“The Pause”** (*Crit Care Nurse.2014;34:74*): after a sad event ask that no one leave, eg, a code, and offer silent recognition of the death before moving on to the next task.

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The Doctor’s Letter of Condolence

Bedell et al. *New Eng Journal of Med.* 2001;344:1162-1164.

A physician’s responsibility for the care of a patient does not end when the patient dies. There is one final responsibility – *to help the bereaved family members.*

A letter of condolence can contribute to the relationship between the physician and the patient’s family.

**“Whether intentional or not, the failure to communicate with family members conveys a lack of concern about their loss”
Pg 1163.**

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What does Acute Grief look like? Time Magazine. Dec. 2019



SHARED GRIEF Leanne O'Brien, center, took part in a ceremony in Cambridge, England, on December 2 to honor her boyfriend, Jack Merritt, 25, and Saskia Jones, 23, who were killed on November 29 in a terrorist attack near London Bridge. The Cambridge graduates were stabbed by Usman Khan, 28, who had been previously convicted of a terrorist plot in 2012. Khan, who wore a fake suicide vest, was tackled by bystanders who wielded a narwhal tusk and a fire extinguisher before he was shot to death by police.

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Acute Grief

- “A single person is missing for you, and the whole world is empty”

• Philippe Aries in Western Attitudes toward Death
• Quoted in Joan Didion's The Year of Magical Thinking. Copyright 2005

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Different type of disclosure: my Son, Nick, died Sept. 19th 2018 of DKA at age 34

- Grief can divide your life into “**the before**” and “**the after**”
- He died at his home, ME case, autopsy came back in January of 2019: Diabetic KetoAcidosis.
- **Grief has no timetable** so I am actively grieving still
- Grief is cultural: I eat thru my grief like a good Greek. I sleep poorly still 6 years out.
- *As a doctor, a Dad and a middle child, I have feelings of responsibility and guilt = **Guilt***

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GRUILT

- **“Gruilt”**: a word that combines the grief that one has to carry as well as the guilt that might be part of the grief, eg, “if only I had done x, then maybe my loved one would be here now”. For the doc, “what did I miss?” “what error did I make?”
- This will be an important concept in talking to families w “acute grief”: “if only I had gotten my husband to Duke sooner”. The notion of a “constituency” – the outside group to whom the proxy decision maker must answer.
- *It is natural for all griever to ask if they did all that they could, and to seek a listener and not a problem solver.*

(Parker J Palmer: “The Gift of Presence, the Perils of Advice.”
<http://www.onbeing.com/blog/parker-palmer-the-gift-of-presence-the-perils-of-advice>

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JOURNAL OF PALLIATIVE MEDICINE
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Palliative Care Specialists Series
 Feature Editors: Christopher A. Jones and Arif H. Kamal

**Top Ten Tips Palliative Care Clinicians
 Should Know About Bereavement and Grief**

Paul A. Riordan, MD,^{1,2} Meghan Price, BS,³ Gregg A. Robbins-Welby, MD, MS,^{2,3}
 Victoria Leff, MSW, LCSW, APHSW-C,⁴ Christopher A. Jones, MD, MBA,⁵
 Holly G. Prigerson, PhD,⁶ and Anthony Galanos, MD^{1,7}

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Tip 1: Bereavement increases risk of death and other illnesses
Tip 2: Grief can be pathological and present as prolonged grief
Tip 3: PG13
Tip 4: Understanding anticipatory grief
Tip 5: Grief may trigger an episode of Major Depression
Tip 6: Medications don't help grief, but may help depression & psychotherapy efficacy
Tip 7: Psychosocial interventions and therapy have benefit and can be provided by clinicians
Tip 8: Hospice can mitigate the adverse effects of bereavement
Tip 9: Choose your words wisely and consider supportive silence
Tip 10: Professional grief can contribute to burnout

“Top Ten Tips”. Journal of Palliative Medicine. Riordan et al. 2020

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Normal Grief vs Prolonged Grief Disorder

Symptoms of normal grief vs Prolonged Grief Disorder	
Normal grief	Prolonged Grief Disorder (DSM-5-TR)
Recurrent feelings of yearning for deceased	Identity disruption (as if part of oneself has died)
Intermittent pangs of deep sadness or remorse with episodes of crying	Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death
Steady stream of thoughts of deceased	Avoidance of reminders that person is dead
Struggle to accept reality of the death	Marked sense of disbelief about the death
Somatic distress like sighing, loss of appetite, sleep disturbance	Difficulty moving on with life (e.g., problems engaging with friends, planning for future)
Feeling disconnected from the world or other people	Intense loneliness (i.e., feeling detached from others)
	Emotional numbness
	Feeling that life is meaningless

Prigerson, H.G., et al. 2009. *PLoS Medicine*, 6(8), 1-12; Miller, M. D. 2012. *Dialogues in clinical neuroscience*, 14(2), 195-202.

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TABLE I. WORDS TO AVOID AND TO USE WHEN TALKING WITH THOSE WHO ARE BEREAVED

What NOT to say/do	What TO say/do instead
<ul style="list-style-type: none"> • How are you doing? • They're in a better place. • Please let me know if there's anything I can do for you. • You can always find/renovate/have another... • I know how you feel. • I guess we all die eventually. • It's God's will. Everything happens for a reason. • You're strong enough to get through this. 	<ul style="list-style-type: none"> • This is so sad and I'm sorry. • I wish you didn't have to go through this. • When you feel ready, I can come over to help out. • Tell me more about [name of deceased]... • I can't imagine how you are feeling. • Tell me more about [name of deceased]... • This is a terrible loss. • I imagine it's tough for you right now.


Sometimes, there are no words.
Adapted from Stebbins in *Real Simple*.²²
Simply being present with the bereaved can be the best approach.

Words Have Power

Riordan, P.A. et al. 2020. *Journal of Palliative Medicine*.

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How to support a grieving friend/colleague

- Grief never really stops. *It is something you carry with you in different ways.* Give plenty of time – “healing” is a myth to many. **There is NO timetable.**
- It could be **hurtful** to say “Shouldn’t you be getting better by now?”
- It could be **helpful** to say “I want you to speak to this faculty member when you are ready”.
- **Be willing to not have any answers.** Listen and be present. **There may be no words,** bec it is impossible to take away another person’s grief.

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How to Help a Grieving Friend. Megan Devine

“It’s OK that you’re not OK.” 2017. Appendix. Pg 237-241.

- Grief belongs to the griever. *Follow their lead. It is their moment, not ours.* Think of their schedule rather than your own. **Ask permission** in a work setting before talking about their loss.
- *It is hard to fix the unfixable.* The loss cannot be fixed, repaired or solved. Hard for us who are trained to “solve”, to just listen. Words simply have limits , so I often say: “I wish I had magic words”.

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How to Help a Grieving Friend or Colleague

It’s OK that You’re Not OK_ by Megan Devine. Boulder, CO 2017. Appendix pg 237-241.

- **Do not say:** “Call me if you need anything” bec your friend will not call. Make concrete offers, like pick ups and deliveries or being there when they have to clean out his room.
- Be mindful of tasks that will remind the caregiver of their former job, eg, same age or same relationship. (Clinical “grief triggers”)

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There is no script

*“No one knows the right thing to say. That’s why it is important to have these dialogues. **Not so that we get it right, but so that we do it better.**”*

Megan Devine. [It’s OK that you’re NOT OK](#), Sounds True. 2017. pg 186.

“Acknowledgement – being seen and heard - is the only real medicine of grief”
 pg 56. (Because it is more of an acknowledgement, I prefer “sorry you have to go through this” over the well intentioned phrase “sorry for your loss”)

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When
 Bad Things
 Happen to
 Good People

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 KUSHNER**

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When Bad Things Happen to Good People by Harold S. Kushner Anchor Books. 1981. pg. 99

- “It is hard to know what to say to a person who has been struck by tragedy, but it is easier to know **what not to say**. Anything critical of the mourner (“Don’t take it so hard”, “try to hold back your tears”) is wrong. Anything which tries to minimize the mourner’s pain (“It’s probably for the best” or “it could be a lot worse” or “she’s better off now”) is likely to be misguided and unappreciated.”

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Rabbi Kushner: What we want to believe

- One of the ways in which people have tried to make sense of the world's suffering has been by assuming we deserve what we get.
- People want to keep the world orderly and understandable, so that the world makes sense...
- And *everything happens for a reason*

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How do I cope with my grief?

- I allow myself to grieve, to be cognitively and emotionally stunned. **Grief attacks** happen and I cry, though this has diminished greatly over time
- I ask Nick his forgiveness and apologize
- I support his Mother and his Sister
- I did a podcast: <https://soundcloud.com/voices-of-duke-health/episode-10-the-gauntlets>
- I lean on friends, eg, The Prostate Bowl

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Summary Points

- Data supports “preparing” patients and families for death
- Look for risk factors of complicated grief in the family, and your trainees.
- Provide resources, eg, Hospice, Pastoral Care, Social Work, CEO, G briefs/Debriefs

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Summary Points

After a patient dies, write a letter of condolence and express what a privilege it was to be involved in their care.

Do not abandon

And be mindful of potential “grief triggers” for the former Caregiver

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Oncologists: Grief is related to burnout.ASCO abstract

- 2023 survey of oncologists, fellows, and APPs in Duke Network
- Used an adaptation of the Traumatic Grief Inventory, and the MBI or Maslach Burnout Inventory
- 128 surveyed (**50% response rate**)
- **94%** endorsing some feelings of personal or professional grief over the past year
- **50% endorsed burnout, and attributed 31% of their burnout to grief by self report**
- Higher grief scores among those respondents:
 - In academic settings compared to community
 - With <10 years in practice

Logistic regression, for each increase in one point on the grief scale, there was a 15% increase in odds of experiencing burnout. ($p < 0.001$)

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“The Case for Peer Support”
 Hu et al. *Arch Surg.* 2012; 147:212-217.

- At the Brigham, a program was set up in 2006 to support health care professionals following adverse events in the OR. The “Peer Support Team or PST” had reps from surgery, anesthesia and nursing to participate in GROUP DEBRIEFING sessions.
- The PST found that physicians failed to access the support offered within these group sessions. So, the Physician Support Survey was distributed at the end of departmental conferences (Surgery, Anesthesia and EM) to better address physician needs, and plan accordingly. **Outcome:**
- **Physician colleagues** were the most commonly identified sources of support. *“As the most desired potential sources of support are other physicians...we advocate for a peer-based system of support.”* pg 216

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On Being a Caregiver

- It is hard work on many levels, eg, the Caregiver as a Medical Intern
- Often, the Caregiver has to answer to a larger constituency that does NOT do the caregiving
- *Most Caregivers are NOT aware of the concept of “self care”*
- *Caregivers start grieving way before the rest of us, ie, “Anticipatory Grief”*

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Grief Leadership: Katharine Manning
<https://www.fastcompany.com/90719917>. Feb. 9, 2022

- Katharine Manning is an expert in trauma-informed leadership. She suggests a new skill.
- In difficult times, we look to our institutions for support and protection
- Those who lead in this era must develop a skill they may not previously have had to cultivate: ***grief leadership***

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Going forward, we can...

- In addition to FMLA, address “bereavement leave policies” with the Caregiver in mind
- . *Time and space* to process aka “*grace and space*”. My job, as of July 1st, is to lead debriefs with physicians and other providers so as to provide the Grace and Space to process
- Teach / mentor MD’s in training, including the “caregiver Intern”, the potential effect patient death has on them. The notion of “self care”

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July 26, 1985
Anthony N. Galanos, MA
JAMA. 1985;254(4):545
doi:10.1001/jama.1985.03360040101038

Nicholas Speaks With His Eyes

Nicholas speaks to his mother with his eyes bright with mixed pigments riveted into hers.


Like his mouth locked onto her breast maintaining a firm seal of quiet trust.

Supported by her arm, his direct gaze up lifts her head down and slightly at an angle as if a magnet were holding their two heads in place.

A smile builds in warmth like rising bread without her awareness.

Of how much she is nourished by Nicholas, sucking on his mother's breast while her face smiles at his eyes talking.

Anthony N. Galanos



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THANK YOU!

- THANK YOU FOR THE OPPORTUNITY TO DISCUSS "GRIEF 101"
- ANTHONY.GALANOS@DUKE.EDU

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Grief Leadership: A New Skill

- **Share information:** receiving information enhances our sense of autonomy, clarity and calm
- **Model Healthy Grieving:** being authentic mitigates your team feeling vulnerable and frightened
- **Provide necessary resources:** there are often tangible forms of support that people need in times of grief and distress
- **Inspire:** project a belief in your team. Admit the challenge but also help others envision a different future.
- **Take care of yourself.** It is not possible to bear the weight of supporting those on your team when you are not supporting yourself.

• <https://www.fastcompany.com/90719917/in-times-of-crisis-managers-must-develop-a-new-skill-grief-leadership>

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