

*A View from the  
Other Side:*

# Caregiver Perspectives on Hospice

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# Disclosures

- Much of this talk is based on my personal experience
- There is not a lot of science!
- Gratuitous pictures of my husband and pets



# Our Story... 2023

- 7/11 – Seizure
  - “Brain inflammation”
- 8/23 – Biopsy
  - “1/10 do not recommend brain surgery”
- 8/28 – High Grade Infiltrative Astrocytoma
- 8/30 – NeuroOnc, RadOnc
- 9/12 – Start treatment



# Diagnosis – Now What?

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- Early engagement of Palliative Care
  - Who initiates this?
- Early discussions of goals
- NeuroOnc Social Worker





# Hospice

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- Referral
  - When? Who? How do you decide?
- What do we need to know?
- How long does it take?
- My takeaway:
  - Woefully uneducated
  - Surprisingly difficult
  - Emotions!

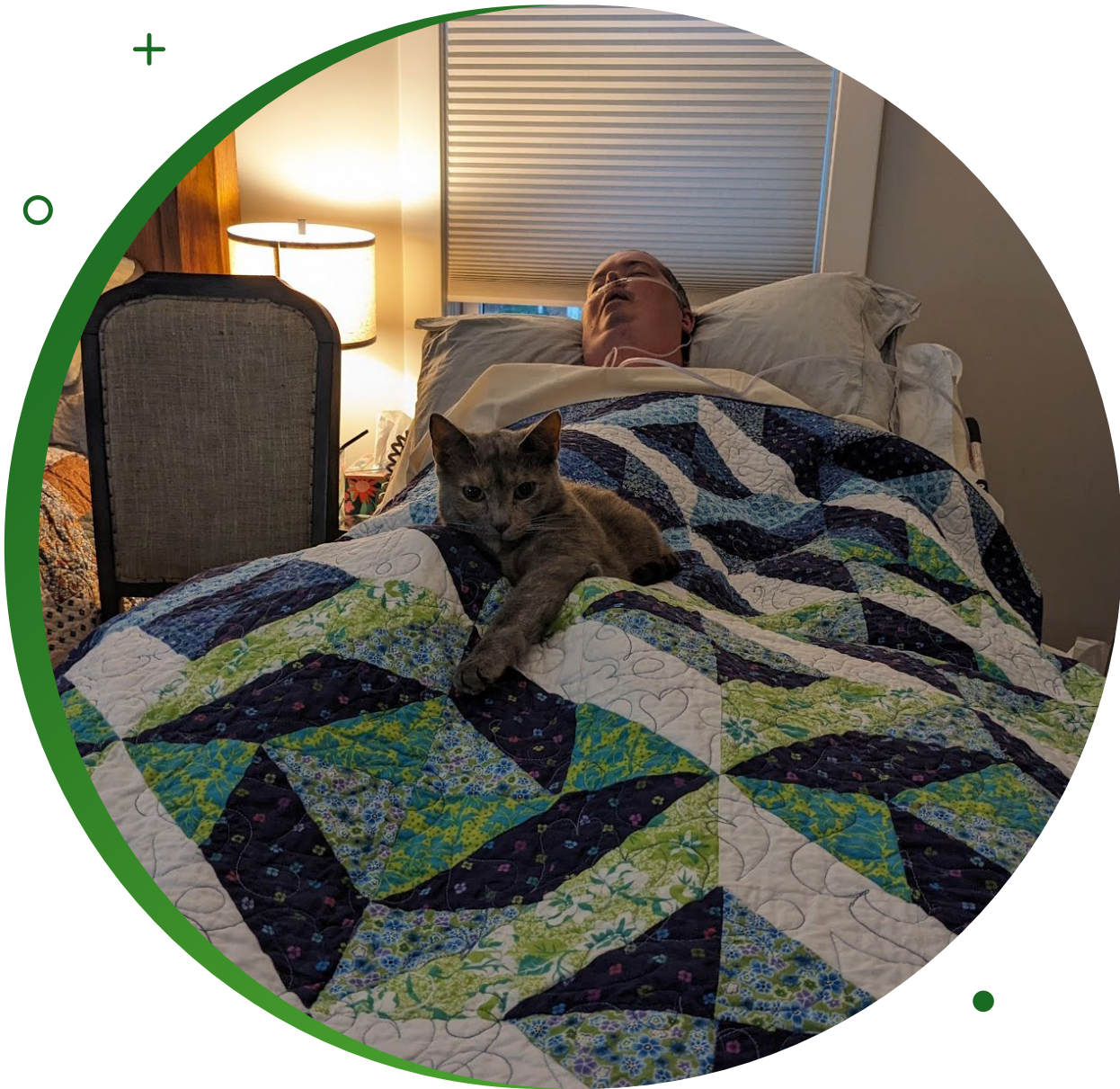
# Hospice... 2024

- Enrolled - 7/1
  - Expectations
  - FMLA
  - Communication
  - Community



When you ask me how I'm doing and I say "I'm functioning" this is what I mean





# Expectations ≠ Reality

- Provided supplies?
- Medications?
- Contingency plans
- Family / Friends



# Caregiving 101

- Safety
- Equipment
- Toileting
- Patient care
  - “That is not the sound of success”



# Caregiving 101



# Family and Friend Support

Jonathan Akers  
5/28/81 – 7/26/24



# Caregiver Experiences

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# Informal Narrative Research

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- Widows of GBM Facebook
- Very limited time frame
- Query: What would you tell hospice providers about your experience?
- Evaluated for themes





# Earlier Engagement

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Please tell them to call hospice in **sooner** rather than later.

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Everything about Hospice is wonderful. As others have said, call hospice in **sooner** than later

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Palliative care was amazing!!!! I just wish we had enlisted their services **sooner** rather than later.

# Expectations

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**I wish I had known** that hospice doesn't have people to come sit with you in their final hours. I didn't know I would have to do that alone.

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since my husband started hospice on a Friday they **wouldn't give us any supplies** because "it's the weekend." They said they would bring supplies on Monday. He died on Sunday.

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I was told they don't deliver drugs in the middle of the night. **Wish I knew** it before he was dying.

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**I was surprised** at how much the hospice team was there to assist me as much as my husband.

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I also came into, in home hospice **with the expectation** that I would have received more hands on assistance. Which also was not the case.



# Communication

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We did have pain meds but with a **poor plan** to administer them since my husband was barely able to swallow.

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...conversation about palliative care vs comfort measures only vs hospice is important...being as transparent about **what those terms mean** with the boundaries of what is and isn't allowed within those terms...

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Our experience with hospice was **impersonal and detached**

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Spouses really need to hear that there is **not any assurance of time** with GBM so we need to do and say all that's important early in diagnosis .



# Staffing

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...the hospice was incredibly **understaffed** at night and it was hard to get someone

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When my husband had a seizure **it took hours** to get any response.

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I wish I had known that nothing is considered an emergency.





# Bereavement

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Our hospice was great BUT the **aftercare was horrible.**

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Hospice were **not supportive** to myself or our children

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They promised lots of follow up in the month after **but didn't show**, call, etc

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They also told me in the beginning, that they would be here to support me and our children for the first year, and they were not. **They never reached out** after he passed.

# Literature

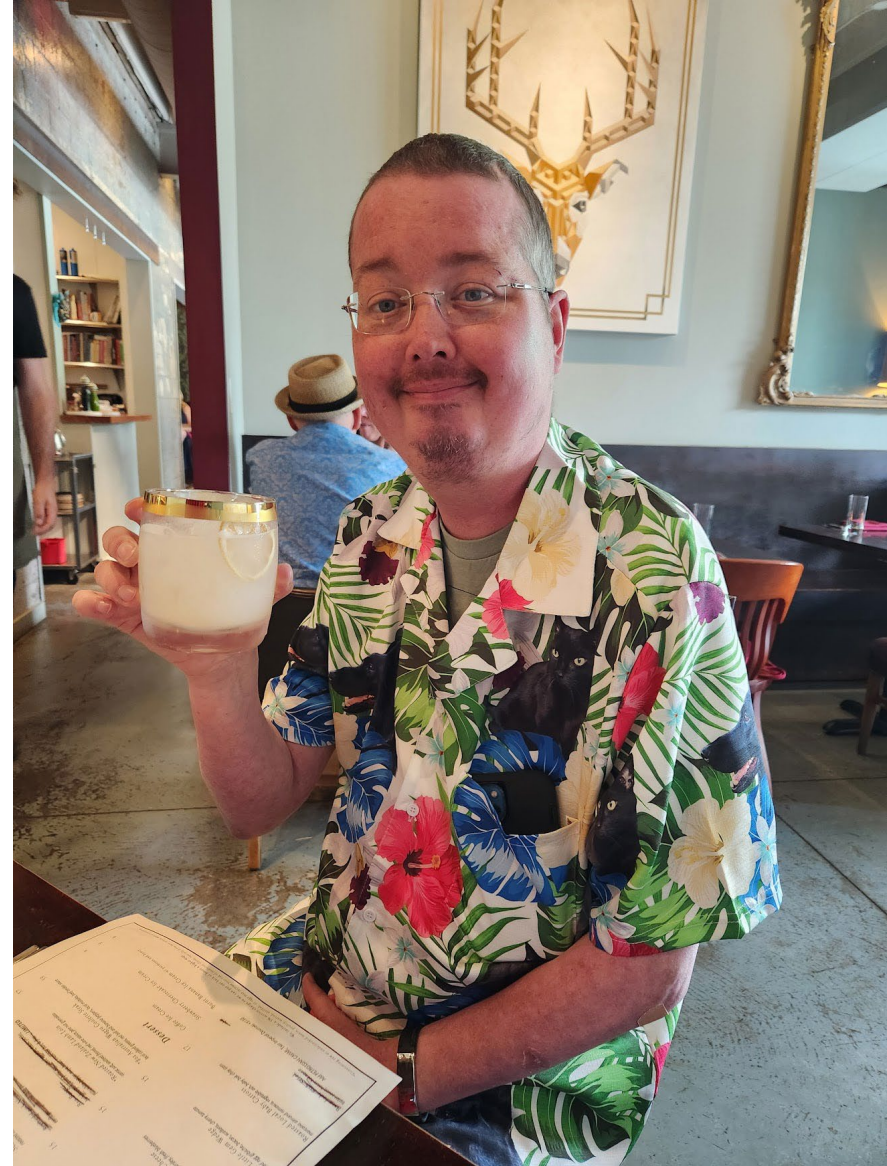
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> [Patient Educ Couns.](#) 2018 Nov;101(11):2025-2030. doi: 10.1016/j.pec.2018.08.005.  
Epub 2018 Aug 4.

**"I just need to know they are going to do what they say they're going to do with my mom." Understanding hospice expectations from the patient, caregiver and admission nurse perspective**

Carey Candrian <sup>1</sup>, Alexandra Tsantes <sup>2</sup>, Dan D Matlock <sup>3</sup>, Channing Tate <sup>4</sup>, Jean S Kutner <sup>5</sup>



# **"I just need to know they are going to do what they say they're going to do with my mom." Understanding hospice expectations from the patient, caregiver and admission nurse perspective**

We identified 4 themes:

- 1) Wide variation in patient and caregiver knowledge about hospice prior to the admission conversation.
- 2) Competing expectations and objectives for the admission conversation.
- 3) Organizational influences around the goals of the admission conversation.
- 4) Importance of integrating the patient and caregiver perspective to improve the quality of the admission conversation.



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- Varied, limited, or misguided knowledge of hospice care.
  - Increased responsibility on admission nurses for assessing knowledge and communication
  - Align patient and family expectations with what the hospice provides
- Caregivers enter conversations with wide ranging understandings and experiences
- Admission nurses have mixed levels of experience, training and motivations
- Increasing financial incentives erode time for communication
  - hospice eligibility criteria and services provided are inconsistently explained and misunderstood.



# Closing Thoughts

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Never assume a caregiver's knowledge base or comfort level.

Consider everyone learns differently.

Cognitive overload is real.

Caregivers don't know what is "required".

Consider 'emergency care' kits similar to emergency med kits.





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# Questions / Discussion

- How can we improve transition to hospice?
- How can we support caregivers?
- What are ways to “right-size” support?

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# Thank you!

Feel free to contact me!

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# Early Palliative Care Improves Patient and Caregiver Quality of Life

Carey T Ramirez <sup>1</sup>, Ravnyssa K Verma <sup>2</sup>



Patients who receive early palliative care may have improved quality of life, survival, and earlier referral to hospice at the end of life. Their caregivers are more likely to benefit from improved communication and decreased risk of burnout, and are less likely to experience depression following the death of a loved one.

# Palliative care and end of life: the caregiver

Deborah B McGuire<sup>1</sup>, Marian Grant, Jumin Park

A number of factors appear to influence caregivers' roles, experiences, and the care they render to care recipients. Little is known about these factors, or how they affect care giving, including who becomes a caregiver, how caregivers give care, and what experiences they undergo as they prepare for and become caregivers.



# Palliative care and end of life: the caregiver

Deborah B McGuire<sup>1</sup>, Marian Grant, Jumin Park

Extensive descriptive research summarized above clearly indicates a strong need for a wide variety of information, support, and resources for caregivers.



That said, the research base on palliative care and caregivers remains small, with few intervention studies to guide clinical practice. Much work remains to be done across populations, diseases, and topics.

