

Dying with a smile on
your face – intimacy
and end of life: we can
all do better

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First, the disconnect:

- Close your eyes.
 - Think about talking about sexual intimacy with a patient/client/friend and their partner.
 - How comfortable are you?
 - What thoughts run through your head?
 - Where and how do you feel your discomfort?
- **Sexuality is not easy to talk about for most people**
 - **It is a risk with patients unless you set it up carefully- and you can lighten the moment with humor**

What do we know about intimacy at end of life?

1. Not Enough
2. Enough to know it is not a priority for healthcare providers
3. Enough to know it IS important to intimate partners facing the dying process and death of one partner
4. Enough to know it is embarrassment and shame that creates the barrier to the conversations for all of us.
5. *It is 2021. We all survived 2020. And we still can't talk about sex and sexuality?*

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The research says we should use humor:



“Steel Magnolias” - the cemetery scene

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- Claxton-Oldfield, S., & Bhatt, A. (2017). Is There a Place for Humor in Hospice Palliative Care? Volunteers Say "Yes!" The American journal of hospice & palliative care, 34(5), 417–422.
- Ridley, J., Dance, D., & Pare, D. (2014). The acceptability of humor between palliative care patients and health care providers. Journal of palliative medicine, 17(4), 472–474.

The long and the short of the research

- Sexual bereavement is a **real** experience and needs to be addressed.
- It occurs during the illness as part of anticipatory grief for the survivor-to-be and for the dying person who is trying to end the relationship with their partner in the most intimate areas of their life. This is part of saying goodbye as well as remaining connected during the end of life.
- The survivor will experience the loss of their sexual connection as well as the relief and positive hormone changes that come from sexual activity.

That's where the humor comes in

- I am focusing on two issues: quality of life for hospice couples &
- Helping griever stay healthier by not forcing them to silence important needs
- We are going to use humor to meet those needs.
- I want to send those attending today out to their work ready to accommodate the needs of end-of-life couples to support them in maintaining their intimate relationship &
- Ready to comfortably talk through the issue of sexual bereavement with griever

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Communication process

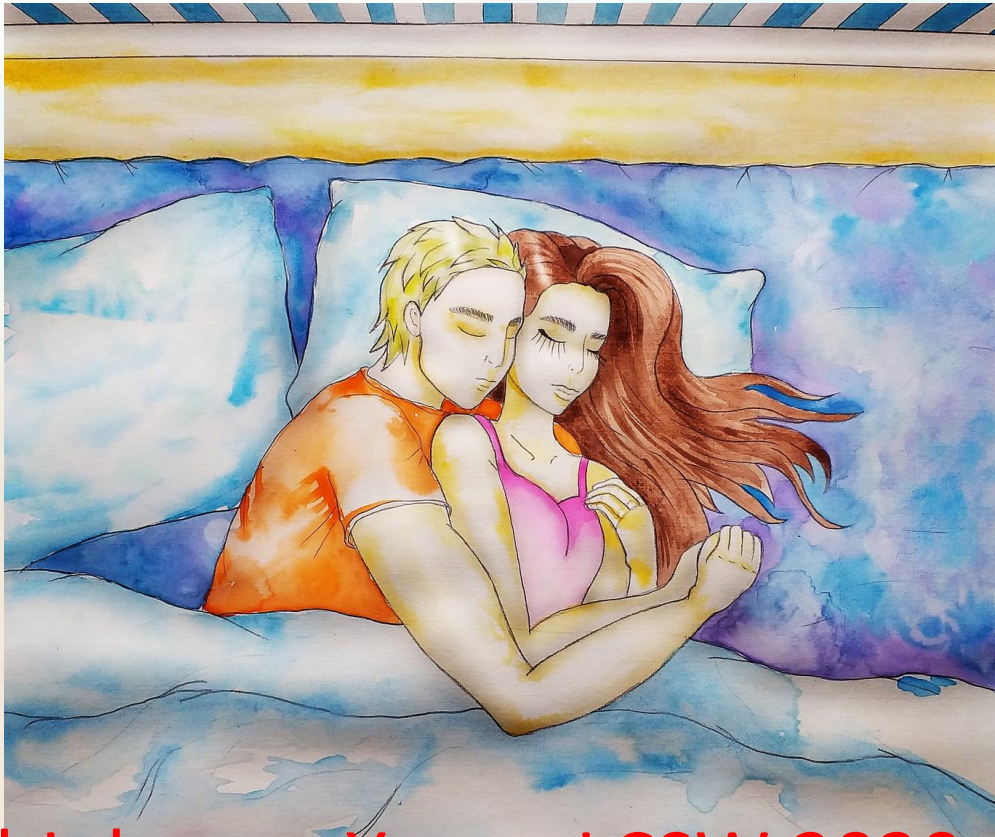
Hospice/medical staff & friends

- Listen for the concerns
- Go directly for the medical issues
- Focus on problem solving
- Do not go into any emotional issues if there is a choice and medical concerns are present

Patient and partner:

- Feel heard in terms of medical needs
- Will not bring up the subject of sexuality or intimacy unless you bring it up first
- If emotional issues are overtaken by medical concerns, they won't bring them back up, and will also be less likely to recover well
- They need you to respond and make it safe- and your humor comes in here. (It is a bit weird to just blurt out "let's talk about sex")

Don't we talk about intimacy
at end of life.
Someone must be! Right?



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- A survey of recent literature had few articles, all concluding we need to talk about this.
- It matters for quality of life and end of life. *It's part of how couples say goodbye*, but not a comfortable subject for hospice staff and grief therapists.
- In an international survey I completed last year, *not one hospice team member (N=124) was willing to broach the subject first.*
- In the same survey, grieving intimate partners after a loss said they wished, as had their late partner, someone would bring it up (N=176). *They were too embarrassed.*
- What would hospice staff think about them talking about missing being partners, not patient and caregiver?
- *What would someone think of a grieving partner missing sex?*

My descriptive survey research about talking through intimate needs:

Hospice staff

- Won't bring up enhancing intimacy
- Won't address use of DME to make more intimacy possible
- Don't consider that an issue because of illness/age
- Report it would be embarrassing to talk about it or fear the reaction of the couple

Grief staff and therapists/groups

- Won't bring up the topic of sexual bereavement unless the griever does first
- Follow old school teaching that there should be no new relationships for at least one year
- Are likely to counsel that anything prior to one year is trying to avoid grief
- Some online grief support groups have a culture of degrading new relationships

Meet Casper (and Fuzzy)

How would your career touch her and the two of us?

Do you see anything in this picture that looks different from a typical hospice set-up?

How would you use humor to introduce intimacy and sexuality to support the health and quality of life for both of us?

Remember, this can include hospice staff, grief staff, therapists, friends, PCP staff, hospital-based folks...Because we all know sexuality exists- we just do not TALK about it.



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How do we talk about this stuff? (Hint- it's not easy sometimes... ask me about talking about sexuality in couples with my mom in the room at a packed conference)...

- Let's talk about ways we can introduce intimacy with a couple where illness has become their life:
 - Tell me about how you met- who thought who was the one?
 - How long did you date?
 - What were some of the best dates then and since then?
 - What makes the two of you laugh together?
 - Can you laugh when things get harder?
 - How hard has it been to be intimate since the illness began?
 - Can you laugh as you are coping with oxygen lines and being careful?
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Integrating humor to normalize talking about sexual intimacy at end of life



With partners:

- Listen for when they laugh- and ask them what makes them smile about their partner
- If you have gotten to know them: what was the hardest part about being intimate the first time?
- Has it been hard since the illness to feel safe being intimate- is it like when one is pregnant and everyone is afraid?

With the partner who is dying:

- What are you missing in your relationship as you get worse?
- Has anyone asked you about it? Do you feel like you were supposed to become chaste just because you were sick?

Think of two ways you can use this with your people this week. Write them down so you keep it with you.

As the patient gets worse, you can talk through how to remain intimate in alternative ways: hand holding, massage, snuggling, talking, music, battery operated candles...



- Move away from thinking medically right now- think about how you create intimacy in your own life. What do you use? How would you flex that if your partner was bedbound?
- These will be the last body memories of the partner for the survivor. How do you help them?
- If you have created the opening for talking initially, you should be able to talk with them now. *You are already doing intimate care for them. Utilize that here.*

Take a moment to think through the courses you have had about grief and anticipatory grief...



- **Have you ever heard anyone normalize sexuality as a response to grief that did not liken it to excessive use of alcohol, drugs, or avoiding grief?**
- **Have you had anyone suggest that intimacy is important through the end of life and in grief?**

What does the research say? (there is not a lot available) (But when you ask griever at a conference without non-griever present...)

- Research: Intimate partners who have experienced a long illness with their deceased partner, and used that time to prepare, grieve, and reorganize, are done with the majority of their grief process in 3 months.
- ***Response from griever at conferences?***
“Thank God someone finally said sex!” (and more, and lots of humor)

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The survivor was preparing for
this moment.

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The partner was trying to ensure their
memory will be there with their
partner after their death.

The surviving partner after the death

**“I have no objection to anyone’s sex life as long as they don’t practice it in the street and frighten the horses.”
— Oscar Wilde**

Have you ever heard any survivor talk about missing intimacy and sex?

- **Kissing**
- **Their sexual happiness**
- **Their toys (yes, I said that!)**
- **Their inside jokes the kids don’t know**
- **The need for physical intimacy and having nowhere to go with it**
- **Fear of making mistakes in dating?**
- **Fear of judgment- it’s real**
- ***Humor makes that easier- as long as it is organic, not forced***



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If we do not give the thoughts and needs a place to go then we get:



Secondary losses as a result of lack of understanding and lack of support from grief providers:

- They will not attend support groups
- They will not accept bereavement calls or visits from a hospice that overrode their emotional needs prior to the death
- They will not engage with a therapist or hospice provider after loss who appears in any way judgmental
- Their grief process is slowed
- Physically they are far more likely to be sick and to not survive as long as those who do reorganize after the death

When we do provide the support and space the outcome is very different:

It's a positive impact for griever who have these needs addressed.

They report relating better and with more trust to providers and friends who approach them nonjudgmentally and with humor

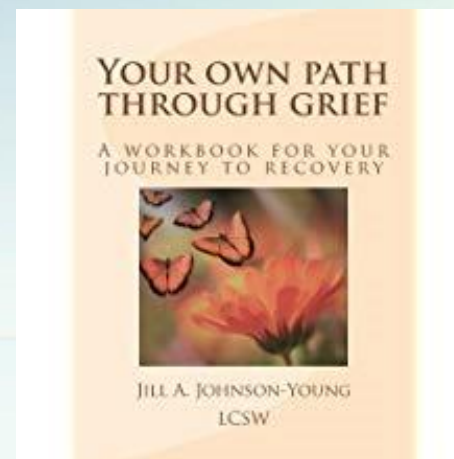
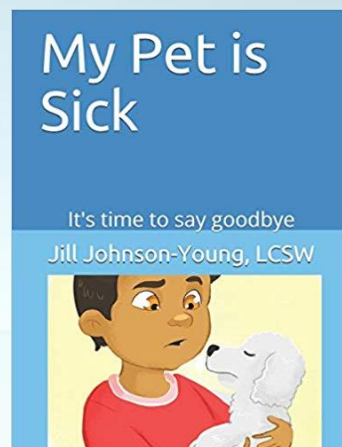
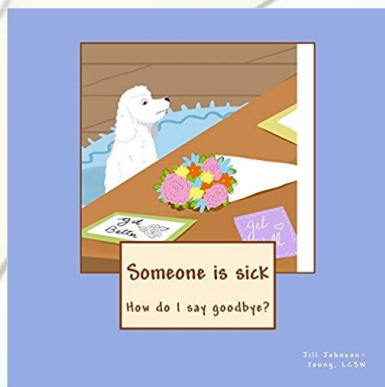
They become grief thrivers- with post loss growth, not PTSD.

They also are given permission to seek new relationships, but without being required to.

Humor is an essential part of healthy grieving.

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