



Being With the Dying and Those Who Love Them

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3/4/2026
FORUM ON AGING
SHARONVILLE, OH

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Today we will discuss:

- ▶ Hospice care
- ▶ The human body prepares to die
 - ▶ Common physical, emotional and spiritual experiences
- ▶ Being present to the dying person
 - ▶ Environment
 - ▶ What you might hear
 - ▶ What to say/not say
- ▶ Supporting loved ones of someone who is dying
 - ▶ What the family might say/feel
 - ▶ What to say/not say
- ▶ Self Care



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Hospice Care

WHAT HOSPICE CARE IS

WHAT HOSPICE CARE IS NOT

WORKING TOGETHER FOR THE GOOD OF THE PATIENT AND FAMILY

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Hospice Care – What It Is

- ▶ Care provided by an interdisciplinary team to patients with a life expectancy of 6 months or less
- ▶ 2 physicians must certify this
- ▶ Can be full code and can receive chemo, radiation or other treatments
- ▶ Care, even if there is no cure....




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Hospice Care – What It Is

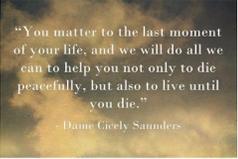
- ▶ 4 levels of care
 - ▶ Routine
 - ▶ Respite
 - ▶ Continuous Care
 - ▶ Hospice Inpatient
- ▶ Payment for Service
 - ▶ Medicare
 - ▶ Medicaid
 - ▶ Private Insurance
 - ▶ Indigent patients




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Hospice Care – What It Isn't

- ▶ Neither expedites nor delays death
- ▶ Does not use medications to facilitate death
- ▶ Doesn't equal death in days/ weeks (hospice is a 6 month benefit)




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Discharge from Hospice Care

- ▶ Clients who no longer meet eligibility criteria, must be discharged and care transferred to other providers



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The Human Body Prepares to Die



WHAT HAPPENS

WHY IT HAPPENS

OFFERING COMFORT

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The Human Body Prepares to Die

- ▶ When death due to a chronic illness approaches, the body has a predictable way of shutting down.
- ▶ Educating families on what's next, helps to reduce anxiety and fear.
- ▶ Providing solutions for anticipated and current issues




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Common Physical Signs Death is Nearing

- ▶ Increased time sleeping
- ▶ Decreased interactions
- ▶ Minimal food or fluid intake
- ▶ Respiratory congestion/distress with breathing
- ▶ Decreased urine output
- ▶ Skin mottled




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Emotional and Spiritual Signs Death is Nearing

- ▶ Withdrawal (little interest in talking, TV)
- ▶ Significant emotional detachment (the circle tightens)
- ▶ Restlessness/agitation
- ▶ "Picking" behavior
- ▶ Visions of people who have already passed




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Remember....

- ▶ **A person's body, mind, and spirit, must align and "be ready" for death to peacefully occur.**




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Looking for "Permission"

- ▶ Is it ok to take pain medicine?
- ▶ Do I need to endure this pain and suffering to please God?
- ▶ What if I get addicted?




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Looking for "Permission"

- ▶ "I don't know what to do: he just won't eat! I feel like I am starving him to death!"
- ▶ He's not dying because he's not eating. He not eating because he is dying
- ▶ Offer small servings of favorite foods using a small plate. Remove if patient doesn't want it (don't push)
- ▶ Minimize food odors




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Looking for "Permission"

- ▶ To Feed or Not To Feed? Use of Tube Feedings
 - ▶ May decline if insufficiently beneficial or excessively burdensome
 - ▶ We must present a realistic picture of the future for a true informed decision
 - ▶ Advance Directives can assist significantly when families are faced with making these decisions




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Offering Comfort at the EOL

- ▶ Emotional Comfort
 - ▶ Life review
 - ▶ Explore impact of person on the world/their family
 - ▶ Address grief issues and related feelings (grief about role changes, leaving family behind, etc.) by making referrals as needed




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Offering Comfort at the EOL

- ▶ Emotional (cont)
 - ▶ Patient may wish to explore treatment decisions (full code, no code, other life sustaining treatment).
 - ▶ We must become comfortable with these discussions...

You are free to make whatever choice you want, but you are not free from the consequences of the choice.



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The Mystery and Awe of Death

- ▶ Vivian – 88yr old cancer patient
 - ▶ Unresponsive for 3 days
 - ▶ Husband and I sat quietly with her
 - ▶ Suddenly raised head, opened eyes with face bright "I've seen heaven and its beautiful"




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An Important Reminder 19

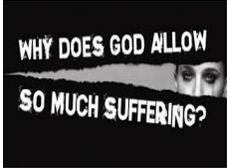
The word
LISTEN
contains
the same letters
as the word
SILENT.



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Responding to Suffering 20

- ▶ It is hard to understand or explain why there is suffering and pain-*it is all part of the great mystery....*
- ▶ I've learned even in the most difficult situations; God is there to help us endure it and get through it.
- ▶ Offer a prayer for God to be with them and to sustain them through their struggle and offer chaplain services




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Being Present to the Dying



ENVIRONMENT
WHAT YOU MIGHT HEAR
WHAT TO SAY/NOT TO SAY

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Being Present to the Dying Person 22




- ▶ Environment
 - ▶ Be at their eye level (pull up a chair, kneel down)
 - ▶ If safe, put down the bed rail (remove barriers-but put it back up before leaving)
 - ▶ If family is present, talk to the patient - then turn to family asking if they have questions.



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Being Present to the Dying 23

- ▶ What does the patient know about their illness/prognosis?
- ▶ Respect where they are and start by meeting them there

"Life is pleasant. Death is peaceful.
It's the transition that's troublesome."
- Isaac Asimov



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Being Present to the Dying (continued) 24

- ▶ Bring calm to the bedside
 - ▶ Take a few deep breaths or say a prayer before entering the room/home
 - ▶ Focus on the patient and ask "What is the most important thing you want me to address today?"
 - ▶ Tell me about....
 - ▶ Be attentive to patient needs (keep visit short if necessary)




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Being Present to the Dying (continued) 25



- ▶ What the patient might say...
 - ▶ Why doesn't God take me?
 - ▶ I want to go home!
 - ▶ I wish this was over...
 - ▶ Why isn't God healing me?
 - ▶ Why am I having to suffer like this?



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Offering Comfort at the EOL 26



- ▶ Spiritual Care
 - ▶ Issues may include "the meaning of life", "the meaning of suffering", forgiveness and everlasting life
 - ▶ Coming from a positive perspective and a place of care serves the patient and family well



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Being present to the dying (continued) 27

- ▶ What NOT to say...
 - ▶ Avoid clichés
 - ▶ God never gives you more than you can handle
 - ▶ God needed another angel
 - ▶ You have to keep fighting
 - ▶ Your family needs you




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Examples of Spiritual Issues 28

- ▶ Chester – WWII Veteran in severe pain who wouldn't take pain medication




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SHARING DIFFICULT NEWS 29



- ▶ Meet with the patient (and family if applicable) when you have ample time to have a possibly prolonged conversation
- ▶ Take a seat in the room and near the patient



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Sharing Difficult news (Continued) 30

- ▶ Provide some indication that you will be sharing bad news...
 1. Reach out and touch them before speaking (if appropriate)
 2. Provide a non-verbal look indicating sadness (look down and pause before speaking, slight downward frown)
 3. Provide a verbal clue...! wish I had better news or I am so sorry.....




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Sharing Difficult news (Continued) 31



- ◀ Once you have shared the difficult news, lean forward and offer empathetic look or nod.
- ◀ Silence here is appropriate while they contemplate and process what's been said
- ◀ If family is not present, consider writing down key points you shared
- ◀ Summarize key next steps



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Bringing up Hospice care 32

- ▶ You are requiring more care...and there is a service that can help
- ▶ The care is 100% covered by Medicare/Medicaid
- ▶ All your medications, equipment and supplies are provided at no cost
- ▶ And it is called HOSPICE




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Being Present to the Dying 33

- ▶ What to say or do...
 - ▶ Silence can speak volumes
 - ▶ Touch, hand holding, hand on shoulder can offer support
 - ▶ Speak from the heart
 - ▶ I am truly sorry you are going through this
 - ▶ I am sorry this isn't turning out as you had hoped...




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Being Present to the Dying (continued) 34



- ▶ Thank you for allowing me the privilege to care for you
- ▶ I have come to admire your.....
- ▶ I know that (fill in blank) will take great care of you (provide confidence with change in care providers)



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Why Didn't God Heal Him? 35

- ▶ **God heals in two ways.....**
 - ▶ Sometimes he takes the disease away from the person....that's earthly healing, cure of the disease
 - ▶ Sometimes He takes the person away from the disease....that's heavenly healing, the eternal cure



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Supporting Family/Friends of Someone Who is Dying 36



- Variables that Impact Coping and Grief
- What the family may say/feel
- What to say/not to say



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Supporting Family and Friends 37

- ▶ Variables which impact grief and coping
 - ▶ Past losses (especially recent)
 - ▶ Young children in home
 - ▶ Health issue of own
 - ▶ Financial stresses
 - ▶ Juggling multiple demands (work, new roles at home, caring for children)




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Offering Support and Comfort 38

- ▶ Think before speaking
 - ▶ Will what I want to say be of comfort to the family now
 - ▶ Will they feel comforted by my words in 5 years?
 - ▶ Now is NOT the time for judgment....

My peace
I give unto you
Let not your *heart*
be troubled,
neither let it be afraid.
John 14:27



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Feelings and Concerns of Family and Friends 39

Let's

Talk

- ▶ Why him and not me?
- ▶ I wish God would take him (often results in guilt later)
- ▶ Financial concerns
- ▶ Child related concerns
 - ▶ Daycare/school
 - ▶ Grief
 - ▶ Attend funeral?
 - ▶ Utilize teammates (SW, BE Counselors)



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Feelings and Concerns of Family and Friends 40

- ▶ Be conscious of caregiver well-being
- ▶ Managing daily roles and juggling work
- ▶ Food (accepting help)
- ▶ Paying bills/deal with financial concerns
- ▶ Exhaustion




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What to Say 41

- ▶ What do you want to ask me?
- ▶ What do you want me to know about him/her?
- ▶ Offer discussion topics when family sitting vigil...
 - Tell me about your favorite memory of....
 - What is the most important thing he/she taught you?

"Cherish your beautiful memories for sometimes these are the BLESSINGS that you are left with."
Truly Yours Truly 2013



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What NOT To Say... 42



- ▶ I know how you feel...
- ▶ My Mom had pancreatic cancer and only lived 3 months
- ▶ Well at least your dad didn't die when you were 10.



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What Not to Say 43



My Hope Path

- ▶ Avoid judgement
- ▶ He should have stopped smoking a lot sooner
- ▶ If only she would have taken the chemo when I offered it!

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Self Care 44



My Hope Path

- Determine How You Manage Stress
- Identify How You Replenish
- Recognize Signs of Burnout
- Ask for Support

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Physician/Healthcare Worker Burn Out 45

- ▶ Burnout is a long-term stress reaction marked by emotional exhaustion, depersonalization, and a lack of sense of personal accomplishment.
- ▶ Physicians reporting symptoms of burnout: 62.8% in 2020, 48.2% in 2023* https://www.ama-assn.org/practice-management/physician-health/physician-burnout-rate-drops-below-50-first-time-4-years



My Hope Path

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Self Care 46

- ▶ Determine How You Manage Stress
 - ▶ Music
 - ▶ Prayer
 - ▶ Walking
 - ▶ Journaling
 - ▶ Meditation
 - ▶ Spending time with a friend
- ▶ Build this into your daily routine



My Hope Path

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Self care 47

- ▶ Recognize Signs of Burnout
 - ▶ Difficulty sleeping or excessive sleep
 - ▶ Lack of hunger or overeating
 - ▶ Irritability
 - ▶ Difficulty concentrating
 - ▶ Tearful/anxious
 - ▶ Don't want to face tomorrow



My Hope Path

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Self care 48

- ▶ Ask for Support as soon as you start to struggle
- ▶ Develop your "go to people" list in advance
- ▶ Ask for support when you are showing early signs of burnout (not weakness)



My Hope Path

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Care of the Dying is Truly Sacred Work

FROM WHICH MANY BLESSINGS COME!



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It's Okay to Cry...



"There is a sacredness in tears. They are not the mark of weakness, but of power. They speak more eloquently than tongues. They are messengers of astonishment, grief and unspeakable love." Washington Irving

PhilosophyWall.com



- ▶ Nursing school taught me to "not get too close with patients and never let them see you cry".
- ▶ They were wrong
- ▶ Your tears (when controlled) show the family you genuinely care

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Does Our Caring Make a Difference?

I will never forget:

- ▶ The staff stopping by at end of shift or coming in on day off
- ▶ Prayer circle
- ▶ Physician last two days of her life
- ▶ All these made a difference, that I will never forget!




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Blessings Come from Unexpected Places





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If I Can Help in Any Way...

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