When the Time is Right: Harnessing the Benefits of Palliative and Hospice Care

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DISCLOSURES & SUPPORT

• I have no stocks, patent rights or employment with any company

• I have consulting/advisory board agreements with:

• I have pre-clinical laboratory and/or clinical trial support from the following companies:
Life Continuum.... Philosophically

- Tumor-directed
- Symptom-directed (palliative)
Despite the vocation of everyone here, only a portion of brain tumors have a curative-intent approach.

Thus, an essential part of our care must include evidenced-based Palliative Care & Hospice Care.
Everyone to Write their Best, Best-longest, Novel

**“Chapters in Care”**

- XXXX
  - XXXX
  - XX
  - XXXXX

- OOOOO
  - OOOOOOOOOOOOOO
  - OOOOOOO

- ?
  - ?
  - ?
  - ?

- Add as many “pages” to each chapter
- Be smart & efficient at changing chapters
- Maintain many good next options

The “Binder” of the novel is one’s KPS and Quality of Life
Incorporating Palliative Care and Hospice into your Life Novel

Prepare for the Unknown and Possible
Incorporating Palliative Care and Hospice: A Environmental Example

Number of Claims as of 11/14/2018

Cat. 5 Hurricane Michael's Trajectory

HURRICANE FORECASTERS SHOWING THEIR PREDICTIONS.
Incorporating Palliative Care and Hospice
A Environmental Example

Prepare for the Unknown and Possible
Simultaneous enrollment in Palliative Care or Hospice Care while placed on Heart Transplant list

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**Integrating Palliative Care Across the Heart Failure Experience**

After heart failure (HF) diagnosis, initiate in tandem:

<table>
<thead>
<tr>
<th>Traditional HF Management</th>
<th>Primary Palliative Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient assessments, Medical and family histories, physical exam, diagnostic tests, patient-reported outcomes</td>
<td><strong>Control pain and other symptoms</strong></td>
</tr>
<tr>
<td>Predict and communicate prognosis</td>
<td><strong>Assist with medical decision-making and advance care planning</strong></td>
</tr>
<tr>
<td>Choose therapy</td>
<td><strong>Assess and reduce emotional distress and burden to patient and family</strong></td>
</tr>
<tr>
<td>Manage “trigger” events</td>
<td><strong>Coordination of care across patient’s care team</strong></td>
</tr>
<tr>
<td>Monitor progress as physical function and quality of life declines</td>
<td><strong>Promote improved quality of life for patient and caregiver</strong></td>
</tr>
</tbody>
</table>

**Specialist Palliative Care**

Consider specialist involvement when problems are especially complex or severe (includes hospice care)

Your best, Best-longest Life’s Novel in your Authorship

• Understand your goals and wishes
  • Medical
  • Material
  • Persons, animals, entities dependent on you
• Share with caregivers
• Document and share with both caregivers and healthcare system
• Other preparations
• Inner peace
• = Advanced Care Planning
Advanced Care Planning

When

How

What
Advanced Care Planning – WHEN

- **PALLIATIVE CARE:**
  - Soon after diagnosis of a serious illness

- **HOSPICE:**
  - “Would you be surprised if” ..... this patient wasn’t alive in 1 year (all-cause)
  - Research demonstrates that this strategy is typically well received by patients and families

Prepare for the Unknown and Possible
Advanced Care Planning – WHEN

Many People Aged ≥65 Years Have Not Discussed EOL Care With a Physician (2015) or Documented EOL Care Wishes (2013)

- Have NOT discussed: 73%
  - Have discussed: 27%

- Have NOT documented: 40%
  - Have documented: 60%

Most Physicians Report Not Being Trained to Discuss EOL Care (2016)

- Report NOT having had training: 68%
  - Report having had training: 32%
    - 68% (29% + 32%)

Before January 1, 2016, Medicare did not reimburse physicians for patient visits to discuss EOL care.
80% of people say that, if seriously ill, they would want to talk to their doctor about end-of-life care.

7% of people report actually having had an end-of-life conversation with their doctor.

25% of doctors knew that their patients had advance directives on file.

**Advance Directive Recommendation**

- Anyone may face a sudden and unexpected acute illness or injury with the risk of becoming incapacitated and unable to make medical decisions.

- Everyone age 18 and older should be encouraged to complete a Health Care Power of Attorney document and to engage in advance care planning discussions with family and loved ones.

- An ongoing conversation over the years with your healthcare decision-maker, family, and healthcare provider is very important.
90% of people say that talking with their loved ones about end-of-life care is important.

27% have actually done so.

Source: The Conversation Project
Advanced Care Planning – HOW

...so what are the Five Wishes

My Five Wishes are:

2. Who I want to make care decisions for me when or if I am not able
3. What kind of medical treatment I do or don’t want
4. How comfortable I want to be
5. How I want people to treat me
6. What I want my loved ones to know
Advanced Care Planning - HOW

- ANYONE can do it!
- Demographics
- Contact
- Primary diagnosis
- Initial suggestions and goals
Advanced Care Planning - WHAT

GEORGIA ADVANCE DIRECTIVE FOR HEALTH CARE

By: ___________________________ Date of Birth: ____________ (Print Name) (mm/dd/yyyy)

This advance directive for health care has four parts:

PART ONE  HEALTH CARE AGENT. This part allows you to choose someone to make health care decisions for you when you cannot or do not want to make health care decisions for yourself. The person you choose is called a health care agent. You may also have your health care agent make decisions for you after your death with respect to an autopsy, organ donation, body donation, and final disposition of your body. You should talk to your health care agent about this important role.

PART TWO  TREATMENT PREFERENCES. This part allows you to state your treatment preferences if you have a terminal condition or if you are in a state of permanent unconsciousness. PART TWO will become effective only if you are unable to communicate your treatment preferences. Reasonable and appropriate efforts will be made to communicate with you about your treatment preferences before PART TWO becomes effective. You should talk to your family and others close to you about your treatment preferences.

PART THREE  GUARDIANSHIP. This part allows you to nominate a person to be your guardian should one ever be needed.

3 - The Primary And Alternate Health Care Agent Information

Locate page 3. The blank spaces below the heading "Part One: Health Care Agent" have been provided so the identity of the Health Care Agent may be documented properly. In the "Health Care Agent" section, enter the First and Last Name of the individual this document shall designate as the Principal's Health Care Agent.

(1) HEALTH CARE AGENT

I select the following person as my health care agent to make health care decisions for me:

Name: ____________________________________________

Address: _________________________________________

Telephone Numbers:

(Home) __________________________________________

(Work) __________________________________________

(Mobile/Cell) ____________________________________

E-Mail Address: _________________________________
Advanced Care Planning - WHAT

Living Will

Also called an advance directive, the living will communicates your personal wishes for a wide variety of treatments, such as using CPR to restart your heart or keeping you alive with breathing machines. You can also make choices in advance about whether you wish to undergo certain surgeries or submit to blood transfusions and other procedures. Some pointers:

› Get a template with suggested language from your healthcare provider, or download a template for your state from the Internet. Words on the template can be inserted or deleted.

› Review the document with a trusted physician or other healthcare professional so you understand the consequences of each decision.

› Revisit your preferences and update the document on a regular basis. You may change your mind about your directives once you better understand your condition.
Advanced Care Planning - WHAT

Healthcare Power of Attorney

This document names a person who will have the responsibility of making decisions about your healthcare based on your living will. Make sure this person is willing to take on the role and will have the time to speak with physicians and other healthcare providers about your care.

DURABLE POWER OF ATTORNEY FOR HEALTH CARE

I, __________________________, am of sound mind and I voluntarily make this designation.

APPOINTMENT OF PATIENT ADVOCATE

I designate __________________________ my________________________

(Address of patient advocate)

living at __________________________ my________________________

(Address of patient advocate)

as my patient advocate. If my first choice cannot serve, I designate __________________________ my________________________

(Name of successor patient advocate) (Spouse, child, friend …)

living at __________________________ my________________________

(Address of successor patient advocate)

to serve as patient advocate.

My patient advocate or successor patient advocate must sign an acceptance before he or she can act. I have discussed this appointment with the individuals I have designated as patient advocate and successor patient advocate.

GENERAL POWERS

My patient advocate or successor patient advocate shall have power to make care, custody and medical treatment decisions for me if attending physician and another physician or licensed psychologist determine I am unable to participate in medical treatment decisions.
Advanced Care Planning - WHAT

- **POLST: Physician Orders for Life-sustaining Treatment**
- Ask your Provider about “resuscitation”
  - Consider watching videos
- It there evidence that your symptoms and illness would respond to resuscitation?
- What ARE the evidenced based treatments for my symptoms and illness?
Palliative care vs. hospice care

Palliative care is aimed at anyone who has been diagnosed with a life-threatening illness.

Palliative care helps maintain quality of life and reduce illness symptoms — and recent findings suggest that cancer patients who receive palliative care alongside standard treatments can live longer.

Hospice care is mostly aimed at patients who have been diagnosed with a terminal illness.

Hospice care is aimed at providing patients with a dignified, pain-free death — in the U.S., hospice care is mostly meant to be administered inside the patient’s home.
MISSION: to provide care, support, and comfort to patients & families
FOCUS: improving or maintaining the highest quality of life through emotional, spiritual and physical support
LOGISTICS: Brought to the patient......single-contact

Interdisciplinary Team of Hospice Professionals
Home Medical Equipment
Medication
Respite Care
Delivered to home “KITS” for seizures, pain, shortness of breath

Continuous Care
Inpatient Care
Routine Home Care
Bereavement Support
For families up to 1 yr after patient’s death

72 hours in-home care for crisis or respite
What

Palliative Care Benefits & Services

Mission:

Palliative care aims to enhance the quality of life for people living with an advanced or terminal illness.

Focus:

- Allows disease-modifying treatment
- Can transition to Hospice
- More robust than Home health

It's a holistic approach with a team of health professionals coming together to provide individualised care to meet the physical, emotional, spiritual, social and practical needs of people affected by illnesses.

Financial assistance

Respite care services

Relief of pain and other symptoms

Equipment needed to aid care at home

In home nurse visits

Home help e.g. housework, meals

Support for emotional, social, cultural and spiritual concerns

Preferences for future care
## Criteria for Palliative and Hospice

<table>
<thead>
<tr>
<th>(Differences) Palliative Care:</th>
<th>Hospice:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic illness</td>
<td>Terminal illness</td>
</tr>
<tr>
<td>Can seek life-prolonging, curative treatment</td>
<td>Not seeking curative treatment</td>
</tr>
<tr>
<td>No eligibility criteria</td>
<td>Expected prognosis &lt; 6 mon</td>
</tr>
<tr>
<td></td>
<td>(if the illness runs its normal course)</td>
</tr>
<tr>
<td>Same Co-pay as other MD visits</td>
<td>Medicare – part A</td>
</tr>
<tr>
<td>Medicare – part B (same co-pay as other MD visits)</td>
<td></td>
</tr>
</tbody>
</table>

This does NOT give an “expiration date”. See below

Palliative treatments, e.g., IVFs, avastin, RT, Optune TTFs, antibiotics, are increasing
Criteria for Hospice

- ANY:
  - Primary Diagnosis
  - Combined Diagnoses
  - General Health

- Prognosis ~ 6 months, if the disease took its natural course

- CAN RENEW
- CAN pause, dis-enroll, re-enroll

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Table 1: Hospice Guidelines for Estimating Survival of Less Than 6 Months in a Patient with Dementia.*

| Stage 1: Has no objective or subjective difficulties |
| Stage 2: Has subjective complaints of forgetting |
| Stage 3: Has decreased job functioning that is evident to coworkers and difficulty traveling to new locations |
| Stage 4: Has decreased ability to perform complex tasks (e.g., planning dinner for guests, handling finances) |
| Stage 5: Requires assistance in choosing proper clothes for the day, season, or occasion |
| Stage 6a: Cannot dress without assistance, occasionally or frequently |
| Stage 6b: Cannot bathe without assistance, occasionally or frequently |
| Stage 6c: Cannot perform mechanics of toileting without assistance, occasionally or frequently |
| Stage 6d: Is incontinent of urine, occasionally or frequently |
| Stage 6e: Is incontinent of bowel, occasionally or frequently |
| Stage 7a: Has speech limited to fewer than six intelligible words during an average day |
| Stage 7b: Has speech limited to one intelligible word during an average day |
| Stage 7c: Is unable to ambulate independently |
| Stage 7d: Cannot sit up independently |
| Stage 7e: Cannot smile |
| Stage 7f: Cannot hold up head independently |

2. The patient must have had at least one of the following medical conditions in the past year:

- Aspiration pneumonia
- Pyelonephritis or other upper urinary tract infection
- Septicemia
- Pressure ulcer, multiple, stage 3 or 4
- Recurrent fever after treatment with antibiotics
- Eating problems, defined as food or fluid intake that is insufficient to sustain life (i.e., in tube-fed patients, weight loss of >10% during the previous 6 months or a serum albumin level of <2.5 g per deciliter)

* Data are from the National Hospice Organization.†

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* Hospice guidelines for estimating survival of less than 6 months in a patient with dementia require that the patient meet the following two criteria regarding the Functional Assessment Staging (FAST) tool and medical conditions.

1. The patient must be at or beyond stage 7c on the FAST tool and have all the features of stages 6a through 7c:

2. The patient must have had at least one of the following medical conditions in the past year:
Myths about Hospice

- Only a doctor can refer
- Can’t pay for it
- Must be a DNR
- Must leave my home
- No say in my care
- Patient Cannot Control the Physicians, Nurses, and Team
- Care is Only for the Patient and Only when they are Alive
- Giving up, surrendering, just waiting to die
- No evaluation and treatment
- Palliative care is “hospice-light”
- Hastening Death

Palliative care is “hospice-light”
Myth: I don’t want to leave my home

• Hospice is a philosophy of care
• Received wherever the patient and caregivers prefers and is comfortable
  • Anyone’s home, assisted living facility, long-term care facility, hospital, hospice “house”
  • NHPCO’s report showed that 58.9% of patients received care in their home
Myth: I Can’t Pay for it

• HOSPICE CARE:
  • Medicare, Medicaid and most insurance plans cover
  • Ability to pay is NOT enrollment criteria (NO denials)
    • Government, donors, charities, etc.
    • Often NON-citizens

• PALLIATIVE CARE:
  • Most insurance plans cover
    • Similar to home health or regular medical visits
Myth: Patient has No Say in their Care

- Patients can change, pause, dis-enroll, re-enroll.
- Hospice plans prioritize patient’s wants and needs.
- Care is individualized & evolves as the patient does.
- NHPCO study:
  - Families are more satisfied with loved one’s care if in Hospice (vs. home health).
  - 80% of Families reported their love one’s wishes were followed.
Myth: Patient Cannot Control the Physicians, Nurses, and Care Team Around Them

- Patient’s current primary care physician or specialist can become their Hospice medical attending....or......
- Can be a consultant
- Most hospices allow patients to go see their doctor, if able, ....or help virtually
- Weekly updates shared with physician and feedback is encouraged.
- Hospice team is NOT a “resolving door of strangers”, but a dedicated team. Patients can request preferences and changes to team.
Myth: Care is Only for the Patient and Only when they are Alive

• Bereavement counseling, financial and social assistance, and education for families at no cost.
• Both during Hospice and for up to a year after the death.
• This is a tremendous gift.
• Increases the chance of a “good death” for all.
Myth: Patients must be a DNR

• A signed DNR is **not** required to receive hospice care
• Hospice extends quality of life during one’s natural lifetime, and, thereby, will not act in ways that prolonging suffering
Myth: Giving up......surrendering.... Just waiting to die

• Proactive, evidenced-based symptom management that helps patients live better, ...... and often better longer.

• Hospice enables wish-fulfillment, special moments, and memories that would otherwise not happen.
Myth: Hastening Death

- Research demonstrates the opposite: the early adoption of palliative care and hospice trends patients living longer
- For example, on average, people live 29+ longer days if enrolled in hospice... for many diseases, it can be several months longer.
- Hospice does NOT “withhold food, water” so patients dies faster.
- **Concept of a care item going from a tool .... to a dull dud ..... to a weapon**
Myth: Only a Doctor can Refer

- Anyone, including a patient, family member, caregiver, or medical and religious persons, can refer.
Myth: No Evaluation and Treatment

• “Don’t look, don’t try”
• “Morphine, hospital bed and sidelined”
• Hospice is expert in the latest medications and devices for symptom relief.
• Hospice evaluates and implements treatments aimed at minimizing improvable/reversible symptoms
• This includes around-the-clock care
• DOES NOT check disease status “just because”
Study links palliative care to lower risk of suicide
A study of veterans with advanced lung cancer found palliative care was linked to an 82% lower risk of suicide, researchers told the American Thoracic Society’s annual meeting. Dr. Donald Sullivan of Oregon Health & Science University said referrals are one barrier to palliative care and not all physicians are aware of the benefits of palliative services. 

Halicu (free registration)/HemOnc Today (5/21)

 Practical Aspects of Palliative Care (PAPC)
E.g., Routes of Administration

Creative Uses based on Goals:

• Aerosolized medicines, e.g., pain meds, anti-anxiety, anti-seizures
• Nose-inserted-feeding-tubes and rectal tubes used to deliver medicines
• Subcutaneous and transdermal hydration and medicines
• PEG tubes for medicines, hydration, satiation ANYWHERE by ANYONE
**E.g., Off-label Medicine Use**

<table>
<thead>
<tr>
<th>Drug</th>
<th>Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cholinesterase inhibitors (donepezil, rivastigmine, galantamine)</td>
<td>Improve memory and sometimes ADL's and mood</td>
</tr>
<tr>
<td>Namenda (memantine)</td>
<td>Mood, memory, language, attention, reasoning, ADLs, migraine relief</td>
</tr>
<tr>
<td>Stimulants (Methylphenidate (Ritalin))</td>
<td>Focus, attention, alertness, wakefulness, endurance (physical and mental), mood</td>
</tr>
<tr>
<td>Fish Oil; Phosphatidylserine; glycerophosphocholine; acetyl-l-carnitine</td>
<td>Safe, few side effects, may improve mood, focus, ADL's</td>
</tr>
</tbody>
</table>

Palliative & Hospice providers have extremely creative, flexible, evidenced-based methods for improving symptoms!
Resources for Harnessing the Benefits of Palliative & Hospice Care

<table>
<thead>
<tr>
<th>Brain Tumor Education</th>
<th>Diagnosis</th>
<th>Treatments &amp; Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Publications</td>
<td>Newly Diagnosed</td>
<td>Find a Brain Tumor Center</td>
</tr>
<tr>
<td>Webinars</td>
<td>Signs &amp; Symptoms</td>
<td>Find a Clinical Trial</td>
</tr>
<tr>
<td>Regional Meetings</td>
<td>Brain Tumor Types</td>
<td>Assisted Care Options</td>
</tr>
<tr>
<td>National Conference</td>
<td>Recurrence</td>
<td>End of Life Care</td>
</tr>
<tr>
<td>Caregiving</td>
<td>Social &amp; Emotional Support</td>
<td>Living with a Brain Tumor</td>
</tr>
<tr>
<td>Pediatric Caregiver Resources Center</td>
<td>Find a Support Group</td>
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<tr>
<td></td>
<td>Connections Support Community</td>
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</tbody>
</table>
Resources for Harnessing the Benefits of Palliative & Hospice Care

Cancer.Net
Doctor-Approved Patient Information from ASCO®

• NAVIGATING CANCER CARE:
  • Cancer Basics
  • Diagnosing Cancer
  • Managing Your Care
  • Financial Considerations
  • How Cancer is Treated
  • Palliative and Supportive Care
  • Dating, Sex, and Reproduction

• Advanced Cancer
  • Completing Your Life
  • Putting Your Health Care Wishes in Writing
  • When You and Your Family Differ on Treatment Choices
  • Caring for a Terminally Ill Child
  • Hospice Care
  • Care Through the Final Days

• For Children
• For Young Adults and Teenagers
• For Older Adults
• Prevention and Healthy Living
• Cancer.Net Videos

https://www.cancer.net/navigating-cancer-care/advanced-cancer/hospice-care
Coping With Cancer

This section is designed to help people with cancer and their families better cope with cancer.

- Managing Emotions
  How to cope with emotional side effects of cancer and its treatment

- Physical, Emotional, and Social Effects of Cancer
  Also called palliative care and supportive care. Focused on reducing symptoms, improving quality of life, and supporting patients and their families.

- Talking With Family and Friends
  How cancer affects loved ones

- Caring for a Loved One
  Tips on caregiving and coping with a loved one's cancer diagnosis

- Finding Social Support and Information
  Resources for cancer support and counseling

- Hearing the Oncologist Perspective
  Essays by doctors about caring for people with cancer
Finding Social Support and Information

After a diagnosis of cancer, it is important to find credible information and seek support.

- **Counseling**
  When to seek it and how it helps

- **Support Groups**
  Reasons to join and how to find one

- **Finding a Support Buddy**
  How to get matched with a survivor of the same type of cancer for one-on-one support

- **Online Communities for Support**
  Options for joining an online community

- **Telephone and E-mail Cancer Helplines**
  List of organizations that offer general medical information

- **Wish Fulfillment Organizations for People With Cancer**
  List of organizations for people with cancer and their families

- **General Cancer Groups**
  Resources for additional information, services, and support

- **Cancer-Specific Resources**
  National organizations that offer support to people with cancer and their families.
Resources for Harnessing the Benefits of Palliative & Hospice Care

CaringInfo, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis.
Resources from Organizations

- Nat. Hospice & Palliative Care Org.
  - www.nhpco.org
- Am. Academy of Hospice & Palliative Medicine
  - www.aahpm.org
- National Institute of Health's Institutes on Aging, Neuro. Disease and Stroke, Cancer, ....
  - www.nia.nih.gov/health/end-of-life
- NIHSeniorHealth.gov
- Religious Organizations
- Many others!

Brochures and Fact Sheets in PDF

CaringInfo offers a range of materials that you can print off and use in your education and outreach efforts. The following list is only a sample of some of the PDF documents available.

End-of-Life Care
- Choosing a Quality Hospice
- What is Hospice?
- Hospice Care: A Consumer's Guide to Selecting a Hospice Program
- Hospice Care and the Medicare Hospice Benefit
- What is Palliative Care?
- How Can Palliative Care Help Me?
- The Dying Process-A Guide for Family Caregivers

Serious Illness
- Living with Serious Illness
- When Someone You Care About is Seriously Ill

Planning Ahead
- End-of-Life Decisions
- Conversations Before the Crisis
- If You or Someone You Love is Very Ill... Ask Tough Questions
- Artificial Nutrition and Hydration at the End of Life
- Communicating End-of-Life Wishes
- Understanding Advance Directives

Resources to Share with Professionals
- A Guide for Clinicians
- Advice for Physicians: Caring for Dying Patients
- Palliative Care: Information and Resources for Healthcare Professionals
- Hospice Patient Rights

Hospice Sabbath Materials:
- A Service of Reflection and Remembrance
- Additional Suggested Readings

For additional materials, visit the CaringInfo website.

Veterans Outreach - visit the We Honor Veterans website.
Resources from Your Team!

- **ASK TO GO OVER YOUR ADVANCED CANCER PLANNING** OFTEN
- **SHARE YOUR GOALS, WISHES, NEEDS** OFTEN

- Providers and their teams
- Social workers
- Counselors
- Blogs
- Support groups
- Financial assistance
- Spiritual services
Resources from Dedicated Providers, Volunteers & Caregivers
What a doctor wishes patients knew about the end

By BJ Miller

Updated 5:15 PM ET, Thu July 18, 2019

(CNN) As a hospice and palliative medicine physician, my job is to help reduce suffering. At the end of life, that job becomes especially intense when time is short, when machines and data seem to be taking over, and so many intense emotions surround a body that is trying to die.

But here in that narrow trench, both providers and patients do have power to shape their experience together, especially if they take the time to have a few crucial conversations. In the spirit of palliation, here are a few things, as a physician, I wish I could share more often with patients and their caregivers.
You don't need to be dying to receive palliative care

In hospitals, it is still common for palliative care clinicians to be pulled aside by a well-meaning though misinformed nurse or doctor who says, "This poor family is miserable, but they're not ready for palliative care yet." They imply that either the patient is not dying, or the patient does not realize that he or she is dying. But what this statement does is to conflate hospice or end-of-life care with palliative care. Palliative care is an approach, framed within the context of serious illness, where easing suffering is the goal. So, you just need to be sick and suffering to qualify for palliative care, not necessarily dying any time soon. Don't be afraid to say you want it.

Don't wait for your doctor to bring up hospice

Doctors tend to wait too long to acknowledge when death is close. And as research has made clear, the closer we feel to the patient, the more wildly we overestimate their prognosis.

The median length of stay in hospice care in the United States is 24 days.

As a rule, this is too short. So here's an inside tip for patients and loved ones starting to wonder about hospice. In an effort to get primary physicians to think sooner about recommending hospice, researchers came up with the "surprise question." As in:
"Doctor, would you be surprised if your patient died within a year?" If the answer is no, then that doctor should start considering a referral to hospice. But there is nothing stopping you from asking the surprise question yourself. If you live with advancing chronic illness and are thinking about how you want your life to go, you might turn the table and ask: "Hey doc, would you be surprised if I died in the next year?" This is a good and bold way to open an honest dialogue with your doctor and get the sort of support you need.

The healthcare system is wired to extend physical life, without much regard to the psychological, spiritual, or financial costs. With advances in technology, we are able to prop up a body practically indefinitely. And it's well known that doctors tend to presume you want aggressive care, even when care geared toward your comfort may be more in line with your wishes. Unless you say otherwise, the doctor's presumption rules the day. This means that at some point you may need to say "no" to that next treatment. So be sure to look up now and again and check that the care you're getting is the care that suits you.
It's OK to laugh

In my book, "A Beginner's Guide to the End: Practical Advice for Living Life and Facing Death," someone tells of their stepfather wearing a shirt that read, "I'm so old I can't find my own nuts," with a doodle of a squirrel on it. His dying wish was to make his daughter laugh, and it helped both of them immensely. To honor him, she buried him in that shirt, sealing his personality in death as it had been in life. Illness isolates people, not just physically. When we get sick, people around us start censoring themselves. The solemnity is supposed to be a form of kindness, perhaps, but it can feel more like yet another loss, almost a premature death. As patients and caregivers know, illness and its indignities offer plenty of rich material for humor. The joke is only on us if we don't find some way to laugh back.
Those guardrails on the hospital bed go down

Dr. Marianne Matzo is a PhD nurse who researches sexuality at the end of life. She told me a story about a patient who died in his hospital bed while he and his wife were in the middle of oral sex. Dr. Matzo tells this story as a triumph rather than a tragedy: The couple had found a way to maintain intimacy until his last breath. We are still living when we are dying. When those guardrails go down, it is possible to cuddle or caress one another. Those moments are about feeling connected, sexually or otherwise, and finding ways to be in that body while you have it. They are about reminding yourself and each other that you are still here, both of you, able to love and be loved. This is how healing works, and it is very much possible to be healed -- to be whole -- even as your body falls apart.
To the caregivers: Don't be afraid to leave the room

In their final days and hours, dying people are usually in and out of consciousness; even when awake, they are often delirious. That means your loved one might say or do things that are completely out of character. Behavior ranges from sweet to insufferable. I met an elderly woman at a conference once who nervously relayed the story of her husband hurling strange and vulgar accusations before losing consciousness for good. Now there was trauma on top of sorrow. I wish someone had told her earlier about the very normal condition of deathbed delirium.

I also wish that caregivers knew it was OK to leave their loved one's bedside. How many times will they have spent hours gathered in the room, not eating or sleeping for days, barely blinking, not wanting to miss that last breath, only to have the person die just when they nod off or use the bathroom?

As any hospice worker can tell you, this is also a well-known phenomenon. It's almost as if the presence of others -- especially deeply loved ones -- gets in the way of the dying person's final step. That big moment may need to happen alone. What dying people seem to need at the very end is to know that the people they love are going to be OK; that life will go on and that you -- the person they care for -- will be able to take care of yourself. So, the kindest thing you can do is to demonstrate that care by leaving the room when you need to. Just be sure to give a kiss and know that it may have to be the last.
QUESTIONS?

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Thank you!
Cause of Death

• Unique from other Cancers
• Educate families about “Foreseen & Unforeseen events”
• Co-morbidities – often sudden, unforeseen
  • VTE
  • Sepsis (often: aspiration PNA & UTI)
  • Complications of seizures and falls
• Progressive disease – often gradual, foreseen
  • Herniation syndrome
Paucity of Literature Detailing the Symptoms at the End of Life

- **Common Time-points & Definitions:**
  - Palliative ("incurable" or "to treat symptoms")
  - Terminal (≤ 6 months median survival)
  - Around the time of Death
  - Last month of Life
  - Last days of Life
  - Actively dying (imminent death)
Symptoms Anytime Around End of Life

- Adult glioma patients, $N = 55$, nurse phone calls, Amsterdam

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Number of patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drowsiness/progressive loss of consciousness</td>
<td>48 (87)</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>39 (71)</td>
</tr>
<tr>
<td>Progressive focal neurological deficits (motor, dysphasia)</td>
<td>28 (51)</td>
</tr>
<tr>
<td>Seizures</td>
<td>25 (45)</td>
</tr>
<tr>
<td>Incontinence $^a$</td>
<td>22 (40)</td>
</tr>
<tr>
<td>Progressive cognitive deficits</td>
<td>18 (33)</td>
</tr>
<tr>
<td>Headache</td>
<td>18 (33)</td>
</tr>
<tr>
<td>Confusion</td>
<td>16 (29)</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>14 (25)</td>
</tr>
</tbody>
</table>

$^a$Before the patient was confined to bed.

* = increased intracranial pressure

Sizoo E et al, Neuro-Oncology, Jan 2010; Sizoo E et al, BMJ Support Palliat Care; Oberndorfer, J Pal Med, 2008; Pace JNO, 2009; Faithfill, Pall Med, 2005
Symptoms within the Last Month of Life

• Adult brain tumor patients N=169, home deaths, records, Italy
  • Drowsiness 85%
  • Dysphagia 85%
  • Headache 36%
  • Epilepsy 30% (>80% had a seizure Hx)
  • Agitation and delirium 15%
  • Death rattle 12%

• Recommendations:
  • Multidisciplinary, well trained neuro-oncology team
  • Know NON-IV, non-PO regimens
  • Home care models may represent an alternative to hospital care AND may improve the quality of end-of-life care.

Symptoms Within the Last Week of Life

- Bedbound
- Food & Fluid Decrease
- Incontinence
- Sleeping & disorientation
- Urine & stool decrease
- Cool, mottled, extremities
- Restlessness, tremors
- Death rattle
- Agonal Breathing
- Unresponsiveness

www.senior-care-resources.com/the-dying-process-what-physical-symptoms-to-expect/
Convey Prognosis in Ways Best Understood and Best Emotionally Received

- **WORST:**
  - Vague terms to avoid prognosis (mass, lesion, tumor)

- **BEST:**
  - Explicate terms emphasizing prognosis (incurable malignancy)
Convey Prognosis in Ways Best Understood and Best Emotionally Received

• **WORST:**
  - Quoting statistics and specific numbers:
    - inherently inaccurate the individual
    - provoke anxiety and anger ("expiration date")

• **BEST:**
Convey Prognosis in Ways Best Understood and Best Emotionally Received

**WORST:**

- Quoting statistics and specific numbers:
  - inherently inaccurate the individual
  - provoke anxiety and anger ("expiration date")

**BEST:**

- Providing general time-frames
  - “Many weeks to several months”
  - “Most patients in a similar situation…”
  - “If you ask doctors, who commonly care for patients like your mom, if they’d be surprised if……most would say…..”
Individualizing Goals of Care → Optimizing Plan of Care

• Goal-directed treatment should be coupled with a **timeline for re-evaluation** and a **plan for changing**:

• E.g., Evidence states that if elderly patients, on mechanical respiration for aspiration pneumonia, have not been extubated by 72 hours, then they have less than 10% of ever being extubated”, thus, ...