

Palliative Care and Hospice

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Hospice history

- ▶ 1200's: the Catholic church had hospice houses, refuge for sick, wounded, dying, frail elders, travelers
- ▶ 1800s: First medical hospice in Lyon, France started by Jeanne Garnier
- ▶ Followed by other hospices in France and Ireland
- ▶ 1967: Dame Cicely Saunders opened St. Christopher's Hospice in London in 1967
- ▶ 1969: Dr. Elisabeth Kubler-Ross published *On Death and Dying* describing the five stages of emotions through which terminally ill patients work

Hospice history

- ▶ 1972: Dr. Kubler-Ross testified before the US Senate on subject of death with dignity
- ▶ 1974: Florence Wald opened Connecticut Hospice in US
- ▶ 1974: first hospice legislation introduced, not passed
- ▶ 1978: National Hospice Organization started, now known as NHPCO
- ▶ 1979: federal government starts hospice programs in 16 states to explore medical hospice
- ▶ 1981: first AIDS case in US
- ▶ 1982: congress creates Medicare hospice benefit

Palliative care- history

- ▶ 1974: Dr. Balfour Mount coins the term
- ▶ 1974: new “terminal care” unit opens in a Winnipeg hospital
- ▶ 1987: Cleveland Clinic Cancer Center opens first palliative medicine service, which becomes the first palliative medicine teaching and research site
- ▶ Currently over 90% of US hospital over 300 beds have PC teams
- ▶ Only 17% of rural hospitals 50-300 beds have PC

What is palliative care?

- Interdisciplinary care that aims to relieve suffering, improve quality of life, optimize function, and assist with decision making for patients with advanced illness and their families
- It is offered **simultaneously with all other appropriate medical treatment**

What is Palliative Care?

- ▶ Palliative means “to cloak”
- ▶ Palliative care is for control of symptoms and practical assistance at any point of a serious illness.
- ▶ Palliative Care is for people at any stage of a life-limiting or life-threatening illness
- ▶ Hospice is palliative care near the end of life

Where is palliative care done?

- ▶ In the hospital-
 - ▶ Patients with severe chronic illness may be seen by the palliative care hospital team to help with symptoms, to discuss goals of care, to help with planning for the future
- ▶ In the office-
 - ▶ Many aspects of palliative care are done by primary care and specialists when the focus on symptoms, comfort, planning for the future
 - ▶ Palliative care specialists may be located in offices in cancer centers, transplant centers etc.
- ▶ At home
 - ▶ especially when office visits become very difficult in later stages of illness

When might palliative care help?

- ▶ When a recent illness or hospital stay has resulted in a decline in function
- ▶ When hospital and ER visits are becoming more frequent
- ▶ When there are big decisions that you need help with
- ▶ When quality of life is getting worse in spite of office visits, ER, hospital visits

Who is on the palliative care team?

- ▶ Physicians of many specialties (board certified?)
- ▶ Nurse Practitioners/Advanced Practice Nurses
- ▶ Chaplain
- ▶ Others, varies by location
 - ▶ MSWs
 - ▶ RNs
 - ▶ Music/art therapists, others

Where is palliative care done?

- ▶ Hospital
- ▶ Emergency departments
- ▶ Home
- ▶ Cancer centers
- ▶ Other specialty centers (Heart failure, neurology)
- ▶ Assisted Living facilities
- ▶ *not nursing homes other than what their providers may offer*

How can palliative care help exactly?

- ▶ Symptom control- pain, breathing, appetite, weight changes
- ▶ Sleep, depression, anxiety, mood problems
- ▶ Assistance with practical issues- equipment, home assessment, finding caregivers
- ▶ Assistance with advance directives, FMLA, living wills
- ▶ Goal setting for end of life
- ▶ Spiritual concerns and support

What can Palliative Care not do?

- ▶ Home Health aides (bathing, dressing)
- ▶ Pay for equipment, although may be able to help order it
- ▶ Pay for medicines, supplies
- ▶ Nurse visits with some exceptions
- ▶ Serve as your primary care physician
- ▶ After-hours coverage
- ▶ See persons in skilled/rehab facilities

When is it time for hospice?

- ▶ When the burden of aggressive medical care outweighs the benefits
- ▶ Pain or other symptoms are harder to control
- ▶ Frequent office/ER/hospital visits are too difficult and no longer helpful

Criteria for Hospice

- ▶ Life expectancy of approximately 6 months
 - ▶ Can be recertified after 6 months as long as they continue to meet criteria
 - ▶ Can be very difficult to predict life expectancy with some diagnoses such as Alzheimer's or Parkinson's disease
- ▶ There are suggested criteria for most disease states to guide the hospice decision
- ▶ Choosing hospice or palliative care does not speed up the dying process!!

Criteria for hospice-chronic illness

- ▶ An increase in hospital and ER visits or frequent medical office visits
- ▶ Episodes of pneumonia or sepsis
- ▶ Frequent urinary tract infections
- ▶ Weight loss or dehydration due to reduced eating/drinking
- ▶ Problems swallowing, coughing and/or choking with food or drink, other signs of aspiration or known silent aspiration
- ▶ Wounds or skin breakdown related to weight loss or poor mobility

Criteria for Hospice-chronic illness

- ▶ Unable to sit upright in chairs, sliding out of chairs or falling forward or to the side when sitting
- ▶ Unable to walk without walker or human assistance or requires a wheelchair
- ▶ No longer able to smile
- ▶ Speech limited to six words or less per day
- ▶ Bowel and bladder incontinence
- ▶ Other significant medical problems- heart disease, diabetes, stroke, chronic lung disease, cancer
 - ▶ Usually hospice appropriate sooner if they have significant comorbid problems

Where is hospice done?

- ▶ In the person's own home
- ▶ In the home of family
- ▶ Assisted living (“aging in place”) -will vary greatly according to the facility
- ▶ Nursing home
 - ▶ Regular nursing home bed (ICF), but not a skilled/rehab bed (SNF)
- ▶ Dedicated hospice facility if available
- ▶ In the hospital
 - ▶ If necessary for the safety or comfort of the person

Who is the hospice team

- ▶ **Physician**
 - ▶ Full board certification now requires fellowship training
 - ▶ Can be a certified medical director (HMDC) without fellowship
 - ▶ Many hospice medical directors don't have either one
- ▶ **Nurse practitioners/Advanced practice nurses**
- ▶ **Registered nurses**
 - ▶ RNs do the majority of the regular visits
- ▶ **LPNs**

Who is on the hospice team?

- ▶ Home Health Aides
 - ▶ Assist with bathing, bed linens, personal care
- ▶ Chaplains
 - ▶ Very important regardless of religious preference
- ▶ Social workers/MSWs/MSSWs
 - ▶ Final arrangements, finances, housing, legal issues, counseling
- ▶ Bereavement staff
 - ▶ Follow the family for 13 months after the loss
- ▶ Volunteer coordinators and volunteers
- ▶ Office support staff

Hospice perks- what is covered

- ▶ Medications- covered by hospice if related to the primary illness or if needed for comfort
 - ▶ *some exceptions*
- ▶ Supplies- disposable briefs, bed pads, wound supplies, etc
- ▶ Equipment- Hospital bed, wheelchair, oxygen, bed table, nebulizer
 - ▶ Not electric wheelchairs or lift chairs
- ▶ 5 day respite stays in nursing facility up to every 30 days
- ▶ 24/7/365 on call coverage- phone calls, on-call visits
- ▶ Not covered- 24 hour care, room and board in facilities

Who pays for all of this?

- ▶ Palliative Care
 - ▶ Limited coverage by Medicare and some insurances
 - ▶ VA system has their own palliative care but will also cover some referrals
 - ▶ Many insurances require preauthorization/allow limited visits
- ▶ Hospice Care
 - ▶ Almost all insurance plans cover
 - ▶ If Medicare, falls under Medicare A (the hospital one)
 - ▶ Uninsured patients may be accepted by many hospice agencies on case-by-case basis

Coping with chronic serious illness- emotional effects

- ▶ Stages of grief (Dr. Kubler-Ross):
 - ▶ Denial, anger, bargaining, depression, acceptance
- ▶ Anger and frustration are common (“why me?”)
- ▶ Facing mortality, possible death, loss of normal life is overwhelming
- ▶ Much of grief happens before death!
- ▶ Endless worry and fear of what the future holds
- ▶ Feeling hopeless, helpless
- ▶ Isolation from others
- ▶ Loss of identity to the disease

Coping with serious illness- effects on caregivers

- ▶ May experience the same emotional effects but on different timeline
- ▶ May be overwhelmed by caregiving and support tasks and unable to care for themselves
- ▶ May have “survivor guilt”
- ▶ Spouses/close family and friends may feel like the disease is the “fifth wheel” in the relationship
- ▶ May not be comfortable sharing their emotions or stress with the affected person or others
- ▶ May have medical problems of their own

Coping with a serious diagnosis

- ▶ “Feelings are facts”- emotions can be intense with every new test, treatment, ups and downs
- ▶ Serious chronic illness is a rollercoaster, so as much as possible try not to react too quickly to every up and down
- ▶ Be very careful where you look for information, whether in person or on the internet. Aim for reputable well-known sources
- ▶ Family and friends will offer all kinds of advice. It can be helpful or not.
- ▶ **Stay connected**, whether by phone, video, in person

Coping with serious illness- finding support

- ▶ Family and friends- retelling your story can be exhausting. Choose where you spend your energy
- ▶ Support groups can be very helpful, especially disease specific. Support groups supported by professional organizations may be most helpful
- ▶ Consider mental health support, especially someone experienced in your disease process
- ▶ Caregivers need mental health support also. Couples and family therapy may be helpful for some
- ▶ For support groups, counselors, etc, may have to look for the “best fit”

Coping with serious illness- support

- ▶ Some primary care providers specialize in chronic illness management now
- ▶ May include things like group appointments for persons with similar illnesses to learn together and help each other
- ▶ Some disease organizations offer peer support programs to match you with someone with the same condition who has survived or navigated the illness longer
- ▶ Be a bit cautious of Facebook and internet support groups unless run by a known clinic or professional organization

How to talk to someone with serious illness

- ▶ Let them know you're available to listen
- ▶ Your presence is more important than what you say
- ▶ It's OK to admit that you don't know what to say
- ▶ If appropriate, a gentle touch or hug may be helpful
- ▶ A card, phone call, text to let them know you're thinking of them can say a lot
- ▶ It's OK to talk about other things. Ask or share positive news or things not about the illness

How to talk with someone-

“Don’ts”

- ▶ Avoid telling them how you know how they feel unless you really do
- ▶ Probably avoid telling about other family/friends with similar illnesses. Every person’s situation is unique.
- ▶ Avoid unrealistic statements/questions like “I know everything will be fine” “I know a cure is out there”
- ▶ Avoid statements like “Try to stay positive” “Try not to worry” Let them know it’s OK to feel how they feel
- ▶ Better options might be “Hoping you get some answers” “Hoping you find some peaceful moments”
- ▶ Don’t take it personally if they don’t want to talk or seem agitated or upset. Chronic illness is exhausting.

Tips on medical visits

- ▶ Make a list of questions ahead of time
- ▶ If it's a new provider, make sure they have your records ahead of time. Best not to assume they will be sent.
- ▶ Take a list of all meds, supplements, OTC meds
- ▶ If you have records of prior procedures, tests, results, take them if possible
- ▶ Take someone with you if possible
- ▶ Make notes, or have your support person do it.
- ▶ It's OK to advocate for yourself especially if there are special needs or certain past experiences that might impact your care (“elevator speech”)

Advance Care Planning

- ▶ A road map for when a person is unable to make their own health care or living decisions
- ▶ Much more than just “code status” and feeding tubes
- ▶ It is never too early to start discussing
- ▶ Capacity vs competence: a person may still be able to make some medical decisions even when they are unable to make legal/financial ones
- ▶ The wishes of the POA should generally not overrule the wishes expressed by the patient

Advance Care Planning

- ▶ Most people want to have these conversations with their clinicians and families but are hesitant/afraid to bring it up
- ▶ Clinicians need to start these conversations early and encourage families to continue the discussions
- ▶ There are many good tools, free or minimal cost, that can help guide these discussions
- ▶ A palliative care provider can help you with this!
- ▶ Videos:
 - ▶ Ellen Goodman Does the Math (The Conversation Project)
 - ▶ ABC World News with Diane Sawyer: The Conversation Project

Palliative Care and Hospice Resources

- ▶ www.getpalliativecare.org CAPC
 - ▶ Includes info on finding Pall Care in your area
- ▶ NIA.NIH.gov- “What are Palliative Care and Hospice Care?”
- ▶ www.agingwithdignity.org/fivewishes
- ▶ www.caringinfo.org NHPCO
- ▶ www.prepareforyourcare.org
- ▶ Theconversationproject.org

Hospice and PC Resources, cont.

- ▶ *Hard Choices for Loving People: CPR, Feeding Tubes, Palliative Care, Comfort Measures, and the patient with a Serious Illness, 6th Edition*, by Hank Dunn
- ▶ *A Beginner's Guide to the End: Practical Advice for Living Life and Facing Death*, by BJ Miller MD and Shoshana Berge
- ▶ *Courageous Conversations on Dying: The Gift of Palliative Care- A Practical Guide for Physicians, Healthcare Providers & All the People They Serve*, by Shahid Aziz MD
- ▶ *The Conversation: A Revolutionary Plan for End-of-Life Care*, by Angelo E. Volandes MD
- ▶ *Being Mortal*, by Atul Gawande MD
- ▶ *On Grief and Grieving*, by Elisabeth Kubler-Ross and David Kessler
- ▶ *Kitchen Table Wisdom: Stories that Heal*, by Rachel Naomi Remen MD

▶ *“You matter to the last minute of your life, and we will do all we can, not only to help you die peacefully, but to live until you die.”*

-Dame Cicely Saunders