

PALLIATIVE CARE: AN OVERVIEW



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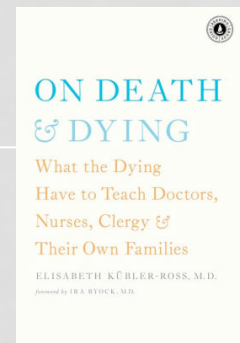
Amy Pilotte has no disclosures

OBJECTIVES

- Define palliative care
- How is palliative care different than hospice
- Who is eligible for palliative care?
- Palliative care support and barriers
- Language used in palliative care
 - Tips for difficult conversations
- Palliative care resources

“When a patient is severely ill, she is often treated like a person with no right to an opinion. It is often someone else who makes the decision if and when and where a patient should be hospitalized. It would take so little to remember that the sick person too has feelings, has wishes and opinions, and has- most important of all – the right to be heard.”

Elisabeth Kübler-Ross, MD
On Death and Dying



KELSEY

- 22 year-old recent college grad
- Diagnosed with a primary pelvic Ewing sarcoma
- Receiving neoadjuvant chemo + XRT prior to planned resection
- Treatment is with curative intent
- Back and leg pain related to tumor
- AYA specific issues



JULIA



- 56 year-old female with advanced biliary cancer
- On chemotherapy - not surgical candidate
- Pain related to tumor
- Depression/Anxiety
- Difficulty coping

HARRY

- 41 year-old husband, father, of 3, computer sales rep
- Diagnosed with colon ca with mets to lung, bone, throughout abdomen
- S/P surgery, XRT, chemotherapy, clinical trials
- Multiple admissions for pain
- Coping Challenges
 - Living with a stoma
- Anxiety, fear



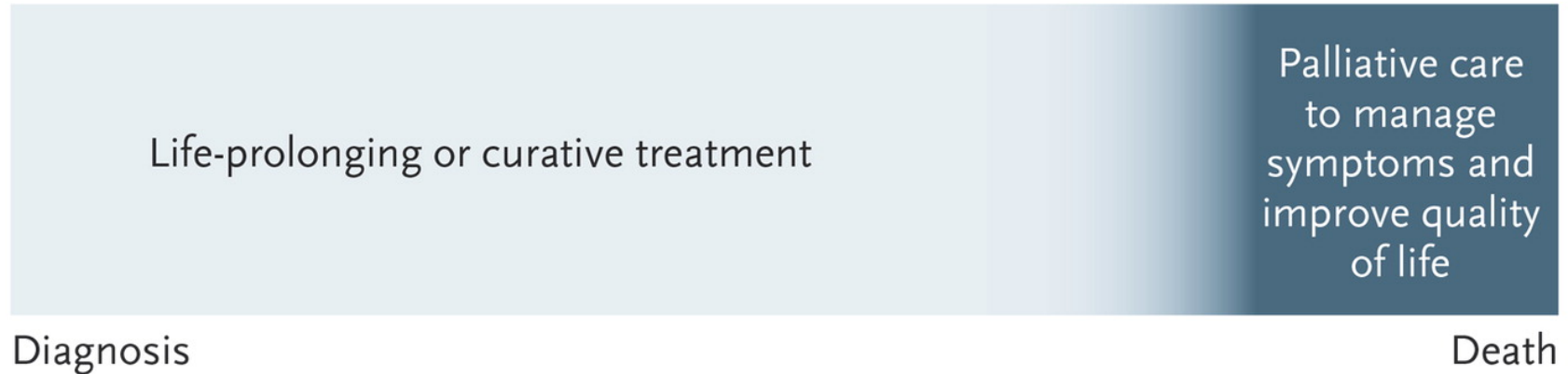
WHAT IS PALLIATIVE CARE?

- From the Latin *palliare*: “to cloak”
- Specialized patient- and family-centered health care that focuses on effective relief of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs, and cultures.

PALLIATIVE CARE GOALS

To anticipate, prevent, and reduce suffering and to support the best possible quality of life for patients and their families.

Traditional Palliative Care



Early Palliative Care



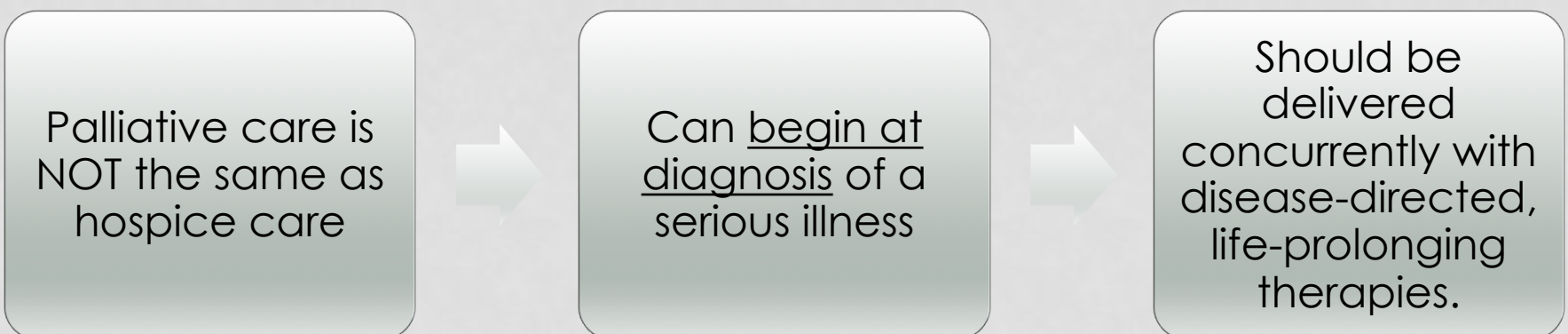
<https://getpalliativecare.org/whatis/>



Palliative Care

WHO NEEDS PALLIATIVE CARE?

Palliative care is
NOT the same as
hospice care



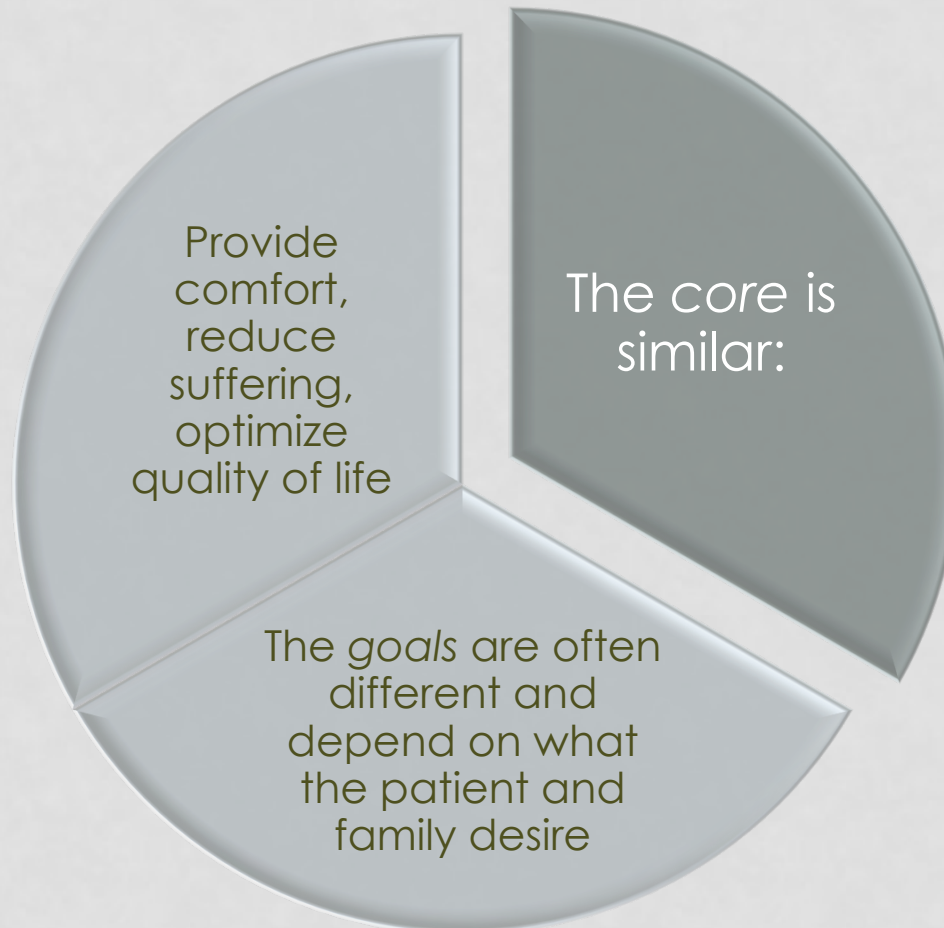
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graph LR; A[Palliative care is NOT the same as hospice care] --> B[Can begin at diagnosis of a serious illness]; B --> C[Should be delivered concurrently with disease-directed, life-prolonging therapies.];
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Can begin at
diagnosis of a
serious illness

Should be
delivered
concurrently with
disease-directed,
life-prolonging
therapies.

**“Hospice care is always palliative,
but not all palliative care is hospice care.”**

PALLIATIVE CARE VS. HOSPICE CARE



HOSPICE VS. PALLIATIVE CARE

- a. Hospice requires certification that if the disease were to run its expected course, the patient would pass away within 6 months
- b. Hospice requires a shift from managing the disease to managing the symptoms, with a focus on quality of life
- c. Specifics depend upon the insurance company (i.e. accepting transfusions), but in general no scans or multiple blood tests
- d. DNR/DNI is NOT required to go on hospice

PALLIATIVE CARE AND HOSPICE DIFFERENCES

Palliative Care

- Chronic illness
- Can seek life-prolonging, curative treatment
- No eligibility criteria
- Same co-pay as other MD visits
- Medicare Part B
 - (Same co-pay as other MD visits)

Hospice

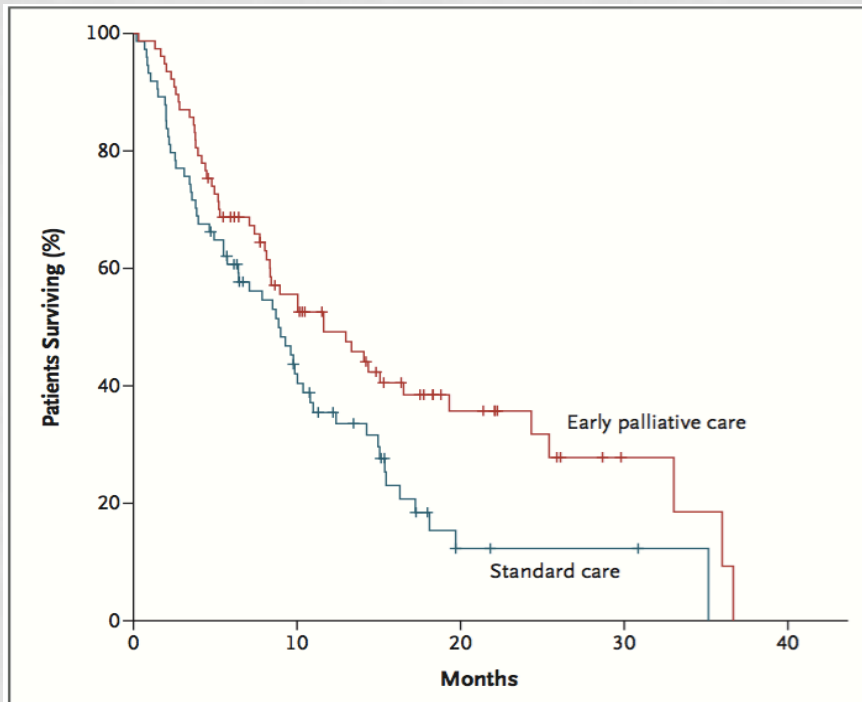
- Terminal Illness
- Not seeking curative treatment
- Expected prognosis < 6 months
 - (if the illness runs its normal course)
- Medicare Part A

PALLIATIVE CARE

- ✧ No requirements for life expectancy
- ✧ No need to forgo life prolonging therapy
- ✧ Focus is on the family unit - not just the patient
- ✧ Specialized training in symptom management *and* in providing psychosocial / spiritual support

THE CASE FOR PALLIATIVE CARE

Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer improves quality of life, decreases depression, and may improve survival.



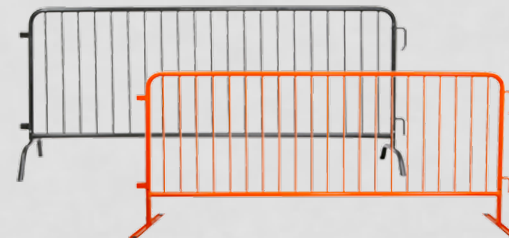
	Early Palliative Care	Standard Care	Diff
Change in Quality of Life (TOI)	+2.3	-2.3	P=0.4
Depression (PHQ-9)	4%	17%	P=0.4
Survival	11.6 mos	8.9 mos	P=0.2
UTILIZATION TRENDS			
Median inpatient days	5.0 d	7.0 d	2.0 d
Hospice admission <3 days prior to death	3.00%	14.70%	11.70%

THE EVIDENCE

- Compared with standard oncology care, there is increasing evidence that integrated palliative care can lead to:
 - Improvements in QOL
 - Lower rates of depression
 - Less aggressive care at the end of life
 - Greater documentation of resuscitation preferences
 - Higher survival rates
 - Better patient and family satisfaction
- *Bakitas, M, et al. (2009). Effects of palliative care intervention on clinical outcomes in patients with advanced cancer: the project ENABLE randomized clinical trial. JAMA, 302 (7): 741-749*
- *Prince-Paul M, et al. (2010) The effects of integrating an advance practice palliative care nurse in a community oncology center: A pilot study. Journal of Supportive Oncology. 8 (1)L 21-27.*
- *Temel JS, et al. (2010) Early palliative care for patients with metastatic non small cell lung cancer. NEJM. 363: 733-42*

BARRIERS TO INTEGRATING PALLIATIVE CARE

- Lack of adequate training of professionals
- Failure to recognize and respond to the realities of life limiting disease- overly optimistic
- TIME
- Culture of ... “I can do it all”
- Failure to recognize suffering at all stages of life threatening illness
- Delayed access to specialized palliative care services
- Some providers see this as not the true practice of medicine ****We are getting better****



“Therapeutic options were discussed. Since he has multiple sites of metastatic disease surgery and radiation are not options. Because he is young and in relatively good health, I have recommended *against best supportive care* in favor of a clinical trial.”

“Since her disease is rapidly progressing, I would *pass at palliative care* in order to expedite the initiation of chemotherapy.”

WHO IS ELIGIBLE FOR PALLIATIVE CARE?



COMMUNICATION

DISCUSSION OF SERIOUS ISSUES IN ADVANCED ILLNESS IS PART OF THE BACKBONE OF PALLIATIVE CARE

- Tips from the pros
- Do they know their prognosis?
- What are their fears about what is to come?
- What are their goals. *What do they want to do as time runs short?*
- What are the trade offs they are willing to make. what suffering are they willing to endure for the possibility of more time?

FUNDAMENTAL COMMUNICATION PRINCIPLES IN PALLIATIVE CARE



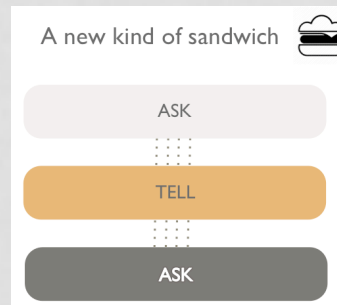
“Ask-Tell-
Ask”

“Tell me
more”

Respond
to: “NURSE”

“ASK-TELL-ASK”

- Based on the notion that education requires knowing what the learner already knows and building on that knowledge
- Fosters relationship building, showing you are willing to listen to and negotiate the patient's agenda
- Communication should never be one-way



ASK

- Ask the patient to describe his current understanding of the issue
- Helps you to craft your message by taking into account the patient's level of knowledge, emotional state, and degree of education

ASK

“To make sure that we are on the same page, can you tell me *what your understanding of your illness is?*”

“What have your doctors been telling you about what is happening with your illness?”

“How much information do you want to know about your illness?”

TELL

- Obtain permission:

“Would it be okay for me to discuss the results of your tests now?”

- In straightforward language give the information:

- NO long pathophysiology lectures.
- Short, digestible chunks.
- NO medical jargon.

“Unfortunately, your CAT scan shows that your cancer has gotten worse. The chemotherapy did not work against your cancer.”

ASK

- Patients often do not hear bad news
- It is important to assess a patient's understanding

“To make sure I did a good job of explaining this to you, can you tell me what you understand from what I said?”

- Gives patient a chance to ask questions and tells you where to go next:
 - what details to elaborate, what implications to discuss, what things to repeat

“TELL ME MORE”

CONVERSATIONS ARE OCCURRING ON 3 DIFFERENT LEVELS:

1. “What is happening?”
 - trying to understand information
2. “How do I feel about this?”
 - trying to figure out emotions, whether they are appropriate, and whether to express them
3. “Identity”
 - how does this impact my sense of self, “What does this mean to me?”

“TELL ME MORE”

“Could you tell me more about what information you need at this point?”

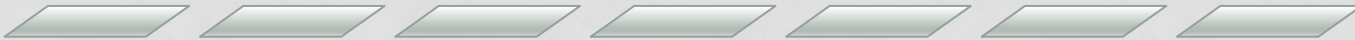
“Could you say something about how you are feeling about what we have discussed?”

“Could you tell me what this means for you and your life?”

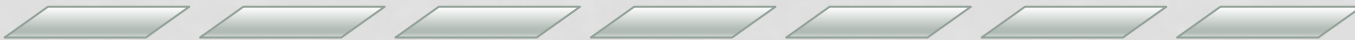
RESPOND TO EMOTION: EMPATHY

“NURSE”

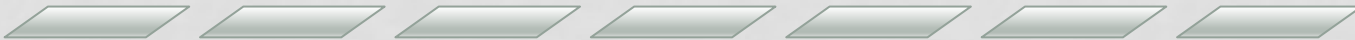
NAMING



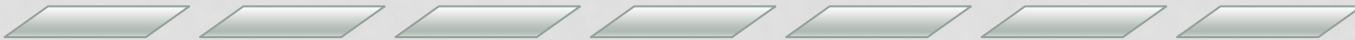
UNDERSTANDING



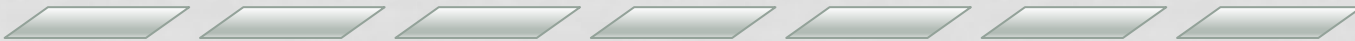
RESPECTING



SUPPORTING



EXPLORING



NAMING

- Name the emotion that you think the patient is feeling
- May require detecting non-verbal clues
- Important to be suggestive, not declarative

*"I wonder if you are
feeling angry"*

*"Some people in this
situation would be
angry"*

- People usually do not like to be told how they are feeling.

UNDERSTANDING

A sensitive appreciation for the patient's feelings is critical for relationship building

Avoid giving false or premature reassurance

May require exploration, active listening, and use of silence

“I think I am understanding that your main concern is the effect this will have on your children”

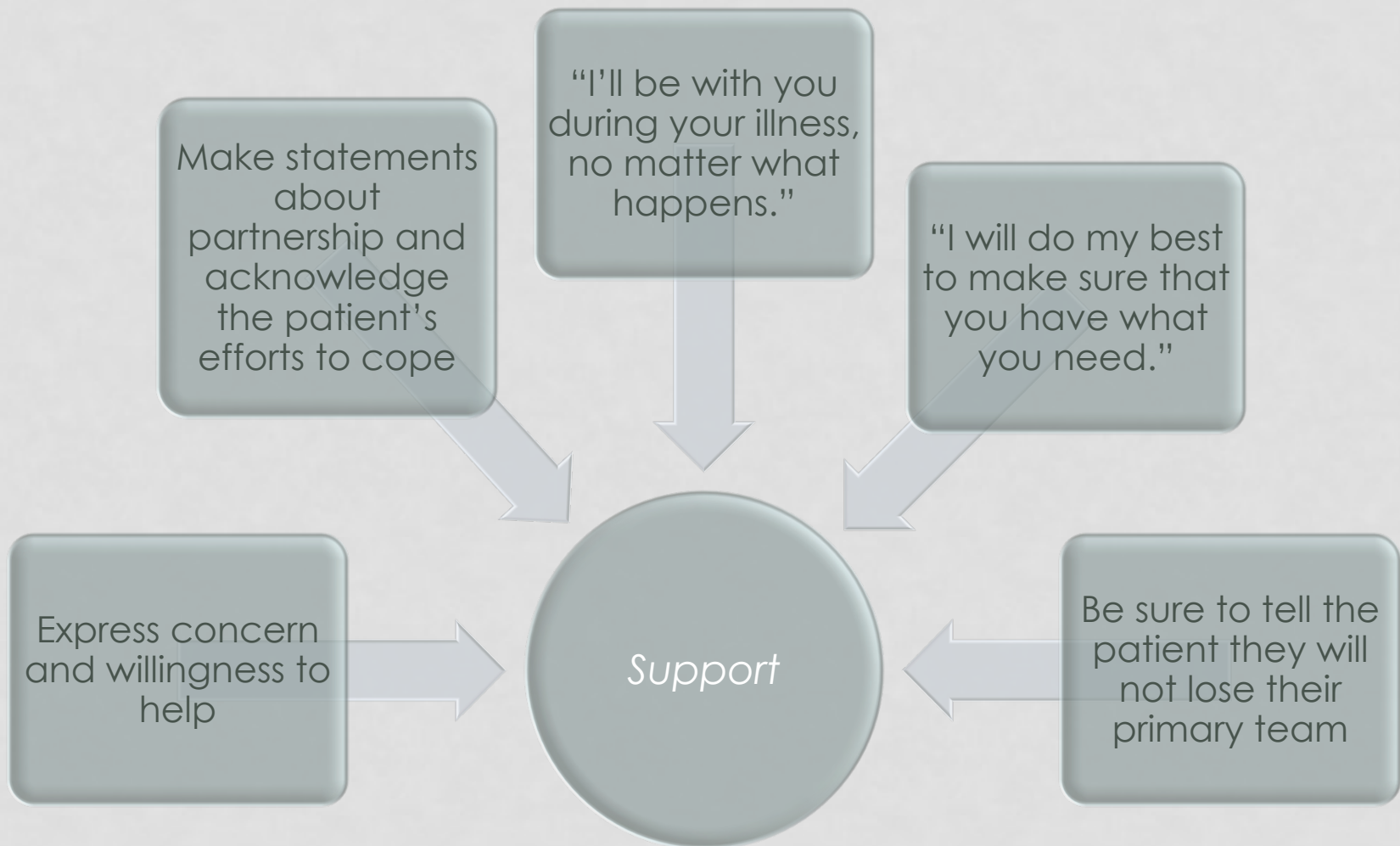
“I cannot imagine what it is like to (X)” is a good way to show you understand


RESPECTING

- A verbal response shows a patient that their emotions are not only allowable but important.
- Praising coping skills can be a good way to show respect.

*"I am so impressed with how well
you've cared for your mother
through this long illness.
You've done a great job."*

SUPPORTING



A photograph of a female doctor with short, curly grey hair, wearing a white lab coat over a pink top. She has a stethoscope around her neck and is smiling warmly at an elderly patient. The patient, seen from the back, has short, curly white hair and is wearing a blue hospital gown. The background is a blurred clinical setting.

Be open
and listen*

*Listen to me
Come sit and listen
Hold my hand*

*Schenck D, Churchill L. *Healers: Extraordinary Clinicians at Work*. Oxford University Press, 2012.

EXPLORING

✧ The most effective empathic statements link the “I” of the provider to the “you” of the patient.

“I sense how upset you are feeling about the result of the CT scan. Could you tell me more about what you are thinking right now?”

✧ It is not necessary to have the experience of the patient to empathize, but it is necessary to put yourself in the patient’s position, and communicate that understanding back to the patient.

PITFALLS/COMMON BARRIERS TO GOOD COMMUNICATION

- ☐ Rushing
- ☐ Giving pathophysiology lectures
- ☐ Talking too much
 - ☐ talk less than 50% of the visit!
- ☐ Making assumptions about what the patient does or does not know
- ☐ Offering reassurance prematurely
- ☐ Ignoring your own feelings

HELPFUL HINTS FOR THE TEAM

- ☐ Always hold the patient's doctor in high regard
- ☐ Collaborate - *call on your colleagues for help*
- ☐ For the RN: at the bedside, you are at the center of the patient's care team and often their primary advocate
- ☐ It is okay to talk to your patients early on about their wishes
- ☐ Support each other
- ☐ Practice good self care

COMMUNICATION SUMMARY

2. Take out the trash:

What happens when you use expert communication techniques at home including "Ask-Tell-Ask," NURSE (Naming-Understanding-Respecting-Supporting-Exploring), and the "teach back" method.



The fundamental principles of palliative care should be a basic component of the attitudes, knowledge base and practice skills of **ALL** clinicians.

Last Acts Palliative Care Task Force (1997). Last Acts Precepts of Palliative Care



PALLIATIVE CARE RESOURCES

- CAPC.org
- PCNOW (fast facts)
- www.geripal.org
- Eprognosis: <https://eprognosis.ucsf.edu/>
- “Being Mortal” by Atul Gawande, MD
- AAHPM.org

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- Bakitas, M, et al. (2009). Effects of palliative care intervention on clinical outcomes in patients with advanced cancer: the project ENABLE randomized clinical trial. JAMA, 302 (7): 741-749
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Thank you for listening

