Patient Family Advisory Council Meeting Minutes

Advisors Present: L. Kaiser, D. Green, J. Ostrander, N. Donahue, E. Lindberg

Staff Present: D. D'Alba, P. Lennon, MSN, RN, NEA-BC, V. Costabile, RN, BSN, OCN, D. Cifferelli

Excused: B. Leafe, MSN, RN, NEA-BC, S. Hill

Date: May 30, 2019 (5:30pm Dinner, 6:00pm Meeting)

AGENDA DISCUSSION Welcome and Patient Story

Monthly Quality Award story shared.

Review of Minutes Approved

Patient experience data trends shared and **Current PX Data Trends** discussed for Inpatient, Outpatient, Emergency

Department and Ambulatory Surgery

Jerry Laureano, Transportation Coordinator and Diversity and Inclusion Committee Chair

Monthly Guest Speakers Jane Curto, BSN, RN, CHPN, OCN, Medical

Oncology, Presentation: Creation of Educational Material for Patient Families and Caregivers of End-of-Life Patients During the End-of Life Treatment Process

Conclusion Meeting was adjourned at 7:00pm

Next Meeting Thursday, June 27, 2019

REFERENCES

Behavioral and Educational Interventions to Support Family Caregivers in End-of-

Life Care: A Systematic Review. [Review]

Chi NC; Demiris G; Lewis FM; Walker AJ; Langer SL. American Journal of Hospice & Palliative Medicine. 33(9):894-908, 2016 Nov. [Journal Article. Review] Bereaved Family Members' Perceptions of the Distressing Symptoms of Terminal Patients With Cancer.

Okamoto Y; Morita T; Tsuneto S; Aoyama M; Kizawa Y; Shima Y; Miyashita M. American Journal of Hospice & Palliative Medicine. 35(7):972-977, 2018 Jul. [Journal Article] Factors Associated With Caregivers' Resilience in a Terminal Cancer Care Setting. Hwang IC; Kim YS; Lee YJ; Choi YS; Hwang SW; Kim HM; Koh SJ. American Journal of Hospice & Palliative Medicine. 35(4):677-683, 2018 Apr. [Journal Article]

Informational and emotional support received by relatives before and after the cancer patient's death.

Eriksson E; Arve S; Lauri S.

European Journal of Oncology Nursing. 10(1):48-58, 2006 Feb.

[Journal Article]

Pain Management Concerns From the Hospice Family Caregivers' Perspective. Chi NC; Demiris G; Pike KC; Washington K; Oliver DP.

American Journal of Hospice & Palliative Medicine. 35(4):601-611, 2018 Apr.

[Journal Article]

The experience of family members caring for a dying loved one. Perreault A; Fothergill-Bourbonnais F; Fiset V.

International Journal of Palliative Nursing. 10(3):133-43, 2004 Mar. [Journal Article. Research Support, Non-U.S. Gov't] By Jane Curto RN, BSN, CHPN, OCN

Preparing for the Loss of a Loved One:

Navigating End-Of-Life Care Together



Yale NewHaven **Health** Greenwich Hospital

FREQUENTLY ASKED QUESTIONS

is my loved one asleep?

CAN hear you, so avoid speaking about the patient as if they will not wake. It is important to remember that the patient Due to metabolic changes occurring within the body, the patient may enter into a sleep-like state from which they are not present.

What is that sound they are making?

this is known as the "death rattle." Not to worry- this noise is much more disturbing to family members and caregivers than Instead, attempt to gently reposition the patient's head and An audible gurgling may be heard coming from the patientto the patient. It is caused by the body's decreased muscle Suctioning is typically avoided as it can lead to agitation. strength and inability to clear away excess secretions. practice good mouth care.

Can they hear me?

Absolutely. Hearing is the very last sense that leaves the patient.

How long do they have?

answer this question, it is nearly impossible. There are certain signs and symptoms we look for to give us a sense of timing As much as health care providers would love to be able to (see chart), but the exact longevity is never certain.

Do they need to eat?

not force food. This is the body's way of telling them that As the body begins to shut down, less food and fluids are required. If a loved one tells you they are not hungry, do things are beginning to slow down.

Can they feel pain?

As the patient is actively dying, they can still feel pain. There are different medications we use as healthcare professionals to ensure our patients are as comfortable as possible during this process. We monitor the patient's heart rate and respirations for signs of pain.

Do end-of-life medications speed up the death process?

the death process. This is untrue-morphine is a vital drug used during end-of-life care to control work of breathing and pain. It is a common misunderstanding that morphine can quicken

What does the term "CMO" mean?

You may hear your doctors and nurses use this term when referring that the healthcare team's primary focus is to keep your loved one to the patient- it stands for "comfort measures only." This means as comfortable as possible during their hospital stay, focusing on treating the symptoms of the patient (pain, nausea, etc.)

What medications are used during end-of-life care?

INDICATION	MEDICATION	DRUG CLASS
Pain, tachypnea	Morphine	Opioid
Pain, tachypnea	Dilaudid	Opioid
	(Hydromorphone)	
Pain	Fentanyl	Opioid
Anxiety/restlessness/	Ativan (Lorazepam)	Benzodiazepine
agitation		
Agitation	Haldol (Haloperidol)	Antipsychotic
Nausea	Zofran (Ondansetron)	5-HT3 antagonist
Terminal fever	Tylenol	Analgesic
	(Acetaminophen)	
Secretions	Robinul (Glycopyrrolate)	Anticholinergic

How do I know that death is near?

SYMPTOMS OF THE ACTIVELY DYING PATIENT Tachypnea (increased respiration rate)

Decreased urine output

Tachycardia (increased heart rate)

- Agonal breathing (breathing with intermittent pauses)
 - Mottling extremities (discoloration of skin)
- Confusion
- Agitation

How do I know if death occurred?

These signs include lack of respirations/heartbeat for one minute, sudden release of bowel and/or bladder, no response to stimuli, There are things we look for to see if death did indeed occur. fixed pupils, and relaxed jaw.