Clinical News

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HopeWest

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Noisy Breathing at the End-of-Life

By Ellissa Tiller, MD, FAAHPM, CPE, VPMA
HopeWest

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Movie deaths do not prepare us for the death rattle. Its unfamiliar noise scares us and makes us feel helpless. It makes us worry that our loved one is suffering. We want it to stop. We're not ready to let go.

Mrs. G. was in her early 60's when she contracted multiple myeloma. Unfortunately, chemotherapy failed and transplantation was ruled out. She was on a rapid downhill course. In her final days, as she lay there unconscious, she developed a pronounced harsh noise with every respiration. Mrs. G. did not grimace or become restless. She was started on various drying agents. Her nurse friend, who was unfamiliar with the dying process, was very worried that Mrs. G. was suffering and ultimately demanded that the patient receive IV atropine in a desperate attempt to stop what she thought was profound suffering. This apprehension transferred to the patient's husband and caused him to have a prolonged grief reaction.

Why do people have noisy breathing at the end-of-life? Our upper airway muscles become relaxed, causing an increase in snoring-like sounds. The depth and rate of our respirations change – leading to changes in the tone or pitch of our breath. We lose the ability to swallow our normal oral and throat secretions, causing a gurgling-like noise in the back of our throats.

Noisy Breathing at the End-of-Life continued on page 2

Education Recap: When Grief is Complicated

For more upcoming educational opportunities at HopeWest visit HopeWestCO.org.

Thank you to all who joined HopeWest and Martin Mortuary for the teleconference, *Living with Grief: When Grief is Complicated*. This professional education opportunity was held in April, at the HopeWest Hospice Care Center.

During this presentation area healthcare workers, educators, social workers, counselors, clergy, funeral directors and other professionals learned how to improve their ability to support people facing serious grief. This seminar hosted by the Hospice Foundation of America focused exclusively on addressing risk factors, assessments, danger signs and current treatments.

Education Recap continued on page 2

Filling in the Gaps in Palliative Care

by Nancy Lofholm

Featured in the National Hospice and Palliative Care Organization's spring publication of the Newsline

Nearly 40 years ago, when Christy Whitney was organizing an all-volunteer hospice in the small Colorado mountain town of Durango, she was struggling with a word, and with a void. The term "palliative care" hadn't yet entered the lexicon as the designation for what would eventually be a range of services encircling hospice care. And ill people were falling through cracks in the fledgling hospice system: There was a gap between those who qualified for hospice because they were close to dying, and those with serious illness who needed care at a lesser level.

Those issues were still conundrums in 1993 when Whitney moved on to Grand Junction, CO and became the founding CEO of HopeWest. The non-profit hospice she organized would grow and expand services to become a respected model for creative and effective palliative care. Through trial and error and leaps of faith – with a cadre of committed volunteers and inventive financing – HopeWest was able to create a continuum of care that operates successfully beyond the confines of the healthcare and insurance industries. . .

. . . Whitney said she sees all that as validation that palliative care is a valuable safety net for the healthcare system. It is an impetus for establishing a more seamless system of delivering palliative care nationwide.

She hopes more hospice organizations will take the same philanthropic view HopeWest has embraced – a mission that it carries out and refines every day. It hasn't been easy. It hasn't been without stumbles. But it has proven that gaps can be filled. It has shown a way forward for delivering the expanded care that didn't even have a name when Whitney entered the hospice field. Whitney's overarching advice for other hospices who want to join this mission is daringly simple: "Decide what you want to do. And jump off that cliff."

To read the full NHPCO feature visit HopeWestCO.org. Visit the "about us" section and click on the "news" tab.

Education Recap: When Grief is Complicated

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The seminar introduced instances when grief becomes complicated. Although, most individuals are able to cope with loss, research shows that 7- 20 percent of those who have lost a loved one will have more disabling reactions. These reactions are labeled as complicated grief.

Complicated grief is defined by the Hospice Foundation of America as "a clinically significant deviation from the norm in either time or intensity of general or specific grief symptoms. It can also be defined as a compromise, failure or distortion of an individual's successful undertaking of one or more of the processes necessary to accommodate the loss."

Attendees learned that complicated grief can appear in many different forms such as PTSD, Major Depressive Disorder, Adjustment Disorder and Separation Anxiety Disorder.

Factors that can cause complicated grief reactions include:

- Relational factors – dependent or highly ambivalent relationships
- Circumstantial factors – including traumatic and sudden loss and perceptions of preventability
- Personal factors – mental illness past history of loss and absence of social support

Some signs of complicated grief reactions are substance abuse, physical illness and self-destructive behaviors.

When assessing individuals for complicated grief reactions, behavioral, medical, physical social and psychological well-being should be considered. Following the assessment appropriate therapeutic approaches should be made available. Treatment and intervention will help individuals experiencing complicated grief through support systems, self-care, minimizing reactions and decreasing likely-hood of secondary traumatization.

For more information about this seminar visit www.HospiceFoundation.org.

Noisy Breathing at the End-of-Life

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The prevalence of the death rattle varies widely, depending on the definition – from 12 to 92% of patients. Three quarters of patients die within 48 hours of onset. It tends to fluctuate and diminish as someone gets closer to death. Surprisingly, there is no association between IV fluids and the development of the death rattle.

What effect does it have on the dying person? There is no difference in distress in patients with or without the death rattle. Most patient are unresponsive in the last 48 hours of life and are presumably unaware.

However, about half of families and caregivers find the death rattle distressing – they worry that it is causing suffering, and it a stark reminder them that they are about to lose their loved one. Some family members, on the other hand, find it reassuring as a useful sign of imminent death.

So, what can we do to help? First and foremost, education, normalization and reassurance. We need to discuss with families that it is likely to occur and unlikely to cause any discomfort for the patient. Repositioning patients on their side or even in the lateral Trendelenberg position can help mobilize secretions and let them drain out of the patient's mouth. Lateral positioning also reduces snoring. White noise or soft music can help take family members' minds off the sound.

Do anti-secretory medications help? Probably not. They don't help with noisy breathing secondary to relaxation of airway musculature or changes in respiratory patterns. A large trial showed no difference between drying agents (atropine, hyoscine and scopolamine). A more recent trial showed no difference between sublingual atropine and placebo. So, if they are not helpful, are they at least benign? Unfortunately, these anticholinergic agents can cause a severely dry mouth, confusion and hallucinations, as well as urinary retention and constipation.

Mrs. G's noisy respirations were mostly related to her history of sleep apnea and snoring, which worsened as her muscles relaxed and her breathing changed. Drying agents were not going to help and the focus on these medications as the only solution probably worsened the anxiety for the family.

So, what do we do? We talk with families and prepare them. We discuss what to expect and reassure them. Soft music. Repositioning. If drying agents are tried in patients with very wet upper airway secretions, there needs to be a low threshold for stopping them. The suffering we need to focus on is that of the family and caregivers. Our calm reassurance and support is what is needed most.

Nearly 2,000 butterfly folders have been distributed thanks to the collaboration of healthcare organizations making a community-wide effort to make health care wishes known. For more information about this advanced directives initiative contact HopeWest at (970) 257-2360

HOPEWEST PHYSICIANS & PROVIDERS
Erin Arthur, MD
Diane Brown, MD
Bryan Gieszl, MD
Carol Fowler, MD
Laura Harrison, NP
Karin Lee Hughes, MD
K. Ellissa Tiller, MD
Heidi Marlin, MD
Crystal Owens, MD
Ona Ridgway, NP
Kellie Turner, MD
David West, MD

OFFICE LOCATIONS

Grand Valley
2754 Compass Drive #377
Grand Junction, CO 81506

Administrative Offices
3090 N. 12th Street, Unit B
Grand Junction, CO 81506
Phone (970) 241-2212
Fax (970) 257-2400

Plateau Valley & DeBeque
P.O. Box 294
Collbran, CO 81624
Phone (970) 487-3844
Fax (970) 487-3422

Delta County
195 Stafford Lane
Delta, CO 81416
Phone (970) 874-6823
Fax (970) 874-6903

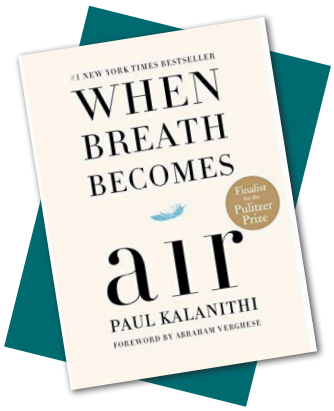
Montrose & Ouray Counties
725 South 4th Street
Montrose, CO 81401
Phone (970) 240-7734
Fax (970) 240-7263

Meeker
575 3rd Street
Meeker, CO 81641
Phone (970) 878-9383

HopeWest

3090 North 12th Street, Unit B
Grand Junction, CO 81506

When Breath Becomes Air:
Inside A Doctor's Mind At The End of His Life



As 36 year-old, Dr. Paul Kalanithi was on the verge of completing his residency in neurosurgery, a CT scan lead to the diagnosis of stage IV lung cancer. This soon-to-be neurosurgeon and father suddenly went from treating patients to becoming one.

When Breath Becomes Air is an account of Dr. Kalanithi's transformation from a naïve medical student to a doctor with terminal illness. Written in the last two years of his life, Kalanithi confronted his own mortality while trying to answer the difficult questions many patients face at the end-of-life.

When Breath Becomes Air was named one of the best books of the year by the Washington Post, The New York Times and NPR.

"One of the most poignant things about Dr. Kalanithi's story is that he had postponed learning how to live while pursuing his career in neurosurgery. By the time he was ready to enjoy a life outside the operating room, what he needed to learn was how to die," wrote Janet Maslin, The New York Times.