CRUCIAL CONVERSATIONS:

Educating Patients & Caregivers on Common Symptoms in Hospice Care

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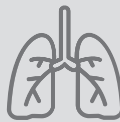
One of the many responsibilities of a hospice nurse is educating patients and their loved ones about disease progression and symptom management. Treating caregivers as part of the interdisciplinary team provides a sense of empowerment that can lead to better outcomes and improved satisfaction. However, with all the competing demands of patient care, it is easy to overlook important points. This free Enclara Pharmacia resource offers simple talking points that clinicians can use alongside their own judgment and expertise to help patients and caregivers better understand the hospice care plan, administer medications safely and effectively, and remain on the lookout for any adverse effects.



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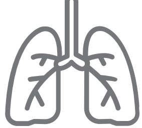
BREATHING



BREATHLESSNESS

Terminally ill patients often experience shortness of breath during their time in hospice care. Shortness of breath is often a symptom of underlying diseases such as lung cancer or COPD. In other cases, it can be caused by pneumonia, or an infection in the lungs. Treatments can reduce severity of symptoms, make patients more comfortable, or both. Symptoms can sometimes worsen suddenly.

Discussion Points:

- Oxygen may be started or continued to improve symptoms. Use of oxygen requires strict adherence to safety guidelines.
- Reduced lung capacity, strength or cognition makes it harder to benefit from inhalers, so the hospice team may recommend use of a nebulizer to deliver the drug instead.
- Opiates aren't just for pain – morphine can be used for breathlessness and can improve quality of life.
- Respiratory infections may be treated with antibiotics or antivirals in hospice (in accordance with goals of care). This is not considered curative care.
- Breathlessness can worsen anxiety and vice versa, so it is important for patients to remain as calm as possible. While anti-anxiety medications can help, non-drug activities like meditation and music therapy are also recommended.
- Keeping the room cool and using fans and humidifiers can improve comfort.

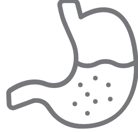
NOISY BREATHING (DEATH RATTLE)

Noisy breathing is likely to be caused by the accumulation of saliva and/or bronchial mucus as patients lose the ability to clear secretions. This may occur as they become weaker, lose swallowing and cough reflexes, and experience decreased consciousness. This symptom generally presents hours to a few days before death. While the sound can be distressing for others, it does not reflect pain or discomfort experienced by the patient.

Discussion Points:

- Noisy breathing is a lot like snoring. The person that is experiencing the noisy breathing is unconscious and not aware of the noise they are making.
- Medications to reduce secretions cannot clear the secretions that are already present and causing noisy breathing.
- Repositioning the patient to a more upright position can help facilitate drainage.
- While some caregivers request suctioning this is generally not recommended as it can cause discomfort.

GASTROINTESTINAL



CONSTIPATION

Constipation is common in older adults and those with advanced illness. It can lead to pain, restlessness, and anxiety. Opiates and other medications used in palliative care can cause constipation. Different types of laxatives and non-drug treatments are used to treat constipation.

Discussion Points:

- Stimulant laxatives (senna, bisacodyl) are first-line treatments, especially when constipation is caused by an opioid.
- Polyethylene glycol (MiraLax®) is appropriate for patients who are unable to tolerate the abdominal cramping that is common with stimulant laxatives but can tolerate drinking the eight ounces of water needed to dissolve the powder.
- Stool softeners and fiber supplements are not recommended.
- Over-the-counter antacids, antihistamines, and supplements (calcium and iron) can cause constipation.
- Hospice patients can safely discontinue some medications that are known to cause constipation and are no longer beneficial.
- Physical movement and increased intake of food and water are recommended when possible.

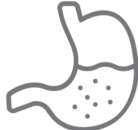
LOSS OF APPETITE

Patients with life-limiting illnesses often experience loss of appetite. While clinicians may consider this a normal part of the dying process, it can be distressing for patients and caregivers. Common diagnoses in end-of-life care as well as aging itself can limit appetite. Reduced or discontinued intake of food and liquid can also be a normal part of the dying process.

Discussion Points:

- Caregivers should offer small portions of food and let the patient know it is not necessary to eat a full meal. Consider offering a favorite food.
- If the patient was previously on a restricted diet, this may no longer be necessary in hospice care.
- Feeding by hand is recommended when a patient is no longer able to feed themselves. Forced nutrition, however, is discouraged as it can cause aspiration (food inhaled into the lungs), indigestion, and nausea, which may decrease the patient's quality of life.
- Many medications can reduce appetite, including those for diabetes and dementia that are often candidates for deprescribing in hospice.
- The use of medications to stimulate appetite lacks strong evidence, but some medications (e.g., corticosteroids) may increase appetite.
- Monitor for symptoms such as constipation and nausea that contribute to low appetite.
- Although high-calorie supplements may increase weight in older adults, there is no evidence that they improve other outcomes.

GASTROINTESTINAL



NAUSEA AND VOMITING

Nausea and vomiting are common in palliative care, especially with cancer. These symptoms often have multiple causes. Left unmanaged, nausea and/or vomiting leads to complications such as dehydration, electrolyte disturbances, decreased appetite, weight loss, and emotional distress.

Discussion Points:

- Patients may vomit without preceding nausea or experience nausea without vomiting.
- Non-drug interventions include small frequent meals, with low-fat, non-gas-forming foods, and drinking lightly carbonated beverages.
- Avoid eating and drinking for one to two hours after vomiting and start with clear liquids.
- When reporting nausea, try to determine where in the body the feeling originates, whether it is accompanied by dizziness, whether constipation is present, and what, if anything, makes it worse or better.
- When reporting vomiting, track frequency and consistency/contents of the vomit.

SWALLOWING

Several diagnoses common in hospice care can impact the ability to swallow. This can lead to malnutrition, weight loss, dehydration, and aspiration pneumonia. Reduced ability to swallow also complicates medication administration. Treatment depends on prognosis and goals of care.

Discussion Points:

- Oral care, including dental hygiene, can decrease risk of complications of food being inhaled in the lungs, which can lead to infection, in patients with swallowing difficulty.
- Depending on severity, cutting food into small pieces, choosing softer foods, and pureeing foods can help.
- Liquids can be thickened to facilitate swallowing, but this may not prevent food from being inhaled in the lungs.
- As swallowing difficulties progress, the hospice team may recommend crushing pills or prescribe liquid medications and medications that can be given under the tongue. Rectal and intravenous administration of some medications may also be options.

MENTAL HEALTH

ANXIETY

Everyone experiences feelings of nervousness, fear, and worry, but for some people these feelings become frequent and overwhelming. Increased anxiety is understandably common with a life-limiting diagnosis. Pain and discomfort can also worsen anxiety, especially for people experiencing symptoms of dementia. About 70 percent of patients will experience anxiety during the hospice treatment journey.

Discussion Points

- It is appropriate to use medications and non-drug practices to reduce anxiety symptoms in hospice even without a diagnosis of anxiety disorder.
- Anxiety symptoms can be physical as well as mental. These include shortness of breath, palpitations, sleep disturbances, sweating, nausea, and diarrhea.
- Some drugs can contribute to anxiety, including corticosteroids and medications used to treat breathing problems, such as over-the-counter allergy and decongestant products. Monitor for symptoms when these drugs are prescribed and always inform the hospice nurse of any over-the-counter medications.
- Non-drug therapies are important. These may include counseling, massage, aromatherapy, music therapy, and meditation.
- Minimizing caffeine, loud noises, bright lights, and other factors can help reduce anxiety.

DELIRIUM

More than 85 percent of people will experience delirium in the final weeks of life. Delirium is an acute episode of confusion, delusions, and/or emotional disturbance. There are two major types, hyperactive and hypoactive. Disruptive behaviors (e.g., agitation, excitability, refusal to cooperate) are associated with the hyperactive type and more likely to be recognized. Hypoactive delirium involves low energy and low enthusiasm and may be confused with severe depression.

Discussion Points

- Delirium can be an inevitable/irreversible part of the dying process, but it can also be a symptom of something else, so it is important to consider what else has changed.
- Reversible causes of delirium include medication side effects/interactions, infections, constipation, and urinary retention.
- Reducing or discontinuing certain medications can help prevent or reverse drug-induced delirium.
- Medications called antipsychotics (e.g., haloperidol) are a first-line treatment.
- Helping the patient remain oriented and engaged can help prevent or minimize delirium. Maintain normal daytime/nighttime routines and access to windows, clocks, and calendars, and use glasses and hearing aids if applicable.
- Physical comfort, companionship, and adequate nutrition/hydration are also important.

MENTAL HEALTH

DEPRESSION

New or worsening depression is common in hospice. The symptoms of depression have a negative impact on quality of life. Untreated depression leads to significant morbidity and mortality and affects both caregivers and decisions on goals of care.

Discussion Points

- It's natural for anyone to feel strong emotions when approaching the end of life, but new or worsening depression can indicate a need for treatment regardless of clinical diagnosis.
- Monitor for new or increased feelings of sadness, irritability, and loss of interest/pleasure in normal activities.
- Antidepressants may require trial and error and up to a month to reach full effect, but improvements can also be rapid.
- If prognosis is too short for antidepressants to provide a meaningful benefit, a stimulant medication may be prescribed.
- Starting, increasing, or changing antidepressant medications can increase the risk of side effects, or withdrawal if the medication is stopped abruptly. After a medication change, monitor for symptoms such as agitation, confusion, sweating, fever, rapid heart rate, muscle stiffness, tremors, and seizures.

INSOMNIA/SLEEP DISTURBANCE

Insomnia is one of the most common symptoms for which adults seek medical attention. While some hospice patients may experience less insomnia because of fatigue associated with their condition and the sedating effects of certain drugs, it remains a problem for many. Unresolved symptoms including pain, cough, and anxiety can contribute to difficulty falling asleep and staying asleep.

Discussion Points

- Trying behavioral changes and maintaining a sleep-friendly environment are important first steps.
- Consider adjusting bedroom temperature, sheets/blankets, noise, and other environmental factors that could make it harder to sleep.
- Encourage healthy sleep-wake cycles – going to bed and waking up at the same time every day and avoiding excessive napping.
- Try relaxation therapy such as muscle relaxation, guided imagery, meditation, breathing exercises, and music.
- Medications can help as part of an integrated approach including treating symptoms that contribute to insomnia.
- Avoid use of over-the-counter sleep remedies, including diphenhydramine (Benadryl®) or cold medications containing DM (dextromethorphan) in the name as these can have unpredictable side effects. Diphenhydramine also loses its effectiveness when used consistently.

PAIN

Pain management is the central promise of hospice care. Pain can be from tissue damage or nerve damage. It can also be local (in one part of the body) or central (all over.) While opiates are the pain treatment most associated with hospice care, they are not appropriate for all types of pain. They may also work best in combination with other drugs. Other drugs include acetaminophen (Tylenol®), nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen, anti-depressants, anticonvulsants, muscle relaxants and topical anesthetics (creams and ointments.)

Discussion Points:

- Pain medications can be prescribed for regular use, as needed, or both. The hospice team will provide guidance on as-needed dosing.
- It can take time to find the right approach for each patient. Typically, prescribers will evaluate the effects of a medication change after 24 hours.
- Different types of pain respond to different medications, including antidepressants and other medications not primarily associated with pain relief.
- For patients on opiates, monitor for new symptoms and report to your hospice team. Symptoms include nausea, constipation, mild confusion or drowsiness, hallucinations, delirium, seizures, and hypersensitivity to touch.

SKIN CONDITIONS

ITCH

Irritated, itchy skin may have a variety of causes. It can be localized to one area or occur all over the body. Treatment depends on cause and severity. Causes include drug side effects, allergies, infections, environmental factors, and psychological issues. Relief of this symptom is an important goal of palliative care. Itching can be extremely distressing, and excessive scratching can lead to pain and infection, so it is important for caregivers to report it to the hospice team.

Discussion Points

- Several medications can cause itching, so caregivers should monitor for new or worsening itch when medications are added, or dosages increased.
- Corticosteroids and antihistamines are common treatments, either by mouth for “all over” cases or topically for localized irritation/rash.
- Other topical options include anesthetics to numb the area (e.g., lidocaine and camphor) and emollients/protectants (e.g., calamine lotion and zinc oxide) to lessen irritation.
- Frequent or excessively hot showers/baths can cause or aggravate itching, as can scented or deodorant soaps and abrasive washcloths or towels. Use emollients/lotions after bathing.
- Loose-fitting cotton clothing, soft sheets, and maintaining indoor humidity levels (especially in winter) can help prevent or lessen itching.

URINARY ISSUES

INCONTINENCE

Incontinence is extremely common in hospice and palliative care but is often not discussed. Because of its potential for embarrassment, conversations about incontinence should be approached with privacy and discretion.

Discussion Points:

- Urinary catheter use may be recommended in hospice care to alleviate skin conditions caused by incontinent product (e.g., pads, briefs) and caregiver burden. However, it may also be uncomfortable and increase the risk of urinary tract infections.
- Barrier creams and careful monitoring are recommended.
- Bedside urinals may be recommended for patients able to use them.
- There are medications used to help manage incontinence issues in those without urinary catheters, but they have troublesome side effects (e.g., constipation, dry mouth, nausea, dizziness, drowsiness), especially in those of advanced age.

If you find this ebook valuable, remember to check out the sequel! *Crucial Conversations II: Deprescribing in Hospice Care* provides background information and scripts to use when discussing deprescribing decisions with patients and families. The ebook focuses on addressing the top 10 medication classes targeted for deprescribing, making it exceptionally relevant to daily operations. **Click here to download it today!**

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