Training Guide for Caregivers/Family Members

Managing Anxiety, Sadness and Depression

Managing Restlessness and Agitation

Managing Tiredness and Fatigue

Managing Pain From Swelling

Side Effects of/Managing Pain Medication

Myths About Opioids

Trouble with Constipation

Trouble Breathing/Shortness of Breath

Skin Care Tips

Spiritual and Emotional Support

Avow wants you to feel comfortable and confident in caring for your loved one while on hospice service. This training guide has information on the most common questions or issues that can occur. Along with printed tips, you can access caregiver training videos with the QR code below. Avow clinicians are also available to train caregivers on how to care for their loved one while on hospice service.

Avow is here for you and your loved one 24 hours a day, 365 days a year by calling 239-261-4404 or 888-484-AVOW (2869).

Caregiver training videos:

- *Open the camera app on your smart device.*
- *Hold your device steady for 2-3 seconds towards the QR code.*
- *Click on the notification to open Avow.TV*

Anxiety & Restlessness

An inability to relax due to worry, or fear, about everyday situations. Experiencing anxiety & restlessness is common and treatable. However, if left unmanaged - these can interfere with you & your loved one's quality of life and create an unsafe situation. Two of the most common origins of anxiety & restlessness are: **pain and trouble breathing**. If you or your loved one is experiencing any symptoms of anxiety, it is important that you report this as soon as possible.

Signs & Symptoms may include:

- Fatigue, or insomnia
- Trouble focusing
- Agitation
- Sadness or depression
- Increased heart rate, breathing, & sweating
- Nausea and/or vomiting
- Unpleasant sensations/cramps in extremities (arms & legs)

What can be done to manage anxiety & restlessness?

- Always try calming relaxation techniques first:
    1. Deep breathing, or the "pursed lip exercise,"
    2. Listen to soothing music, or
    3. Watch the Avow.tv "Safe Place Guided Imagery" video
- Express thoughts & feelings with an Avow Hospice Social Worker and/or Chaplain
- In combination with holistic treatments, an Avow Hospice nurse, or medical provider, is always available to discuss with you medication options, potential side effects, and frequency of when to give prescribed treatments.

What should be reported to your Avow hospice team?

- Past history of anxiety and/or depression
- If your symptoms worsen or do not respond to your current interventions

Common Side Effects of Pain Medication

Patients may receive help with pain, trouble breathing, or anxiety by their medical provider prescribing opioid (***oh***-*pee-oyd*) pain medications. These strong drugs help relieve discomfort and should **always be taken as prescribed** to avoid complications.

Tell your Avow team if the patient is experiencing these common and manageable side effects:

- **Constipation:** Pain medications can allow too much water to be absorbed, which can lead to hard or infrequent stools. Avow can prescribe medication (stool softener or laxative) to help manage constipation. **Tell your Avow team** if the patient has not had a bowel movement for three (3) days.

- **Sleepiness:** Feeling drowsy or sleepy only lasts a few days when starting, or increasing, a pain medication dose. This should go away as the body adjusts. Opioids are used to provide comfort, so this is normal.

  Patient caregivers: **If you feel the patient is in their final weeks or days, tell the Avow team as soon as possible.**

- **Dizziness:** When starting, or increasing, a pain medication dose, the patient may experience dizziness for the first couple of days. Dizziness typically decreases within that time. Be careful when changing positions (sitting to standing.) The patient may need assistance to prevent falls. **Tell your Avow team** about dizziness that does not go away after the first couple of days or if you or the patient has a fall.

- **Ineffectiveness:** If your loved one is still in pain after taking medication, he or she may need additional treatment. **Tell your Avow team** so we can make medicine or dosage changes that bring you relief.

- **Nausea:** Opioids can cause an upset stomach for the first few days, as the body adjusts to the medicine. Encourage the patient to eat a light snack (such as crackers) when taking opioid pain medication. Your Avow team may also treat the nausea with medication until it goes away. **Tell your Avow team** about nausea that does not go away, as it may be related to your condition.

Remember: Do not skip or provide extra doses unless instructed by the Avow Hospice nurse

Constipation

Hospice patients may experience constipation as a result of taking pain medication, moving less, eating and/or drinking less, or transitioning into a new phase of illness. They may suffer hard or infrequent stools that cause a great deal of anxiety, pain, and agitation. While bowel habits can vary from person to person, hospice patients should have a bowel movement at least once every three (3) days.

Signs and Symptoms:

- Dry, hard (pellet-like) stools
- Inability to pass stool
- Abdominal bloating
- Oozing, watery leakage
- Rectal pain or pressure

If the patient's constipation is left unmanaged, he or she may experience extreme pain, cramping, nausea, and vomiting.

What can help with constipation?

1. If the patient is physically able to tolerate, or if his or her diet allows:
    - Increase fluid intake to 6-8 glasses per day
        - Choose warm fluids such as water with lemon, tea, or prune juice
    - Eat fibrous foods
        - Examples are bran, whole grains, fruits and vegetables
    - Walk or do light Range of Motion (ROM) exercises
    - Sit upright on the toilet, bedside commode, or bedpan
    - Avoid fiber supplements (like Metamucil) as these can make symptoms worse
2. Keep a record of the patient's bowel movements including date/time, consistency of stool (hard, soft, watery).
3. Talk to your Avow hospice nurse about prescribing a stool softener or laxative to help manage constipation.

What should you report to your Avow hospice team?

- The patient feels constipated or has not had a bowel movement in three (3) days
- Other symptoms such as nausea/vomiting, straining, diarrhea, pain, or rectal bleeding

Dispelling the Myths of Opioids

Opioids (*oh-pee-oyd*) is a class of drug that interacts with nerve cells in the body and brain to reduce feelings of pain and trouble breathing. Use of opioids in hospice care is common, necessary and a safe treatment option for pain and other symptom management. Your Avow Hospice nurse can address any questions or concerns you or the patient may have regarding the treatment plan and/or side effects of medications.

Top 5 Myths of Opioid Use

1. **"Opioids are addicting"**

   Prescribed use of opioids to treat pain and other symptoms does not lead to addiction. This fearfulness to take pain medication can lead to suffering. Addiction is a chronic disease and only happens when a person misuses drugs despite physical or social harm. Addicts are not in control of their drug use. Opioids are strictly monitored and assessed on a routine basis. Always tell your care team if there is history of drug or alcohol abuse.

2. **"If a person takes large doses of opioids early in their disease process, the opioids will not be as effective later on when he/she needs higher doses."**

   Tolerance is a reduced response to a drug used repeatedly. Hospice patients develop tolerance as their disease and symptom management needs increase. The right dose should give the same relief for quite a while. In many cases, the dose may increase when symptoms are worsening, then treatment could change to a lower dose once relief has been reached. If you are worried about this, talk to your care team about preferred options.

3. **"Giving opioids to a terminally ill patient will speed up death."**

   Research shows that the use of opioids does not lead to a faster death. It is the disease that causes death, not the pain medicine. The small opioid dose for a hospice patient in their final weeks, days, or hours is to be used for comfort and relief of suffering and to allow the patient to experience a peaceful and dignified death. Withholding or withdrawing pain medication at the end of life is not appropriate or safe.

Dyspnea (Trouble Breathing)

Dyspnea (disp-nee-uh) is a medical term for troubled breathing. This symptom is closely related to heart and lung diseases. Experiencing difficulty breathing causes anxiety, agitation, fatigue and restlessness. It may also interfere with daily activities such as eating, bathing, walking, talking and visiting with friends and family.

Signs and Symptoms

- Rapid breathing
- Tightness in the chest
- A feeling of being "winded"
- Inability to speak in full sentences
- Fear or panic about not getting enough air in or out of the lungs

What can be done to prevent and treat troubled breathing?

- Remain calm and reassuring for the patient
  - Watch the Avow.TV Safe Place Imagery & Relaxation Music video
- Reposition the patient until his/her breathing improves
  - Raise the head of bed
  - Place pillows under the patient's head, back and neck
  - Transfer the patient to a chair or recliner
- Increase air movement in the room by opening a window or using a fan
- Apply a cool cloth to the patient's head or neck
- Lead the patient in the "pursed lip breathing" exercise shown in the Avow.TV Caregiver Training video
- Ask your Avow team about oxygen therapy for the patient
  - Your Avow Hospice nurse will train you how and when to safely administer oxygen
- Medications (such as morphine or a nebulizer) may be needed to help
  - Your Avow Hospice nurse will discuss this with you and train on potential side effects

What should you report to your Avow hospice team?

- Breathing problems that continue or worsen
- New or worsening cough
- Need for additional oxygen or medication supplies for the patient

Edema (Swelling)

Edema is unusual fluid buildup in the feet, ankles, legs, arms, hands or face. Congestive Heart Failure (CHF), liver, kidney or thyroid disease, and cancer can cause edema. Medications and diets with high salt can make the swelling worse.

Signs and Symptoms:

- Swollen joints, extremities or face
- Trouble breathing
- Tightness in the skin or clothing
- Indents or dimples left by accessories such as rings, watches or necklaces
- Fluid oozing from the skin

What can be done to prevent and treat edema?

- Elevate the patient's head, arms and/ or legs to a comfortable position
    - Your Avow Hospice nurse or aide will train you how to safely position and move the patient using pillows and assistive devices
- Avoid sitting, standing or crossing legs for long periods of time
- Limit consumption of high amounts of sodium (salt)
    - Examples are canned soups, processed foods and preserved meats
- Wear compression stockings
    - Your Avow Hospice nurse can discuss this option with you and train you on their use
- Medications (such as diuretics) may be needed to treat edema
    - Your Avow Hospice nurse can discuss this option with you and train you on potential side effects and dosage frequency

What should you report to your Avow hospice team?

- Any new or changed swollen areas
- Tenderness or pain in a reddened area
- Changes in the color or temperature of the skin
- Trouble breathing or a persistent cough

Managing Fatigue

Fatigue is defined as feeling tired, exhausted or generally lacking energy. This is a common symptom in both hospice patients and their primary caregivers. In hospice patients, fatigue may be caused by the person's illness, treatment, medications, emotions and other changes. For the caregivers, it is compassion fatigue and burnout. Education and support are essential with managing fatigue.

Signs and Symptoms:

- Increased agitation or restlessness
- Decreased motivation or lack of interest
- Emotional numbness
- Anxiety or sadness
- Sleep disruptions

What can be done to prevent and treat fatigue in patients and their caregivers?

- Tell your Avow team about signs and symptoms you or the patient are experiencing
- Listen to your body and rest when you are feeling tired
- Establish a routine bedtime
    - Take shorter naps earlier in the day
    - Avoid caffeine before bedtime
    - For patients: wear oxygen to sleep, if prescribed
- Prioritize and plan activities you enjoy
    - Allow time for self-care
    - Utilize respite care
- Eat nutritious foods in small, easy-to-digest portions, as able
    - Protein, beans, fruitsand vegetables
    - Ensure or Boost

What should you report to your Avow hospice team?

- Lifestyle or behavioral changes
- Treatments that are not working
- Medication side effects

Sadness & Depression

Sadness is normal and expected; however, depression can be challenging. Depression is strong feelings of sadness that last more than two weeks. If left untreated, it can lead to physical, or mental; symptoms and decreased quality of life. A person living with a serious illness can feel wide ranges of emotions; such as sadness, grief, anxiety, anger, and fatigue. The important people around them and caring for them can also feel these emotions. Discussion with your Avow Hospice team can help to determine the cause of your symptoms and to find an appropriate plan of care.

Signs and Symptoms

- Loss of interest in enjoyable activities
- Changes in mood and behavior
- Change in appetite
- Withdrawal from family and friends
- Change in sleeping schedule (insomnia or exhaustion)
- Thoughts of death or suicide
- Feelings of worthlessness, hopelessness, or guilt

What can be done to prevent and treat sadness & depression?

- Always try calming relaxation techniques first:
    1. Listen to soothing music,
    2. Deep breathing exercises, or
    3. Watch the Avow.tv “Safe Place Guided Imagery” video for meditation
- Express thoughts & feelings with an Avow Hospice Social Worker and/or Chaplain
- Avow Hospice also offers Complementary Therapy (music, massage, reiki, PAWS)
- In combination with holistic treatments, an Avow Hospice nurse, or medical provider, is always available to discuss with you medication options, potential side effects, and frequency of when to give prescribed treatments.

What should you report to your Avow hospice team?

- Past history of anxiety and/ or depression
- Other symptoms such as pain, nausea, or trouble breathing
- Notify Avow Hospice right away if you or your loved one is having thoughts of suicide

Skin Care Tips

Seriously ill patients may experience two common skin problems: pressure ulcers and chafed skin.

Pressure Ulcer (Bedsore): is an area of the skin that loses its blood supply for extended periods of time. The skin reddens, breaks down, and becomes painful. If left untreated, wounds and infections could develop. Bedsores can be found on tailbones/ buttocks, joints (elbows, heels, ankles), back of the head, hips and spine.

Chafed Skin: is an irritation caused by heat, moisture or friction. Chafed skin occurs in areas of the body where there are skin folds. Examples are: groin, under breasts or in the abdomen. It is especially important to keep these areas clean and dry.

Even with the most attentive care, patients may still develop skin problems because of their declining condition. Here's what you can do:

- Make sure the patient changes position at least every 2 hours
    - If the patient is unable to move safely by himself/herself, you may need to help
- Use warm water and gentle soap for baths
- Apply a lightweight lotion to the skin after bathing to increase moisture
- Keep bed linens clean, dry and free from wrinkles
- Change and apply clean absorbent pads and diapers often to keep skin dry
    - If the patient uses a bedpan or bedside commode, move the patient off after a couple minutes to avoid pressure on the tailbone
- Never apply heat or further irritate reddened skin
- Your Avow team can order special supplies for the patient if needed, including:
    - Alternating pressure pad
    - Special dressings

What should you report to your Avow hospice care team?

- Irritated, itching or reddened areas of the skin
- Painful, burning or tingling of the skin
- Open wounds or new growths

Do not attempt to lift or reposition anyone if you are unsure about your ability to do so safely. Use the push or rolling techniques that your hospice team members train you to use.

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