



Handbook

Resources, Tips
and Training

Share a
digital copy
of this
handbook.



Your Hospice & Community Care Team

Team Name _____

Team Leader _____

RN _____

LPN _____

Hospice Aide _____

Social Worker _____

Chaplain _____

Volunteer _____

Faith Community _____

We welcome collaboration with your faith community as you desire.

Funeral Home _____ Phone # _____

Other _____

Translation service and additional resources available upon request.

Call our 24-hour number
to speak with a Hospice
team member with
questions or for guidance.

1 (877) 506-0149
or 1 (855) 665-2273

Llame a nuestro número de
24 horas para hablar con
un miembro del equipo de
hospicio si tiene preguntas
o si necesita orientación.

1 (877) 506-0149
or 1 (855) 665-2273

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To Our Patients and Families:

Welcome to Hospice & Community Care. Thank you for trusting us to serve you and your family. We are committed to providing you and your loved ones with personalized care and comfort every step of your journey.

Our specialized interdisciplinary team of physicians, nurses, aides, social workers, chaplains, bereavement counselors, and massage and music therapists will be with you throughout your care. Please take comfort in knowing we are available by phone 24 hours a day by calling the number below.

We are committed to providing the best quality care our community has received from us for more than 40 years. To ensure we achieve these goals, family caregivers will be mailed a survey after the patient's death from HEALTHCAREfirst to share their experience with our organization. Throughout care, please reach out to your Hospice team with any questions or concerns. We are here to support you.

Thank you for allowing us to care for you and your family.

Sincerely,



Steve Knaub

President and CEO

Hospice & Community Care is dedicated to providing exceptional care to all in our community. We support patients, families, and caregivers regardless of sexual orientation, gender identity, age, culture, religion, ethnicity, disability, perceived disability or socioeconomic status.

We do not want to assume we know about you as an individual, please tell us what you think we should know so that we can provide the care that you want in the manner that you want. Please let us know how you would prefer that we address you and share with us your beliefs and values so we can honor what is most important to you.

Our Mission

To provide personalized care and comfort to help patients and families live better with serious illness through end of life.



Our Vision

Every person living in our community will receive the care and compassion they need while coping with serious illness, facing end of life, or experiencing the loss of a loved one.

For helpful tips,
please watch for 

For important information,
please watch for 

Confidentiality Code

Hospice & Community Care is committed to protecting patient privacy and confidential medical information. The patient or their primary caregiver (if the patient is unable to speak for themselves) is given a Confidentiality Code. The patient controls who has the code and therefore, controls who receives protected information. Concerned family members and friends may call Hospice & Community Care staff to ask about the patient's care, needs, treatments or services. Before they are given any information, they will be asked for the patient's Confidentiality Code. **If callers do not know the code, no patient information will be given to them.** These callers will be advised to talk with the patient or primary caregiver. Patients or primary caregivers may share the code with others. If you have questions about using the Confidentiality Code, please ask any member of the Hospice Team.

Patient Confidentiality Code is: _____

What Is Hospice Care?

Hospice care provides medical, emotional and spiritual support for individuals and families who are coping with a life-limiting illness. Hospice care focuses on comfort for individuals of all ages with any serious illness who have weeks or months rather than years to live. Hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support tailored to the patient's needs and wishes.



The Bob Fryer & Family Inpatient Center offers around the clock, short-term treatment for patients experiencing difficult or challenging symptoms.

Throughout the Course of Care...

Routine Home Care (Hospice Care)

Routine home care is provided in a patient's home setting. Support includes intermittent nursing visits, personal care, home medical equipment, medications, medical social services, spiritual support, volunteer visits, bereavement counseling and supplies related to the hospice diagnosis.

Intensive Comfort Care at Home (Continuous Home Care)

Continuous home care is for patients in their homes who are experiencing severe medical symptoms. To help alleviate pain and symptoms, continuous home care nurses will provide care for at least 8 hours a day. The goal of continuous home care is to provide intensive support and training to enable patients and their families to return to stable, routine home care.

Caregiver Breaks (Respite Care)

Hospice respite care enables a patient's caregiver to rest and recover from the demands of in-home care. Respite is also available when caregivers are traveling or attending an event such as a wedding or graduation. It is offered at Hospice & Community Care's Bob Fryer & Family Inpatient Center for up to five days at a time on an occasional basis.

Care for Unmanaged Symptoms (General Inpatient Care)

General inpatient care includes around-the-clock care at an inpatient hospice facility or hospital. Hospice & Community Care's Bob Fryer & Family Inpatient Center offers general inpatient level of care to manage pain or other difficult symptoms. Inpatient care is short-term and patients return home when symptoms are managed. The Inpatient Center is open 24 hours a day for visitors, and features living rooms and fully equipped kitchens so patients and their families can spend time together in a home-like environment.

See how the Bob Fryer & Family Inpatient Center can provide a needed break.



Take an interactive virtual tour of the Inpatient Center.



What to Expect

Things to Consider

Where in the home is the best place to provide care? If someone is still mobile, the answer is *anywhere*! As activities become more difficult to complete, consider clustering the items needed for care in one area.

What is the space like?

[See page 14 for a full listing of things to consider.]

- If there are stairs to climb, everything on the ground floor is often most convenient.
- If there is furniture to be moved, who can help make space?
- Is the bathroom nearby? If it's not, we can provide a bedside commode if needed.

Receiving a hospital bed

[See page 15.]

- The bed is about 84 inches long by 36 inches wide.
- The bed plugs directly into the outlet.
- The bed will need XL Twin size (or larger) sheets.
- Read the materials provided by the equipment company.

Giving baths in bed

[See page 37, *Making an Occupied Bed*.]

- Keep soap, washcloth, lotion, toothbrush and toothpaste in a basin to make it easier to carry to the bedside.
- Use the basin to bring water to the bedside for bathing.
- Hospice staff can train caregivers how to bathe and change someone in a bed.

Receiving oxygen

[See page 18.]

- Please display the "Oxygen In Use" sign prominently at the front door or window.
- The concentrator must be plugged directly into a wall outlet.
- Do not smoke or vape in the home with oxygen present and do not allow others to do so either.
- Read the materials provided by the equipment company.

Balancing working and caregiving

[See page 38.]

- Our routine visits will take place during the daytime. If a caregiver is unable to be at a visit, please let the Hospice team know how they would like to receive an update, such as a phone call or email. They should also tell the team if someone will be at the visit in their place.
- Sometimes it is helpful to have a notepad with questions for the Hospice team. We can answer them during the visit and leave updates and questions as well.

Keeping track of medications

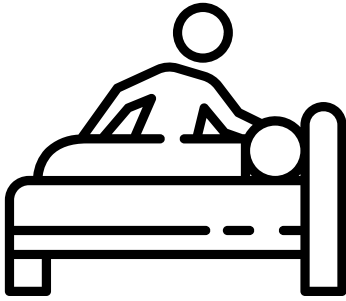
- Would a pill box help? They allow patients and caregivers to easily see if the morning or afternoon medications have been given. The Hospice team can help set that up.
- Lock boxes to keep medications safe are available. The Hospice team can provide one.
- We will provide a list of all medications being taken.

General Reminders for Visits

- If your pets are unsure around new people, please keep them in a separate room for our visit.
- If there are weapons in the home, they must be secured away from where care is provided.
- Per Pennsylvania state law, staff must be notified of audio or video recording in use when we are present.



First Days of Care



Day of Enrollment

- Complete enrollment paperwork.
- Establish initial plan of care.
- Confirm initial equipment and medication orders.
- Identify where care will be provided. (See page 8, *Things to Consider*.)

First Days to Week of Care

- The Hospice team leader will check in to see how you are doing.
- Medications and equipment are delivered.
- Hospice team introduces themselves by phone and in person.
- Visit schedule established.
 - Nursing visits are flexible based on patient need. Minimum is once every 14 days.
 - Personal care visits are based on patient need. Visit days for the week are scheduled based on availability.
 - Counseling disciplines, volunteers and other team members will visit based on need.

First Week to Month of Care

- You may receive a survey via text or email from SimpliSurvey asking you for feedback on how we're doing. Please let us know via the survey or in person!
- By the end of week two you should be in a fairly routine pattern for visits and care.

Ongoing Care

Once care is established, your Hospice team will work with you to determine the number of visits per week that works best for care. These visits may increase or decrease in frequency depending on what is happening with the patient's care. As care needs change, we will evaluate the appropriate levels of care as described on page 7.

Throughout Care

- You can call us at any time 24/7 at **1 (877) 506-0149**.
- *Routine* medications, equipment, and supply needs are best handled between Monday – Friday, 8:00 a.m. – 5:00 p.m.
- We will ask about medications at every visit. Please have them ready for us to assess and make sure that there is enough medication to last until the next planned visit.
- If a piece of medical equipment—such as a hospital bed or wheelchair— is needed, or is no longer being used, please notify your Hospice team. (See page 15 for more information.)

Third Month of Care

- Hospice eligibility discussion occurs with your Hospice team and Hospice physician.
- Continuation of hospice services is based on insurance criteria.

Sixth Month of Care and Every 60 Days Thereafter

- Hospice eligibility assessment visit with Hospice practitioner.
- Hospice eligibility discussion with Hospice team and Hospice physician.
- Continuation of hospice services is based on insurance criteria.



We want to meet your expectations. If things aren't going as expected, call our 24-hour number to speak with a Hospice team member with questions or for guidance.

**1 (877) 506-0149
or 1 (855) 665-2273**

Support at the Time of Death

Throughout our care we help to prepare and train families and caregivers for what people commonly experience as life nears its natural end. Our support continues after someone dies.



How to know when death occurs

What appears to be the last breath is often followed by one or two long spaced breaths. Signs of death include breathing stopping, heartbeat stopping, loss of control of bowel and bladder, eyes not moving and seemingly fixed on one spot, jaw relaxed and mouth slightly open, and change of color in face (sometimes described as waxy).

When death occurs

Death is a unique experience for each person. Family members often want to be present at the time of death. But there are many stories of people who died after families or caregivers left the room or went to sleep.

Hospice staff will support you and your family, make calls, contact clergy, notify funeral home, and/or be a supportive presence.

What to do when death occurs

- If death is believed to have occurred, please contact our 24-hour number, 1 (877) 506-0149. Hospice staff will provide support to you and your family.
- **DO NOT** call 911 or the paramedics.
- Note the time that death occurred.

In the First Hours

- Hospice staff will visit the home to confirm that death has occurred.
- Hospice staff notifies medical staff and clergy, if desired.
- Hospice staff will notify the funeral home selected by the patient or family.
- Hospice staff will assist with disposing of controlled medications.

In the First Days

- If medical equipment was provided, such as a bed, oxygen or wheelchair, the company will call the primary caregiver to arrange pick up.
- A Hospice staff member contacts the primary caregiver, sends a referral to our Pathways Center for Grief & Loss, and provides information about our support programs.
- If there are unopened supplies that families wish to donate, such as wound care supplies or incontinence products, please call us.



After approximately six weeks, a counselor from the Pathways Center for Grief & Loss will contact the primary caregiver to offer grief support. See page 57 for additional information about coping with grief and loss.

Coordination of Contracted Services

Additional services beyond those directly provided by Hospice may be necessary as part of care. To ensure coordination under hospice insurance benefits, those additional services are accessed through your Hospice team and provided in the following ways.

Pharmacy

Medications covered by Hospice are provided and coordinated by one of our contracted pharmacies. It is necessary for your Hospice nurse to stay informed of all medications being taken. While Hospice-covered medications must be filled through our pharmacy, non-Hospice-covered medications may continue to be filled at the pharmacy of choice.

Equipment

In order to facilitate care in the home, your Hospice team may recommend the use of medical equipment. This equipment will be provided and coordinated by one of our contracted medical equipment providers. We consider them part of our team, dedicated to providing patient comfort. Should equipment be needed, expect the following:

- Hospice will make the necessary arrangements.
- One of our contracted medical equipment companies will reach out via phone to discuss a delivery time.
- All equipment will be completely set up for you and you will receive instructions before the technician leaves your home.
- If you have any concerns or questions about your equipment call Hospice at 1 (877) 506-0149.

Medical equipment company personnel are not permitted to move furniture or transfer patients.

Hospitals

Hospice & Community Care will remain involved with our patients even if their care has been transferred to the hospital, continuing to visit and provide support. In fact, with Hospice Medicare or Medicaid Benefits, Hospice is responsible for payment to the hospitals when care is related to the illness for which Hospice is involved.

Admittance to a non-contracted hospital may be at the patient's own expense, or they may elect to revoke the Hospice Medicare or Medicaid Benefit. Hospice & Community Care will negotiate with non-contracted hospitals.

Ambulance

Hospice & Community Care will pay for ambulance services to transport Medicare or Medicaid Hospice Benefit patients when it's related to the hospice diagnosis and when the patient cannot be safely transported by car. The Hospice team must give prior approval before we accept charges for ambulance transport and the ambulance must be ordered by the Hospice team. Access to advanced life support through the county's 911 emergency response system is not covered under the Hospice Medicare or Medicaid Benefit.

Outpatient Services

Call Hospice for approval before scheduling tests or procedures. 1 (877) 506-0149

Care at Home

Ideal Location for Care

Most people want to live at home as long as they can. When living with serious illness, getting around in the house and managing normal daily tasks can be very challenging.

- Stairs can be difficult when weakness, immobility or pain are present. Consider moving a bed to the first floor. Having a bell or other signaling device may be helpful.
- Toileting and bathing may pose safety concerns. Consider handrails, grab bars or raised toilet seats.
- If home alone, or slow to respond to open a locked door, a security key storage box can allow access to the home by only those you have given a code/combination.
- Schedule calls and visits by friends, neighbors and faith community members at intervals to provide the greatest support and allow for rest.

What If the Best Care May Not Be at Home?

Sometimes more care is needed. The need to go to another home, skilled nursing facility or inpatient hospice center may need to happen for several reasons:

- Pain or other symptoms that cannot be monitored and managed at home.
- Professional care is needed around the clock.
- Home is no longer a safe environment.

The Hospice team will provide assistance and support throughout these transitions.

What to Have on Hand

Being prepared for care at home is essential to promote health and safety. Here are common items to have on hand when providing care.

- This handbook. It will help provide guidance and necessary forms throughout the course of care.

There may be additional needs based on equipment. Please see pages 13–21 for details.

- Preferred toiletries
- A basin for care at the bedside
- Washcloths and towels
- Liquid hand soap
- Paper towels
- Disposable gloves
- Plastic bags for disposing of trash
- A clean, dry and secure place to keep medications or mediset for easy access.
**Keep the patient's medication list and schedule with their medications/mediset.
- Covered beverage cup with straw
- Twin XL or larger size sheet for a hospital bed. Sheets are not provided.
- Disposable bed pads
- A written schedule of daily routines, including favorite music, television programs or pastimes, and descriptions of frequently needed items provides guidance to those assisting with caregiving.
- A list of contacts (family, physician, clergy, or other helpers). Be sure to inform your Hospice team if there are private duty or other helpers to assure coordination of care and support.
- A place for your visitors or Hospice team members to sit

Medical Equipment

If medical equipment is needed for patient comfort and safety, Hospice will make the arrangements.

Equipment will be set up in the location you identify. It is important to consider where the item(s) will be used. The personnel delivering the equipment are not permitted to move furniture or transfer patients.

Frequently needed equipment includes:

Hospital Bed—Helpful for positioning or providing care. Optional side rails can be helpful when turning from side to side or to decrease the risk of falling out of bed.

- Hospital beds have a hand crank for use when the electricity is off or the bed doesn't work.
- When raising or lowering side rails, make sure hands and feet are clear to avoid pinching.
- Make sure the electric bed is plugged directly into an outlet.
- Bed brakes should be on at all times.
- Keep the bed in the lowest position unless providing care.
- Keep the floor beneath the bed clear.

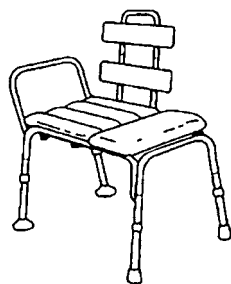
Overbed Table—Height adjustable; useful for meals, reading or electronic devices.

Bath Aids—Using a shower chair or bath chair helps to increase safety by decreasing the chance of falling. Shower seats and bath seats are useful for those that have pain, difficulty moving or tire easily. Several options are available.

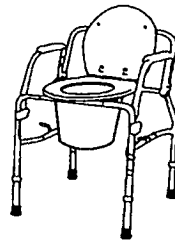
A bath seat or tub seat is 15–16 inch seat height. The seat height is positioned level with the tub wall. If it is lower, it may be difficult to get out of the tub.

A shower seat is 20–21 inches, and is ideal in a stall shower.

Tub Transfer Bench—Permits a sliding transfer from a wheelchair to a tub or for patients that have difficulty safely stepping over the side of the tub. Once seated on the bench with legs outside the tub, lift one leg at a time into the tub. Use of a hand held shower is helpful.



Bedside Commode—May be helpful when getting to the bathroom is difficult. The commode may be positioned over an existing toilet (with bucket removed) when railings



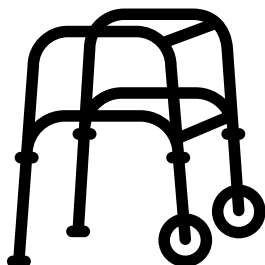
are needed for stability and support or next to bed or chair (with bucket in place). The commode height can be raised or lowered by adjusting the height of each of the four legs.

For proper use:

- All four legs must be at the same height (same number of holes showing on each leg).
 - Make sure the spring tension button on each leg is completely through the hole.
1. Wash hands.
 2. Place the commode as close to the bed as possible.
 3. Help the patient to transfer safely from the bed to the commode.
 4. Place toilet tissue within reach.
 5. Encourage the patient to call when done or if needing assistance.
 6. If the patient is safe to be left alone, wait outside the room.
 7. When getting up or down, the patient must push straight down on the arms with both arms to avoid tipping.
 8. Put on gloves.
 9. Aid with cleaning and pulling up pants or briefs as needed.
 10. Assist the patient back to the bed or chair.
 11. Help them to wash hands.
 12. Remove the commode bucket and empty into toilet.
 13. Rinse with a diluted bleach solution of:
 - ¼ cup bleach
 - 2½ cups water
 14. Clean with a toilet brush if necessary.
 15. Remove gloves and wash your hands.

Safety Tips

- Make sure the surface you are walking on is clear, flat, dry and well lit. Wear shoes with non-slip soles.
- Remember to look ahead when walking, instead of at your feet or the floor in front of you.
- Stand up as straight as possible; avoid leaning out over the walker.



Walkers—Help patients with balance and stability by transferring weight from the legs and feet to the arms and hands. To determine the right height the patient should:

- Put on the shoes they will be wearing when they use the walker.
- Stand up straight with their feet close together, relax their shoulders, and put the walker in front and partially around them.
- The tops of the handgrips should be at the crease of their wrist; if not, adjust the walker's height by pushing in the button on each of the walker's legs and sliding the tubing up or down.
- Make certain the button locks back into place, and the legs are adjusted to the same height.
- Walk slightly behind the walker. Lift or push the walker forward so the rear legs are a few inches ahead of them. Step forward so their legs are even with the rear legs of the walker.



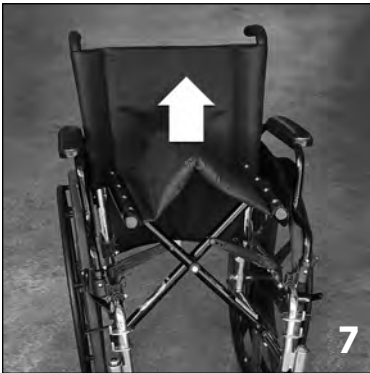
Wheelchairs—When symptoms like pain, fatigue, dizziness, or weakness make walking difficult

or unsafe, using a wheelchair allows the patient to be safely mobile and active. Wheelchairs have larger wheels in the back to provide greater support and stability over rough or uneven surfaces, such as gravel, dirt or grass.



Transport Chair—Light weight; has 4 smaller wheels. Good on smooth, level surfaces such as wood, vinyl, cement and carpet.

Wheelchair Use and Safety Tips



Folding a wheelchair



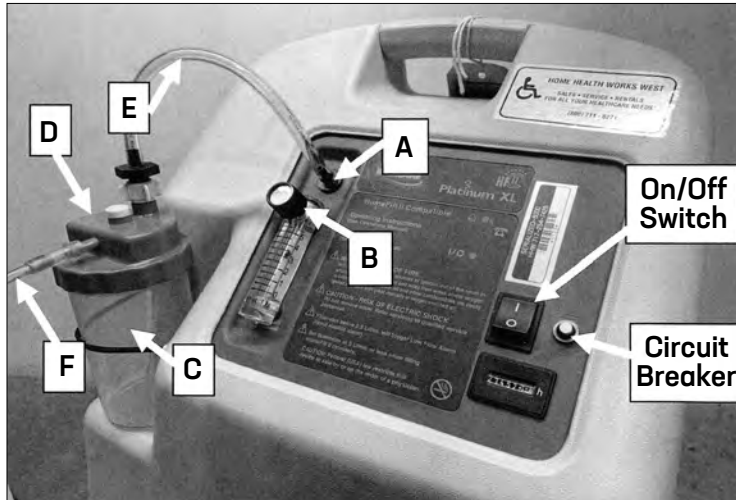
Unfolding a wheelchair

1. Always lock the brakes before getting in and out of the wheelchair. Applying the wheel locks: push forward on the lock tips until the locks snap in the locked position. Reverse the process to unlock.
2. Remove or swing the foot rests aside before transferring.
3. Before moving the wheelchair, make sure the rider's feet are securely in the foot rests.
4. Notify the rider before moving the wheelchair or going over an uneven surface.
5. Face the wheelchair forward when going uphill.
6. When going up a curb or step, pull the wheelchair facing backwards, tilting the front wheels up and off the ground while pulling the rear wheels up and over the curb.
7. To fold the chair, grasp the center edge of the seat and lift up. The sides and wheels will come together.
8. To unfold the chair, press down on the seat inside along the seat rails.
9. If the wheelchair has elevating leg rests, the legs can be elevated by lifting the rests up to desired position. To lower them, support the leg rest with one hand while activating the elevation release mechanism with the other hand and lower the leg rest to the preferred position.

Oxygen

Supplemental oxygen therapy may be ordered to be used continuously or as needed. Hospice will arrange for delivery and the provider will set it up and explain how to use it.

Oxygen Concentrator



- | | |
|-----------------------|-----------------------|
| A - Output | D - Humidifier Lid |
| B - Flow Meter | E - Humidifier Tubing |
| C - Humidifier Bottle | F - Oxygen Tubing |

This machine filters oxygen from the surrounding room, producing oxygen enriched (concentrated) air. The concentrator plugs into an electrical outlet. Portable oxygen is supplied as a back-up and is provided with each concentrator in case of power failure. The concentrator makes a low humming sound and produces warm air when in use.

How to use:

- Make sure the tubing is not kinked and is properly connected to the outlet port of the concentrator. The plastic piece that fits into the nostrils (cannula) is attached to the other end of the tubing.
- Turn the concentrator on and after a brief alarm, adjust the flow gauge to the ordered liter flow.
- To test if the oxygen is getting through the tubing, put the nasal cannula in a cup of water while the concentrator is running. If it bubbles, it is working.

Concentrator Cleaning Instructions

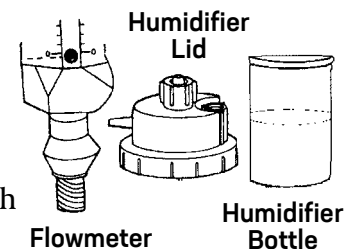
- Wipe off as necessary with a damp cloth (do not use any type of cleaner or cleaning solution)



- The cannula can be cleaned with a damp cloth. Replace as needed, usually about every 2 weeks.
- Foam air filter at the side or back of the concentrator must be cleaned weekly for best performance. Remove the filter from concentrator. Wash in warm water and mild detergent. Rinse thoroughly. Dry the filter well with a towel/paper towel to remove excess water. Replace the filter in the concentrator.
- There may be a small secondary filter present; it should be cleaned as above.

Humidifier

For liter flow greater than 4L per minute.



- Once a day, refill the bottle to the maximum line with distilled water.
- Securely screw the bottle to the lid, being careful to avoid cross-threading the bottle and lid.
- Clean the humidifier bottle and lid weekly with warm water and liquid detergent.
- Rinse thoroughly in tap water.
- Dry the exterior, refill with distilled water to the maximum line, and reattach the clean humidifier to flowmeter.
- Attach the cannula and resume use.

Troubleshooting

Water in the Tubing—Occasionally, oxygen tubing can be blocked by water from condensation or from overfilling the humidifier bottle.

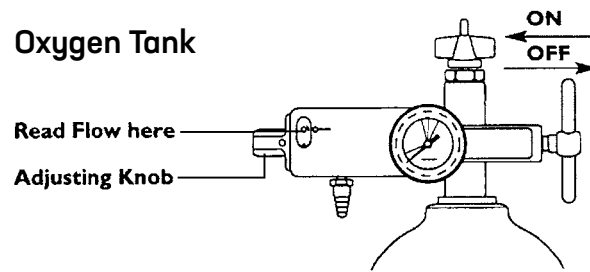
- Remove the cannula and drain water from the tubing.
- Remove the humidifier bottle.
- Attach the nipple adapter and increase the oxygen flow to maximum. The high rate will evaporate the water in the tubing.
- Return the flow rate to the ordered setting after the water is out of the tubing.
- Remove the adapter and reattach the humidifier bottle OR leave the humidifier off.
- Call Hospice if moisture continues to accumulate.

What if the concentrator isn't working?

Switch to the portable oxygen tank.

(See instructions next column)

- Make sure the ON/OFF switch is ON.
- Make sure the concentrator is plugged into an outlet that has power.
- Push the reset button on the concentrator.
- Call Hospice if the concentrator still isn't working or if it is making unusual noises, odors or shuts itself off.



How to switch to a portable oxygen tank:

Make sure the washer is in place on the inside of the regulator.

- Place the regulator over the cylinder valve.
- Place the indexing pins into the holes on the cylinder valve.
- Tighten the “T” handle clockwise until the regulator is securely attached to the cylinder.
- Disconnect nasal cannula tubing from the concentrator and attach to the portable tank nipple.
- Place the wrench supplied on top of the cylinder valve. Turn the wrench counter clockwise (to the left) until the needle on the cylinder gauge shows how full the tank is (usually around 2000 when full).
- This turns on the portable oxygen tank. Turn the liter flow knob to the right (clockwise) until the needle on the gauge shows the prescribed liter flow (matches the liter flow setting of the concentrator.)
- Place the nasal cannula in the nose.
- To turn the regulator off, first turn the wrench clockwise until it stops. The needles will drop. When both needles show ‘zero’ (“0”), turn the liter flow knob counter clockwise until it stops.
- An oxygen conserving device may be ordered to increase how long the tanks lasts. The only way oxygen will be delivered if wearing a nasal cannula is when you inhale through your nose. If you breathe through your mouth, you may not trigger the oxygen sensors and will not get the amount of oxygen ordered.
- Turn off the concentrator by pressing the OFF button.

Safety When Using Oxygen



DO NOT

- **DO NOT** smoke, vape, use candles, or use space heaters in a room with oxygen equipment.
- **DO NOT** operate equipment within 15 feet of open flame sources, including candles, gas stoves, fire pits, and fireplaces.
- **DO NOT** place concentrators in closets or cover the concentrator.
- **DO NOT** keep equipment within 5 feet of any heat source.
- **DO NOT** plug equipment into extension cords, multi-outlet adapters, or power strips.
- **DO NOT** use aerosol sprays, like hairspray, near oxygen as they may be flammable.
- **DO NOT** use petroleum products, like Vaseline, on your face or lips; use non-petroleum products.
- **DO NOT** use electrical appliances that may produce sparks such as heating pads, electric blankets, hair dryers, or electric razors.
- **DO NOT** store portable tanks near gasoline or propane tanks, grills, in the trunk of an automobile, in garages, or in outdoor sheds because of temperature extremes.

Oxygen Tips



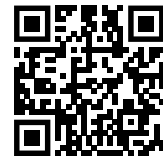
- Post “Oxygen in Use” signs provided by the equipment company at the door, in plain sight.
- Make sure smoke detectors are present and working.
- Storage:
 - Store oxygen in areas with adequate ventilation.
 - Oxygen tanks/cylinders should be stored in a stand or cart to prevent falling or tipping.
 - When transporting tanks, oxygen should be in the passenger area of the vehicle only with the windows slightly open for proper ventilation.
- Cooking:
 - A microwave is the safest option.
 - If using an electric stove, secure the cannula over the ears and behind the head, instead of under the chin.
 - Move the tubing to one side and secure it to clothing without puncturing the tubing to keep it away from heat source.

Nebulizer

Used to administer breathing treatments

Putting the nebulizer kit together

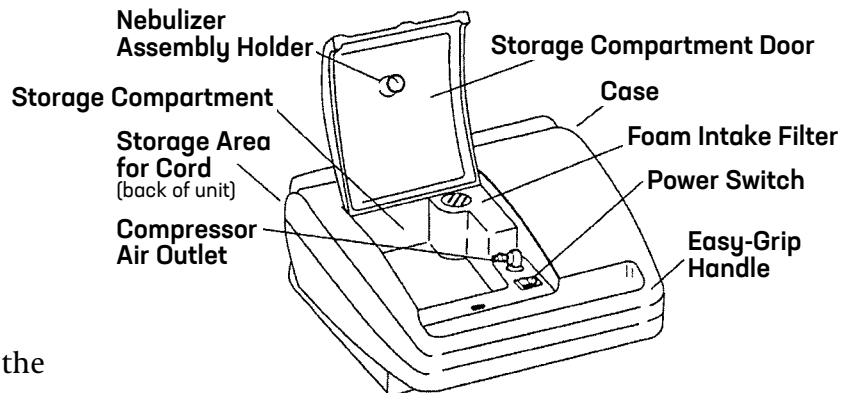
- Attach the tubing to the nebulizer compressor.
- Unscrew the lid from the nebulizer cup and set it aside.
- Before opening a vial of medication, shake all the liquid to the bottom of the vial.
- Remove the top of the vial and squeeze contents into nebulizer cup.
- Screw the lid back onto the nebulizer cup.
- Attach cup to tubing.



See video on nebulizer assembly and use.

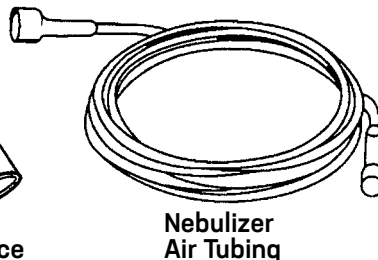
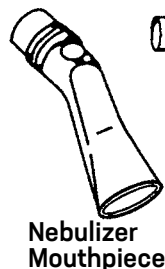
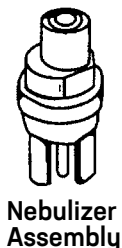
Using the nebulizer

- Turn on the machine.
- Sit up straight and exhale completely. Put the mouthpiece into your mouth and seal your lips around it.
- Breathe normally in and out through the mouth piece. If you are using a mask, breathe through your mouth not your nose.
- Every 4th breath, take a slow deep breath in and hold it for a count of 5. Let the breath out slowly then continue to breathe normally.
- When the treatment is nearly finished, you will hear a sputtering sound. Tap the side of the nebulizer cup to allow all of the medication to turn into an aerosol for your treatment.
- After the treatment, take a slow deep breath in and cough several times to help get mucus out of your lungs.
- Turn off the nebulizer.



Cleaning and storing the nebulizer equipment

- Remove the tubing from the nebulizer cup and disassemble the parts.
- Rinse with warm water.
- Allow the cup and parts to air dry on a paper towel.
- Reassemble when dry and store in a clean area or plastic bag until next treatment.



Medication Safety & Storage

Medication Storage

Most medications may be stored at room temperature, in a cool, dry place. It is best to avoid storing it in a bathroom medicine cabinet or kitchen cabinet that is near the stove or dishwasher; those can be areas of high heat and humidity and may damage certain medicines. Store all over-the-counter and prescription medicines in their original packaging. Consider buying a small safe or lockbox to lock up all medicines.



Put Medicine Away After Every Use

Even if there needs to be another dose given in a few hours, resist the urge to keep the medicine handy. Put it up and away after each dose.

Do not take other's medications or share medications.

Medications should only be taken as prescribed. Please contact the Hospice team with questions regarding your medications or if there are concerns that someone else may be taking the patient's medications.

Safely dispose of medications

Safely discard all unused medications, particularly powerful drugs like opioids.

- See page 60 for complete disposal details.

Children and medication safety

Put all medicines up and away, out of reach and sight. Avoid leaving medicines on a nightstand or dresser. Check to see if any pills have accidentally fallen on the floor or under the bed and other furniture. Consider products you might not think about as medicines. Health products such as vitamins, diaper-rash creams, eye drops and even hand sanitizers can be harmful if children get into them. Remember, child-resistant does not mean childproof.

Take the same safety steps for anyone who has dementia.

See page 35 and page 60.



Children and pets will be the first to find medications!

Store medications:

- 1) Out of reach and sight
- 2) Consider the use of a lockbox
- 3) Close medicine caps tightly after each use
- 4) Check the floor for dropped medications

Safety Is No Accident! Make YOUR Home Safe!

Hospice & Community Care wants you to be in an environment that is as safe as possible.

You can help prevent injuries by being aware of safety issues. The following check list will assist you to make simple changes that can make the home safer!

Check Yes or No	Yes	No	If No...
Are emergency numbers current and is a telephone handy?			Create an easy-to-read list of emergency numbers to place next to the telephone.
Are appliance, lighting, extension and phone cords out of the flow of traffic?			Remove extension and phone cords or tape them securely down.
Are light switches conveniently located in each room?			Place lamps in dark halls or rooms. Leave lights on in the room if used frequently.
Are hallways well lit using non-glare bulbs?			Place lamps in dark halls or rooms.
Are rooms, hallways and stairways free of clutter?			Remove clutter and create a clear pathway for walking.
Are stairwells well lit with sturdy handrails?			Add stair rails.
Are stairs painted with rough textured paint or edged with non-slip tread?			Add non-slip tread if the patient needs to use stairs regularly.
Are carpeting and throw rugs securely tacked?			Remove throw rugs or tape rug edges securely.
Are necessary items well within reach when sitting or lying down?			Create a convenient 'care area' where necessary items, such as medications or drinks are easily reached.
Are bathmats or non-skid strips on the floor of the bathtub?			Add non-skid strips to tub.
Are surfaces safe when they become wet?			Clean up spills promptly.
Are there grab bars on each side of the toilet? The shower?			Place a grab bar next to the toilet and shower.
Do shoes and slippers have non-skid soles?			Wear shoes and slippers with non-skid soles.
Are working smoke detectors and fire extinguishers present?			Place detectors in key areas and check battery regularly.
Are you ready with a fire evacuation plan?			Make a plan to get out of the house quickly.
Are 'Oxygen In Use' signs and 'No Smoking' signs posted?			Do not smoke with oxygen in the home. Post 'Oxygen In Use' signs.

Emergency Preparedness Plan

Hospice & Community Care wants to help you prepare and inform you of how we can help in the event of a disaster.

Hospice & Community Care will make telephone contact before a disaster occurs, if known ahead of time. We want to ensure you have enough medications, food and water to last at least 4 days. Our 24-hour telephone number 1 (877) 506-0149 is a resource you can use if phone lines are open.

When starting hospice services, the Hospice team will assess any special needs you may have in the event of an evacuation and assist you to the best of our ability in the event you need to evacuate.

If choosing to leave the home in the event of an emergency/evacuation, please call our 24-hour number to notify us of your new location and contact number.

Here are some precautions you can take now to prepare your family for a disaster:

1. Learn about potential threats.

Learn what disasters or emergencies may occur in your area. These events can range from a home fire to a medical emergency, or to those that affect the entire community. In our area weather events such as snow, ice and flooding are the most common occurrences.

2. Use community resources.

During a disaster you will be able to obtain information from local radio, TV or National Oceanic and Atmospheric Administration (NOAA) Weather Radio stations. You can also access NOAA on the internet. Familiarize yourself with NOAA weather alerts such as watches and warnings and what actions to take.

3. Plan escape routes.

Identify ways to escape from every room. Practice your escape plan. Identify responsibilities for each member of your household and plan to work together as a team. Select a safe location away from the home where others can meet after escaping. Escape ladders can be purchased for rooms above ground level. If you see smoke or fire in your first escape route, use a second way out.

4. Establish a communication plan.

Your family may not be together when disaster strikes, so plan how you will contact one another. Think about how you will communicate in different situations.

5. Make an emergency kit.

You may need to survive on your own after a disaster. Assemble a disaster recovery kit and make sure everyone in the home knows where it is. You can build your own.

6. Maintain your disaster supply kit.

Just as important as putting your supplies together is maintaining them so they are safe to use when needed. Here are some tips to keep your supplies in good condition:

- Keep canned foods in a dry place where the temperature is cool.
- Store boxed food in tightly closed plastic or metal containers to protect from pests and to extend its shelf life.
- Throw out any canned items that become swollen, dented or corroded.
- Write the date on all containers you store. Use foods before they go bad and replace them with fresh supplies.
- Re-think your needs every year and update your kit as your family's needs change.
- Keep items in airtight plastic bags and put your entire disaster supplies kit in one or two easy-to-carry containers.

7. Make emergency contact cards.

Complete an emergency contact and health card for each family member and keep the cards handy in a wallet, purse, backpack, etc. Include information about medications, adaptive equipment, blood type, allergies and immunizations, do not resuscitate papers and communication difficulties, as well as emergency contact information.

8. Make copies of important papers.

Duplicate important documents, such as passport, driver's license, social security card, wills, deeds, financial statements, advance directives, insurance information, marriage license and prescriptions. Keep copies off-site, either in a safety deposit box or with someone you trust.

9. Consider an elder's special needs.

Elders and people with disabilities must take additional precautions.

- **Wheelchairs:** For people in a wheelchair or with mobility problems, plan for how they will evacuate and discuss it with their care providers. If they use a motorized wheelchair, have a manual wheelchair as a backup.
- **Blind or visually impaired:** Keep an extra cane by the bed and attach a whistle to it. Exercise caution when moving, as paths may have become obstructed.
- **Hearing impaired:** Keep extra batteries for hearing aids with emergency supplies. Store hearing aids in a container attached to the person's nightstand or bedpost so they can be located quickly after a disaster.

10. Oxygen

Portable and/or backup oxygen should be taken along during an evacuation. Ensure you have enough oxygen to get to your destination.

11. Plan for pets.

Take enough food and water for 4 days along with a pet carrier when evacuating.

Emergency Kit Checklist

- ☐ 4-day supply of non-perishable food
- ☐ 4-day supply of water
(one gallon of water per person, per day)
- ☐ Portable, battery-powered radio or television and extra batteries
- ☐ Flashlight and extra batteries
- ☐ First aid kit and manual
- ☐ Sanitation and hygiene items
(moist towelettes and toilet paper)
- ☐ Matches in a waterproof container
- ☐ Extra clothing
- ☐ Blankets
- ☐ Basic kitchen accessories and cooking utensils
- ☐ Manual can opener
- ☐ Multi-purpose tool, such as a Swiss army knife
- ☐ Photocopies of credit and identification cards
- ☐ Cash and coins
- ☐ Special needs items, such as prescription medications, eye glasses, contact lens solutions and hearing aid batteries
- ☐ Cell phone with charger
- ☐ Whistle
- ☐ Extra set of car and house keys

Resource: American Red Cross: Emergency Preparedness Plan

Safe Driving



Factors Affecting Safe Driving

- Changes in vision
- Decline in hearing
- Slowing of mental function/reaction time
- Impact of medications

Questions to Consider

- Is driving less comfortable now than it was five years ago?
- Have more near-accidents occurred in the last year or so?
- Are intersections bothersome because of all the cars and activity in several directions?
- Is it harder to judge the distance and speed of cars when merging into traffic?
- Is night driving more difficult because of glare/blurred vision?

Caregiver Considerations

- Be respectful to the person.
- Offer safer alternatives/methods of transportation.
- Anticipate grief due to loss of independence.
- Consider what types of driving may still be safe.
(day/night, short trips)

Here are some of the symptoms that may impair a person's ability to drive safely.

- | | |
|-----------------------|--------------------|
| • Low blood pressure | • Seizures |
| • Dizziness | • Severe pain |
| • Lightheadedness | • Confusion |
| • Mobility Concerns | • Memory problems |
| • Chest pain | • Fatigue |
| • Shortness of breath | • Loss of strength |

When to Call

We want you to know that you are never alone with your concerns. Call us at any time, 24/7, at 1 (877) 506-0149. An important part of our mission is providing guidance and training to patients and families.

Common reasons to call:



- Concern about any symptoms.
Do not wait until the next scheduled visit or the next morning.
- Question about medication, equipment, supplies or need instructions.
- When medical appointments, tests or treatment are scheduled, call us so we can collaborate with the provider and arrange proper billing.
- Changing a planned visit.
- Planning a trip. Call us to coordinate support and assure you have what you need.

Routine medications, equipment, and supply needs are best handled Monday - Friday, 8am - 5pm.

But, you can always call our 24-hour number to speak with a Hospice team member with questions or for guidance.

**1 (877) 506-0149
or 1 (855) 665-2273**

After 5:00 p.m. or on weekends and holidays, your call will be answered by our on-call staff. The on-call staff includes a nurse available to answer questions, assist with symptom management or when appropriate have one of our on-call staff make a visit. Please do not hesitate to call at any time.

Before calling your physician, please call us. In most situations the nurse will be able to answer your question or help you decide next steps to take. If you do speak with the physician, please notify our nurse so we will know what has occurred.

Call us first before going to the hospital. It's likely the Hospice nurse will visit and handle the situation in the patient's home. However, if the situation cannot be dealt with in the home, we will discuss how we can best support the patient which may include care in our Inpatient Center.

Examples of after-hour situations

- | | |
|---|---|
| • Pain that does not respond to pain medication on hand | • Catheter leaking |
| • Difficulty breathing | • Uncontrolled bleeding |
| • New onset of agitation or restlessness | • Temperature above 101°F that does not respond to Tylenol® (acetaminophen) |
| • Falls where possible injury has occurred | • Unable to awaken patient (new problem) |
| • No urine in 8 hours associated with discomfort | • Chest pain |
| • Uncontrolled nausea, vomiting or diarrhea | • Patient taken to the hospital |
| | • Patient death |

To reach your Hospice team call 1 (877) 506-0149

Coordination with the Facility

Home is wherever a patient may be. Sometimes that home is a nursing facility or retirement campus. We work together with facility staff to develop a plan of care that meets individual needs, reflects a hospice philosophy and ensures great communication. Your Hospice team will complement and support the care provided by the facility staff, as well as provide the same symptom monitoring and management we provide at home. Our Hospice teams work with all areas of a senior living campus.

When to Call

The Hospice team will keep primary caregivers up to date by phone or email per their preference. Please use our 24-hour number, 1 (877) 506-0149, if there are things that we should be aware of.

Accessing Care in Our Inpatient Center

Hospice & Community Care offers residential care at the Bob Fryer & Family Inpatient Center. This option is designed for patients with a short prognosis (weeks to a month) who could benefit from utilizing our Inpatient Center for 24-hour support in a residential setting. The Center is equipped to handle the needs of patients and families who are facing end of life in a home-like environment with plenty of space for family and friends to gather. Benefits of the Center for residential care include:

- Around the clock care by a team of nurses, aides, social workers, chaplains, and Hospice volunteers who are trained in end-of-life care.
- Families can focus on spending quality time with their loved ones rather than having to meet the demands of being a caregiver.

Talk with a team member for more information and availability of our Inpatient Center services.

The Bob Fryer & Family
Inpatient Center is located
at 4075 Old Harrisburg
Pike in Mount Joy.



Care in Our Inpatient Center



The Bob Fryer & Family Inpatient Center offers around the clock, short-term treatment for



Take a video tour of the Inpatient Center.

patients experiencing difficult or challenging symptoms such as pain, nausea, shortness of breath, agitation, restlessness, constipation, advanced wounds or nutrition concerns. Our team of nurses, aides, physicians, social workers and chaplains work together to help the patient and family with what is most important to them. Patients often return home once their symptoms are under control. Our goal is to manage symptoms quickly and coordinate a plan to return home. Visit our website at www.HospiceCommunity.org for a virtual tour or talk to a Hospice team member to schedule an in-person tour of our Inpatient Center.

“Thank you for your care and comfort that you provided to my mom... You were amazingly strong and supportive to my mom, my brother and me during my mom’s short stay at your facility. We are grateful that you were there to guide us in our time of need.”

~Patient Family

Fall Prevention



A person who is unsteady, a little confused, or just generally weak is at high risk for falling. Side effects from some medication may also cause weakness or dizziness. There is a greater risk for falls while trying to get out of bed or into the bathroom. Here are some tips to help prevent patient falls:

- When getting out of bed, sit on the side of the bed for a minute or two if sudden change of position causes dizziness or unsteadiness.
- Wear non-slip shoes or slippers.
- If needed, assist by walking side by side, holding an arm and perhaps a belt in the center of the back.
- Avoid long clothing that can cause tripping.
- Remove small scatter rugs and tape edges of large rugs to the floor.
- Do not have electrical cords or oxygen tubing running across the floor.
- Keep all walkways free of clutter.
- Wipe up any spills immediately.
- Use rubber bathmats or non-slip strips in the bathtub and shower.
- Use a bath or shower chair.
- Do not use bath oil.
- Install grab bars or handrails to improve safety in the tub or shower.
- Use raised toilet seats and install handrails.
- Have a bedpan/urinal or bedside commode close by.
- Use good lighting, including a night light.
- Use of a cane or walker may reduce the risk of falling. See page 16 for instructions on proper walker use.

If a Fall Occurs

- If caregivers are unable to move the person, place a pillow under their head and cover them with a blanket. Seek help before moving them.
- Call the Hospice team for guidance.

Infection Control

When people are ill, they cannot fight infections as well as they can when they are healthy. Close, personal contact with others increases the possibility of the spread of infection. **It is important to follow infection control procedures to protect everyone. Handwashing is the number one way to prevent infection. When soap and water are not available, use hand sanitizer to help prevent the spread of germs. Remind visitors of handwashing and infection control. Ask friends and family to call, rather than visit, if they are ill.**



Wash Hands

- Before and after providing care.
- When you return home after being out, such as after trips to the doctor's office, to visit friends, or to the store.
- After contact with someone who is ill.
- After everyday activities such as playing with pets or children, handling money, cleaning the house, doing yard work or running errands.
- Before and after contact with body fluids such as using the toilet, changing dressings, cleaning wounds, or emptying the bedpan or catheter bag.
- After any activity that puts you in contact with bodily secretions, such as stool, urine, blood, saliva, or phlegm.
- Before preparing medications or tube feedings.
- Before preparing or eating meals.

Disposable Gloves

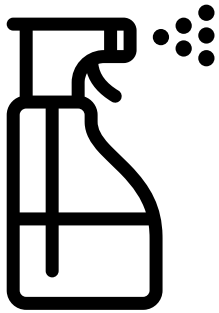
- Wear disposable gloves when there is expected contact with phlegm, urine, stool, blood, vomit, or wound drainage.
- Never reuse gloves.
- Always wash hands after removing disposable gloves.

Cough Etiquette

- Phlegm should be coughed or wiped into tissues. Double bag them and put them into the household trash.
- Wash hands thoroughly after any contact with phlegm or soiled tissues.

To wash hands with soap and water, turn on the water to a comfortable temperature, wet hands and put a small amount of liquid soap on your palm. Vigorously rub hands together for at least 20 seconds (hum 'Happy Birthday' twice); make sure to wash your thumbs, between fingers, and just above the wrists. Rinse hands well under running water. Dry hands with a paper towel and discard. Use a clean paper towel to turn off the water.





Clean any spills of blood or body fluids with a bleach/water solution of $\frac{1}{4}$ cup bleach to $2\frac{1}{2}$ cups water. Keep away from children. Replace every two days.

Soiled Linens

- Bed linens, towels, and clothing soiled with phlegm, urine, stool, blood, vomit, or wound drainage should be placed in a plastic bag and tied shut until ready to be laundered.
- If soiled with blood, rinse linens and clothing first in a solution of $\frac{1}{4}$ cup bleach to $2\frac{1}{2}$ cups cold water.
- Wash all soiled items using hot, soapy water.
- Wash soiled items in a separate load from other laundry.

Trash/Disposable Items

- Contaminated disposable items, excluding sharp objects, should be placed in a plastic bag and tied shut, then placed in a second plastic bag and tied shut (double bagging). The bag can then be discarded with regular household trash.
- Sharp items must be disposed of in a leak-proof, puncture-proof, heavy plastic container. An empty detergent bottle works well. Label the container “Do Not Recycle” and tape the lid on securely when full. Dispose with household trash.
- To prevent needle stick injuries, immediately drop needles and lancets into the heavy plastic container. Do not try to recap, bend, break or remove needles from the syringe.

Medicine Information (Basics)

Some commonly used medications, their use and possible side effects are listed on page 52.

Getting Medications

- Medications paid for by Hospice are provided and coordinated by one of our contracted pharmacies.
- It is necessary for the Hospice team to stay informed of all medication, including over-the-counter and illicit medications, a patient is taking.
- While Hospice covered medications must be filled through our pharmacy, you may continue to fill your non-Hospice covered medication at the pharmacy of your choice.

Giving Medicine

- A list of the patient’s medicines and side effects is kept in the home. This list is reviewed frequently and revised as needed to maintain accuracy. The Hospice nurse will provide training on how to measure and administer medicines.
- Medicines come in many forms. The first step to safely give all types of medicine is to review the medicine list to make sure that the correct dosage is being given.

Tablet/Capsule (Pills)

- Give the tablet or capsule to the patient to swallow with water, juice, or another drink they like.
- If someone has trouble swallowing, the medicine can be given on a spoon with applesauce, pudding, jello, or custard.
- Some tablets may be crushed and given with a very small amount of water. Please ask the nurse if the medicine can be crushed.
- Put on gloves and remove the old patch, if one is present, before applying the new one. (See page 35, *Disposing of Medicine*, for how to safely discard patches.)
- Clean the skin to remove lotions or powders—use plain warm water or a soap that does not contain lotion.
- Carefully open the packaging by cutting on the marked line with scissors and remove the patch. If you tear or cut the patch by accident do not use it.

Suppository

- Gather supplies, including gloves, lubricant, and the suppository.
- Position the patient on their left side with their knees pulled up towards their chest if possible.
- Put on your gloves and locate the patient's rectum. Let them know you will be giving the suppository.
- Open the packaging of the suppository, and place a fair amount of lubricant on the pointed end.
- Place the lubricated, pointed end of the suppository at the rectum and gently insert until it has gone completely inside the patient. You should not see any of the suppository outside of the patient.
- The medicine will absorb this way.
- Peel back the protective liner halfway. Do not touch the sticky part of the patch.
- Place the patch sticky side down against the patient's skin, peel the rest of the liner back, and push down on the patch with your hand to be certain it has stuck.

Topical

- Topical medicines are applied directly to the area needing treatment.
- Wash and dry your hands, and apply gloves if desired.
- Remove a small amount of the ointment, cream or lotion and apply a thin layer to the area being treated. Do not rub it in.
- If using a powder, dust it lightly onto the area.
- Follow the instructions you have been given for covering the area.

Patch

- Patches should be placed in an area that will not be rubbed by tight clothing, waistbands/cuffs, or another body part. Do not place a patch on skin that has a cut or wound.

Please call Hospice if you have any questions or concerns before giving any medicines. To reach Hospice, please call
1 (877) 506-0149



See video
on nebulizer
assembly
and use.

Nebulized (Inhaled)

- Wash hands well.
- Connect the tubing to the nebulizer machine.
- Fill the medicine cup with the patient's medicine.
- Attach the hose and mouthpiece, or hose and mask to the cup.
- Place the mouthpiece in the patient's mouth, or apply the mask over their nose and mouth.
- If using the mouthpiece, they should breathe through their mouth until the medicine is used up. If using the mask, they breathe normally.
- Turn off the machine when done.
- Rinse out the medicine cup and allow it to dry between treatments.

See page 21 for more information on Nebulizers.

Medicines can be dangerous if not taken as prescribed. If symptoms are not being managed by the medicines on the patient's list, please call us.

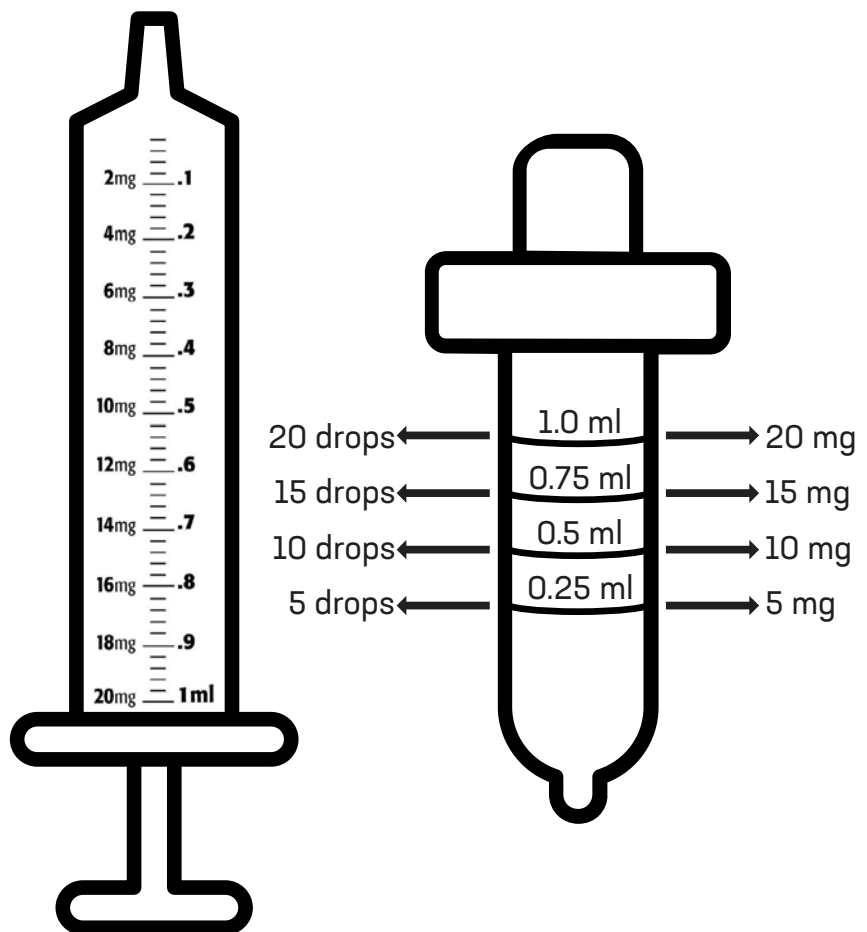
Liquid Medicine

- Fill the syringe or dropper with the right amount of liquid medicine.
- Place the medicine into the side of the mouth or place in a very small amount of liquid or juice for the patient to swallow.

Concentrated Liquid Morphine OR Oxycodone

20 milligrams (mg) per milliliter (ml)

1 drop = 1 mg



Storing Medicine

- Safe and secure storage of medicine can help avoid accidents.
- How to store medicine safely:
 1. Get organized. Check for and discard expired medicines.
Taking expired medicine may be harmful.
 2. Store medicine in the original packaging in a cool, dry place unless refrigeration is noted on the package/bottle.
 3. Keep your medicine out of reach of children and pets.

Paying for Medicine

- After electing the Hospice Medicare Benefit, selected medications are paid for in a different way. The Hospice team will provide details on the Medicare Coverage Form.
- Medicare Prescription Drug Coverage (“Medicare Part D”) will continue to pay for medications not related to Hospice.
- The pharmacy will be denied payment when attempting to fill or refill the patient’s prescription related to the hospice diagnosis.
- If the patient’s pharmacy has problems with payment for medications not covered under the Hospice Medicare Benefit, please have them call Hospice & Community Care at 1 (877) 506-0149. The Hospice team will discuss related- and non-related medications.

Disposing of Medicine

- Discard unneeded or expired medicine as soon as possible to reduce the risk of others taking the medicine accidentally or intentionally.
- The best way to dispose of medicine is through a drug take-back program.
- If there are no special instructions on the package or nearby take-back locations, discard medicine in the trash by following these five steps:
 1. Mix the medicine with an undesirable substance like used coffee grounds, kitty litter, dirt, or dish soap.
 2. If discarding patches, fold the sticky sides together and follow the remaining steps.
 3. Put the mixture in a container, such as a sealed plastic bag.
 4. Throw the container in the household trash.
 5. Scratch out all personal information on the label then dispose or recycle the empty medicine bottle.

Safety Tip

Store all medicines out of the reach of children or pets living in or visiting the home. See page 22.

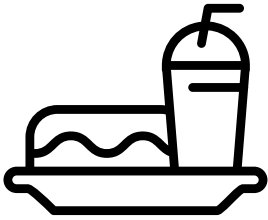
Locate a drug take-back program at
<https://takebackday.dea.gov>



Please refer to the full disposal guidelines on page 60 for details.

Changing Appetite at End of Life

Bodies go through changes as they move towards the natural end of life. A person becomes more tired, moves more slowly and sleeps more. Inside, the body is working more slowly and it doesn't need as much fuel (food and drink) to do its job. The body does not signal that it is hungry or thirsty as often as it used to, and this is very normal. Eating or drinking may be uncomfortable. When not hungry, please do not force someone to eat or drink. Instead, try this:



- Offer drinks and sips often, as tolerated.
- Provide mouth care (using swab).
- Clean the mouth often. A pleasant tasting mouth may make food taste better.
- Encourage favorite foods and drinks but understand it may be declined.
- Offer small portions of foods and use small dishes.
- If nauseous, try small portions of salty, dry foods and clear liquids.
- Encourage rest before and after a meal.
- Offer sips and bites of favorite foods/drinks.
- Ice chips (when tolerated) will reduce a dry mouth.
- When feeding someone NEVER FORCE food; cues such as turning the head away when offered food or clamping the mouth shut are signals that food/drink are not desired.

Hearing someone say they're not hungry or seeing them only take a bite of a favorite food can be hard for caregivers. When this happens, there are still ways to care.

- Offer a hand or foot massage.
- Look through a photo album together.
- Talk about a trip, event or other happy memory together.
- Read them their favorite book.

While appetite loss is a natural process, it can feel overwhelming and sometimes confusing. If changes to the patient begin to occur, talk with the Hospice team. We want to help make a plan for everyone's comfort.

Making an Occupied Bed

The best time to change the bed is just after the person has a bath, although caregivers should periodically check for crumbs, creases or moisture as these can make the bed uncomfortable and contribute to skin breakdown.

When the patient becomes too weak to get out of bed, follow this procedure to make an occupied bed. It is usually helpful to think of the bed as two halves: change one half of the bed while the patient lies on the other, then move onto the clean half and make the other side.

Guidelines for changing an occupied bed

1. Leave one pillow on the bed, supporting the head. Keep the body covered loosely with a sheet or light blanket.
2. If changing in an electric bed, raise it to a height that is comfortable to work at the bedside.
3. Help the patient roll to one side of the bed. If in an electric bed, be sure the rail on the side the patient is rolling toward is up.
4. Work from the side with the patient's back facing you. Loosen all bedding on that side and roll the bottom sheet to the middle of the bed.
5. Place a fresh sheet on the bed, with the middle of the sheet in the middle of the bed. If using a pull sheet or incontinence pad, place those in the same way.
6. Tuck in the side, top, and bottom of the sheet on the side being worked on, then roll the rest of the bedding to the middle of the bed, tucking the roll under the back and legs.
7. Have the patient roll toward you over the folded linen and onto the clean side of the bed. If there's a side rail, pull it up before moving to the other side of the bed.
8. Pull out the dirty linen.
9. Unroll the clean bedding and tuck in side, top, and bottom of the sheet on the second side.
10. Position the patient as you have been taught, covering with a clean top sheet or blanket if desired.

If the patient prefers to be on their side, remember to use pillows between the knees. If the patient prefers to be on their back, consider placing a pillow under the lower calves to elevate the heels.



See Bathing, Dressing & Making an Occupied Bed.



Self-Care Techniques

Take a 5-minute Self-Care Break

- **Rehydrate**

(1 minute): Slowly drink an 8-16 ounce glass of water. Between sips, scan your body and notice areas of stress.

- **Breathe**

(1 minute): Sit up straight. Do slow, deep abdominal breathing. (6-10 breaths)

- **Self Massage**

(1 minute): Gently massage your neck, shoulders, arms, and hands to relieve tight muscles.

- **Stretch**

(1 minute): Do slow, gentle neck stretches and shoulder/neck rolls.

- **Mindful Thinking**

(1 minute): Your thoughts impact your body. Finish your break with some positive thinking.

Caregiving is challenging work and can tax you physically, emotionally and spiritually. It is important to acknowledge that you are human and that caregiving will affect you. Clarifying and expressing your feelings will help you provide optimal care to the patient as well as to yourself. Good self-care is critical to offset negative feelings associated with caregiver stress.

Everyone has occasional days when their motivation and energy levels are low. Ignoring your physical and emotional needs repeatedly during stressful times can lead to burnout. For continued well-being, consider practicing the following self-care options:

- Take time to rest and renew.
- Develop support systems; keep in touch with friends.
- Ask others for help.
- Maintain routines. Eat the right food and get enough sleep.
- Learn time management skills and use them.
- Find healthy ways to express feelings as they arise—don't let them build up.
- Exercise regularly to help reduce tension.
- Listen to your body as best you can and give it what it needs.

Each caregiver has their own unique style of relating to the stress of living. Tune in to yourself and reflect on ways you can take positive action.

- **Physically:** How is your health being affected by the patient's illness?
- **Emotionally:** Do your emotions feel like a rollercoaster? Perhaps somewhat out of control?
- **Mentally:** Do you feel overloaded with information? Perhaps too many decisions?
- **Socially:** Do your friends and coworkers get it? Are they supportive?
- **Spiritually:** Where do you find comfort, purpose, and meaning?

Consider the ways you are most impacted, as this will give you a sense of what you need to address. Develop a toolkit of coping skills that work for you. You will be more effective as a caregiver if you take the time you need for yourself. When you feel empty or depleted, it's important to take time to refill, refuel, and recharge.

Develop a Support System

Planning ahead can make things less stressful. Knowing who to call in times of need can help.

Family/Friends _____

Faith Community Contact _____

Community Physician _____

Counselor/Therapist _____

Other _____

Call our 24-hour number to speak with a Hospice team member with questions or for guidance.

1 (877) 506-0149
or 1 (855) 665-2273

Need additional help
finding food, mental health assistance, paying your bills, or other issues? 211 may be able to help!



211 is a confidential helpline that can help you connect with local resources.
<https://pa211east.org/>



“I Need a Break” – Respite Care



Take an interactive virtual tour of our Inpatient Center.

Being a caregiver is both rewarding and sometimes challenging. At times, you may feel overwhelmed or fatigued in this role. While honoring the patient's preference to receive care at home, occasionally there may be times to consider the Bob Fryer & Family Inpatient Center for temporary caregiving, up to 5 days at a time. Respite, or caregiver breaks, is available for you to rest, travel or attend special events while the patient is cared for in the Inpatient Center. During these respite stays, the Inpatient Center team follows the patient's home care plan, and the patient's physician continues

to manage the patient's care. Patients and/or their caregivers may choose to return home early from a respite stay should they desire. Visit our website at www.HospiceCommunity.org for a virtual tour or talk to your social worker to schedule an in-person tour and/or to schedule a respite stay.



How to plan for your respite stay.

Balancing Caregiving and Work



Get more caregiver tips.

Juggling work and caregiver responsibilities can be stressful. Consider the following tips for ways to manage both responsibilities:

- Decide how much information you want to share with your coworkers. This helps your colleagues know if you do or do not want to talk about your situation.
- Talk to your supervisor. Discuss potential areas for flexibility such as reducing hours, working from home or hiring a temporary replacement.

When not at work or providing care, consider options to give yourself a break. Family members, friends, neighbors, paid caregivers or Hospice respite care can help you take time for yourself.

Pain

Pain management is one of the most important services provided by Hospice. Although not all Hospice patients will have pain, it is very important to manage pain if it occurs.

Unrelieved pain can cause irritability, anger, sadness and withdrawal, nausea or loss of appetite, and sleep alterations (sleep loss or excess), difficulty caring for oneself, depression, and anxiety.

Our goal is to manage pain by reducing it to a tolerable level and then maintaining comfort. To do this, pain medication may be needed on a regular basis. If medication is not taken as scheduled, and the patient waits until the pain returns or becomes worse, it may take longer to manage the pain.

The Hospice team will want to know how bad the pain is and what has been done to relieve it.

Some questions the team may ask include:

- Where is the pain?
- What does the pain feel like?
- Does it come and go, or is it there all of the time?
- How bad is it? Rate the severity of the pain on a 0 to 10 scale: 0 means no pain, 10 is the worst pain imaginable. If it is not possible to give the pain a number, is the pain mild, moderate or severe?
- When did it start and how long has it lasted?
- What makes it worse or better?
- How does the pain affect your life?

Tips for managing pain

- Lower sound and light levels in the room.
- Try distracting activities such as reading, watching a movie, playing a game or painting.
- Play soothing music or nature sounds.
- Suggest deep breathing and relaxation exercises.
- Ask to recall pleasant places or memories.
- Assist with changing positions.

If pain cannot be managed at home, a short-term stay at the Bob Fryer & Family Inpatient Center may be recommended. The same personalized support received at home is provided in the comforting atmosphere of the Inpatient Center. See pages 6-7, 14, 28-29 and 40 for information about the Inpatient Center.

Common medications for pain

- Acetaminophen (Tylenol®)
- NSAIDS (non-steroidal anti-inflammatory drugs): Ibuprofen (Advil®), Naproxen (Aleve®)
- Opioids: Morphine, Hydromorphone, Oxycodone, Methadone
- Muscle relaxants: Baclofen, Flexeril, Zanaflex, Diazepam
- Topicals: Lidocaine (gel or patch), Capsaicin cream

These medications are usually prescribed to be taken on a specific 24-hour schedule to achieve adequate pain control. It is very important to follow the instructions. Instructions may be given to continue taking pain medication even though the pain seems to have gone away. When medication is taken only at the time of actual



SYMPTOMS

If you are concerned about any symptoms, please tell any Hospice team member. Do not wait until the next morning to tell us.

1 (877) 506-0149
or 1 (855) 665-2273

pain, the pain control will be less effective. Changing the prescribed dosage or frequency on your own could create uncomfortable side effects. Please write down the time each dose is given and the Hospice team can review this information during the visit.

Concerns about Pain Medication

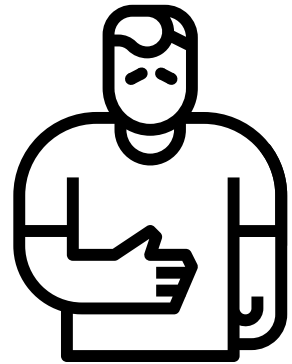
People often worry that pain medication causes sleepiness or a state of sedation. The sleepiness associated with pain medication is usually temporary. Keep in mind that if the patient has not slept well for a period of time, due to pain, that may cause additional sleep for a while to catch up once the pain is better.

Some families are concerned about addiction to pain medication. When medication is used as prescribed, it is not addicting. Addiction occurs when people abuse the medication. This is not the case when using the medication as ordered by the physician. Addiction never improves the quality of life, but good pain management will.

Opioids and Their Side Effects

Hospice makes every effort to manage the patient's pain with medications that help them feel better and have the fewest side effects.

- **Sedation** — Caregivers often worry that pain medication will make the patient too sleepy or sedated. The sleepiness associated with pain medication is usually temporary. However, if the pain has led to a lack of sleep, the patient might sleep more for a while to catch up once the pain is better.
- **Constipation** — Opioid pain medication commonly causes constipation. A plan to prevent constipation is discussed as soon as any of these pain medications are started.
- **Nausea** — Nausea associated with opioid pain medication is usually temporary. If this occurs, or opioids have caused nausea in the past, please let the Hospice team know so that medication can be added to prevent nausea.
- **Confusion/Delirium** — Confusion can have many causes. Please call Hospice if this is a new symptom, or if existing confusion worsens, so that a team member can assess the patient.



Shortness of Breath

Tips to manage breathing difficulty

- Turn on a fan or open the window to improve air circulation.
- Direct a hand-held fan towards the face.
- Apply a damp cloth to forehead.
- Raise the head and shoulders to a 45-degree



angle using extra pillows or assist to a sitting position. If using an adjustable bed, raise the head of the bed. Support the arms on pillows to help the chest and lungs expand.

- Assist the patient with sitting on the side of the

bed with their feet resting on a chair or stool and their arms resting on an over bed bed table or small table with pillows on it.

- Limit the number of people in the room.
- Keep the room temperature comfortably cool.
- Arrange the room so there is a clear line of sight to the outdoors.
- Give oxygen if available as prescribed by the physician.
- Provide medication or administer nebulized treatments to the patient as prescribed for breathing difficulty.
- Encourage relaxation.
- Provide emotional support and reassurance.
- Eliminate/avoid allergens and smoke.

Oxygen is flammable!

Do NOT allow smoking, vaping, candles, space heaters, a lit fireplace or operate a gas stove/oven in a room with oxygen equipment.

(See page 20 for additional Oxygen safety information)

Common medications for shortness of breath

- Morphine
- Lorazepam (Ativan®)
- Albuterol/Atrovent Nebulizer (Duoneb®)
- Dexamethasone (Decadron®)

Call Hospice for any of these symptoms

- Shortness of breath or difficulty breathing
 - Rapid or excessively deep breathing
 - Chest pain or discomfort
 - Unusually pale or bluish skin, especially around the lips
 - Cold and clammy skin
 - Wheezing or coughing that is new or different
 - Anxiety
 - New or increased confusion
-

Nausea and Vomiting

There are many common causes of nausea and vomiting, including anxiety, motion-sickness, and constipation. These symptoms may be experienced as a part of the natural progression of an illness or related to some medications. Tell the Hospice team if nausea and vomiting occur. The team will provide different methods to prevent nausea and may talk with the physician about anti-nausea medicine.

Tips to relieve nausea and vomiting

- Give anti-nausea medication as prescribed.
- Ice chips may help.
- Avoid strong odors.
- Make the living area a relaxed atmosphere.
- Use a cool, damp cloth to wipe the forehead, neck and hands.
- Provide good ventilation. A small personal fan may be helpful.
- When food is desired, begin with clear liquids, such as tea, broth, ginger ale or apple juice, in small sips.
- Plain toast and saltine crackers may help diminish nausea. Forcing food and fluids usually increases discomfort.
- Serve small, frequent meals throughout the day rather than three large meals.
- Try to avoid eating favorite foods when nauseated to avoid associating favorite foods with the sick feeling.

Common medications for nausea and vomiting

There is a wide range of treatment options, depending on the suspected cause of the nausea. Common medications include:

- Haloperidol (Haldol®)
- Ondansetron (Zofran®)
- Prochlorperazine (Compazine®)

SYMPTOMS

If you are concerned about any symptoms, please tell any Hospice team member. Do not wait until the next morning to tell us.

1 (877) 506-0149
or 1 (855) 665-2273

Constipation

Constipation is a common problem when diet has changed, when taking certain medications, or if one is less active. Prevention is important! Although everyone has their own pattern, bowels should move at least every 3 days, even if not eating or drinking very much. The Hospice team will provide steps to prevent constipation, which may include diet, activity and medications.

Tips

- Increase fluids as tolerated.
- Offer soft fruits and vegetables such as prunes, raisins, apricots, oatmeal, or applesauce.
- NEVER stop or decrease pain medication because of constipation.
- Avoid over the counter or fiber products without talking with the Hospice team.
- Medications may be prescribed to assist with regulating bowel movements.
- Record bowel movements on a calendar.
- Call Hospice if a bowel movement has not occurred in 3 days.

Common medications for constipation

- Milk of Magnesia
- Bisacodyl (Dulcolax®)
- Sorbitol
- Senna

Anxiety and Sadness

People coping with a serious illness often experience anxiety. Their distress may be related to any number of issues, including fears and uncertainties about the future, family or spiritual concerns, or physical causes such as pain, shortness of breath or other symptoms.

Anxiety may cause

- Difficulty sleeping
- Tension
- Irritability
- Shortness of breath
- Increased pain
- Restlessness

Tips to reduce mild anxiety

- Reduce environmental stimuli such as limiting the number of visitors at one time.
- Soften the lights and reduce noises.
- Provide familiar surroundings, objects or people.
- Offer a distraction such as conversation, watching a movie, or listening to music.
- Encourage slow, deep breaths.

Severe or persistent anxiety is a symptom that will affect daily life and so it is important to manage it well. To reduce the severity of the anxiety, medication may be helpful.

Common medications for anxiety

- Lorazepam (Ativan®)



View more information on Anxiety and Sadness.

Depression

Depression is common in people coping with serious illness, as well as their caregivers. Some may feel a general sadness for months, while others suffer more sudden and intense changes in their mood. The type and degree of symptoms vary for each person and can change over time. Depression is a medical condition, often brought on or made worse by severe illness. It is not due to a lack of faith or a failure to try hard enough to do better.

Possible signs of depression:

- Change in sleep patterns—either too much or not enough sleep.
- Loss of interest in people and/or activities that once brought pleasure.
- Episodes of becoming easily agitated or angered.
- Feelings of hopelessness or concern about being a burden.
- Ongoing physical symptoms that do not respond to treatment, such as headaches, digestive issues, and pain.

If caregivers or the patient has experienced any of these signs for longer than 2 weeks, talk to the Hospice team. There are therapies and medications available to help manage depression.

Common medications for depression

- Sertraline (Zoloft®)
- Citalopram (Celexa®)
- Mirtazapine (Remeron®)

Important Hot Lines

• Suicide and Crisis Lifeline: Dial 988

1-800-799-4889 (hearing/speech impairments)

• Nacional de Prevención del Suicidio:
1-888-628-9454

• The Trevor Lifeline (LGBTQ):
1-866-488-7386

• SAMHSA National Helpline/
Treatment Locator: 800-622-4357
(Substance Abuse and Mental Health
Services Administration)

• Veteran Crisis Line: 988 then press 1

• Disaster Distress Helpline:
1-800-985-5990

Hot Lines for Texting

• National Crisis Text:
Text *HOME* to 741741

• Trevor Text: 678678

• Veterans Crisis Text: 838255

• Disaster Distress Helpline:
Text *TalkWithUs* to 66746

Local Crisis Services

• Berks County (610) 379-2007

• Chester County (610) 280-3270

• Dauphin County (717) 232-7511

• Lebanon County (717) 274-3363

• Lancaster County (717) 394-2631

• York/Adams County (717) 851-5320

Existential Distress

People living with a terminal illness commonly experience existential pain and suffering. Existential suffering is an inherently human response to dying. Normal, emotional responses to dying may include:

Fear of death—coming to an end to all that someone has and is. The unknown of the eternal or the unknown of where someone is going and what will happen after they are gone.

Fear of loss of freedom—inability to have a choice in one's own life and circumstances. Loss of identity and independence as one becomes more debilitated and dependent on others; fear of being a burden; or fear of lingering or “waiting to die.”

Fear of isolation—inability to connect and have love, acceptance and relationship with others and self.

Fear of meaninglessness—lack of purpose, hopelessness.

Reconnect with the simple aspects of life that have brought depth, meaning and significance in one's life. Facilitate open and honest conversation and sharing, giving space to feel and grieve; in so doing, we walk together and bear witness to their suffering. Activities that may be helpful include:

- Share memories.
- Spend time with loved ones.
- Discuss fears and anxieties.
- Visit special places of personal meaning.
- Explore sources of meaning.
- Redefine hope.
- Move toward a greater sense of peace and wholeness through meditation or prayer.
- Establish a physical connection through touch, massage, hand holding, etc.
- Having a family, friend, staff, or volunteer presence.
- Connect through music, aroma therapy, journaling, or life review.

SYMPTOMS

If you are concerned about any symptoms, please tell any Hospice team member. Do not wait until the next morning to tell us.

1 (877) 506-0149
or 1 (855) 665-2273

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

~ Cicely Saunders

Nurse, medical social worker, physician, writer and founder of the first modern hospice

Restlessness and Agitation

Restlessness is the need to move around, often without knowing the reason why. Agitation is severe restlessness affecting someone who also has difficulty with memory, confusion, or concentration. Several things may cause restlessness and agitation or make them worse:

- Pain
- Anxiety
- Low oxygen levels
- Constipation
- Inability to empty the bladder
- Infection
- Emotional or spiritual distress
- Effects of medication or stopping medication too fast



View our
caregiver
video.

Tips to decrease restlessness and agitation

- Keep the environment quiet and subdued.
- Play soft, soothing, familiar music.
- Stay close by and provide a calm presence.
- Tell familiar, comforting stories.
- Provide a gentle hand massage.
- Keep a soft light on in the room at all times.
- Use oxygen as prescribed.
- Consider if any situations or events may be causing distress or anxiety.
- Provide anti-anxiety medication as prescribed.

Common medications for restlessness and agitation

- Haloperidol (Haldol®)
- Lorazepam (Ativan®)
- Quetiapine (Seroquel®)

Noisy Breathing at End of Life

Sometimes in the last hours/days of life, secretions can cause “noisy” breathing. There is no need to be alarmed, a change in breathing pattern is natural and expected in some patients at end of life.

Why is this happening?

- The body still makes saliva. When a patient does not have the strength to clear the throat, cough or swallow to move the saliva, secretions pool in the back of the throat where they vibrate with breathing.
- The noise and the secretions are not distressing or painful for the patient.

Tips to help

- Position changes may help: With bed flat, position the patient fully on one side. Place a soft towel under their cheek to absorb secretions. Reposition the patient from one side to the other every 3–4 hours. If noisy secretions persist, elevate the head of the bed slightly.
- Provide mouth care every 1–2 hours. Use a washcloth or swab to remove visible oral secretions.
- Use background music or a fan to diffuse the sound.

Medication is not usually needed; instead, the Hospice team will demonstrate how to turn and reposition the patient.

Weakness and Fatigue

As illness progresses, it is normal for the patient to feel weaker and tire more easily, even after very little activity. This is an expected occurrence as the disease progresses. Tasks that were once easy may now be physically draining. The primary concern about weakness is the higher risk of falling. The Hospice team may suggest equipment to aid in support or safety.

Tips for conserving energy

- Plan and prioritize activities so that energy is saved for the activities that are most important.
- Plan frequent rest periods.
- Ask family/friends to call before visiting, and schedule rest periods before and after the visit.
- Ask visitors to limit visits to a specific length of time.
- Consider rearrangement of the home to reduce exertion.
- Consider use of a bedside commode or urinal to reduce or eliminate tiring bathroom trips.

SYMPTOMS

If you are concerned about any symptoms, please tell any Hospice team member. Do not wait until the next morning to tell us.

1 (877) 506-0149
or 1 (855) 665-2273

Difficulty Swallowing (Dysphagia)

Difficulty swallowing is a common problem for people living with a terminal illness. If the patient is having trouble swallowing or has any of these symptoms, speak to a Hospice team member as soon as possible.

Symptoms of swallowing problems include

- Coughing or spluttering, particularly when eating or drinking.
- Choking.
- Feeling like food is stuck in the throat.
- Having more saliva in the mouth, which can cause drooling or problems talking.
- Bringing food back up through the mouth or nose.

Talk to the Hospice team if there are other mouth problems including mouth pain, dryness, redness, swelling, bleeding, ulcers or other sores, white patches on the mouth or tongue (this can be a sign of infection), and difficulty cleaning teeth or dentures.

Tips to help with eating and drinking

- Sit in an upright position when eating or drinking if possible—this can make it easier to swallow.
- Keep the mouth clean—this can make it more comfortable to chew and less likely to get an infection.
- Have small, regular meals rather than three large meals a day.
- Do not rush when eating or drinking—allow plenty of time.
- Chew the food thoroughly before swallowing.
- Brush teeth.

Insomnia and Trouble Sleeping

Insomnia is a common sleep disorder that can make it difficult to fall asleep, hard to stay asleep, or cause people to wake up too early and not be able to get back to sleep which can lead to still feeling tired after waking up. Insomnia can drain energy levels, disrupt mood and impair quality of life.

Insomnia symptoms may include

- Difficulty falling asleep at night
- Waking up during the night
- Waking up too early
- Not feeling well-rested after a night's sleep
- Daytime tiredness or sleepiness
- Irritability, depression or anxiety
- Difficulty paying attention, focusing on tasks or remembering
- Increased errors or accidents
- Ongoing worries about sleep

Tips to promote sound sleep

- Avoid or limit caffeine and alcohol, and don't use nicotine.
- Avoid large meals and beverages before bedtime.
- Create a relaxing bedtime ritual, such as reading or listening to soft music.
- Medication may be prescribed to help promote sleep.

Common medications for insomnia

- Melatonin
- Lorazepam (Ativan®)
- Mirtazapine (Remeron®)

When to Call Hospice for Symptom-Related Concerns

If concerned about any symptoms that the patient is experiencing, please tell any Hospice team member or call our 24-hour number. Do not wait until the next nursing visit. Remember that a nurse and other members of the Hospice team are available by phone.

- **Keep our 24-hour number handy, 1 (877) 506-0149.**
- Call with any questions, concerns or issues (urgent and non-urgent); do not call 911.
- Write down questions or make notes to discuss with your Hospice team.
- If the patient is scheduled to see a physician or have tests or blood work done, please let us know so billing can occur properly so you are not billed for these services.

Commonly Used Medications and Side Effects

Generic Name	Brand Name	Often Used For:	Common Side Effects
Albuterol Ipratropium	Duoneb®	Shortness of breath, wheezing	Headache, dizziness, cough, dry mouth, nervousness, tremor
Dexamethasone Prednisone	Decadron®	Pain, inflammation, appetite, breathing difficulty	Increased appetite, upset stomach, headache, trouble sleeping
Diazepam	Valium®	Seizures, anxiety	Drowsiness, increased confusion (especially in elderly)
Fentanyl Hydrocodone Hydromorphone Oxycodone	Duragesic® Norco®, Vicodin® Dilaudid®, Roxicodone® Oxyfast®, OxyContin®	Pain, Sometimes shortness of breath	Constipation, drowsiness, confusion, nausea and vomiting
Fluconazole	Diflucan®	Thrush, other fungal infections	Nausea, diarrhea, stomach pain, headache. Caution if taking other medications that affect heart rhythm.
Gabapentin	Neurontin®	Nerve pain, sometimes to help with anxiety/depression	Drowsiness, edema, skin reaction (rare but serious)
Guaifenesin	Robitussin®, Mucinex®	Cough and congestion, to thin secretions	Nausea and vomiting
Haloperidol	Haldol®	Nausea and vomiting, agitation, hallucinations	Drowsiness, dizziness, headache
Levetiracetam	Keppra®	Seizures	Drowsiness, headache, dizziness
Lorazepam	Ativan®	Anxiety, shortness of breath, difficulty sleeping	Drowsiness, confusion (especially in the elderly)
Morphine	Roxanol® MS Contin®	Pain, shortness of breath	Constipation, drowsiness, confusion, nausea and vomiting
Nystatin	Mycostatin®	Thrush, other fungal infections	Mouth irritation, diarrhea, nausea and vomiting or stomach upset
Omeprazole Pantoprazole Lansoprazole	Prilosec® Protonix® Prevacid®	Acid reflux, protect the stomach when certain medications are used (e.g. dexamethasone)	Headache, diarrhea, stomach pain
Ondansetron	Zofran®	Nausea and vomiting	Headache, constipation Caution with heart rhythm problems
Prochlorperazine	Compazine®	Nausea and vomiting	Drowsiness, constipation, blurred vision
Sennosides	Senna, Senokot®	Constipation	Diarrhea, abdominal pain
Valproate	Depakote®	Seizures	Diarrhea, drowsiness, dizziness
Warfarin	Jantoven®	Blood thinner used to treat blood clots, atrial fibrillation, heart valve disorders	Bleeding, bruising, nausea, loss of appetite, stomach pain

This information does not represent a complete listing of all the indications or side effects of the above medications. Ask your physician or Hospice & Community Care nurse if you have any questions or concerns.

Honoring Those Who Served

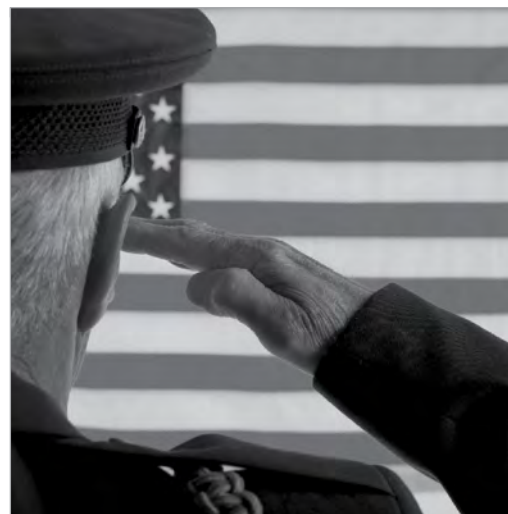
Hospice & Community Care staff and volunteers are specially trained to care for Veteran patients and their families, providing compassionate physical, emotional, and spiritual support at end of life. Hospice recognizes the unique end-of-life needs of Veterans in our community and educates staff and volunteers to commemorate a Veteran's history and be cognizant of the emotional, spiritual and physical associations that accompany serving our country. The specialized support that we can provide can be especially meaningful to Veterans at end of life. It is common for Veterans at this stage to face unique issues related to their military experiences that possibly have never been addressed with their families. Compassionate support is provided not only for patients but also for their family members.



**Learn how
we care for
our Veterans.**

Our mission is to care for Veterans with the respect, comfort and compassion they deserve. Hospice & Community Care is a proud partner of We Honor

Veterans, a pioneering program of the National Hospice and Palliative Care Organization in collaboration with the Department of Veterans Affairs. We have achieved the highest attainable level recognizing the implementation of specialized training and programs focused on respectful inquiry, compassionate listening and grateful acknowledgement of the Veterans in our care.



Honoring the Veterans that we serve.

We pay special tribute to the Veterans that we serve by providing a pinning ceremony to publicly acknowledge the military service and sacrifices made by Veterans and their families. The ceremony gives an opportunity for veterans to share their story.



“These men and women experienced combat and sacrificed so much for our country. It is an honor to care for these patients at the end of their lives.”

~ Hospice & Community Care LPN and Veteran

Sunflower Pediatric Program



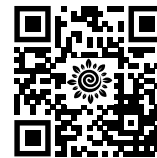
When a child or teen is diagnosed with a life-threatening illness, the associated physical, emotional, and spiritual challenges can be overwhelming. Hospice & Community Care's Sunflower Pediatric Program offers specialized pediatric care and comfort designed around the unique needs of children and teens with serious illness and

their families. Hospice & Community Care aims to enhance a child's or teen's quality of life through relief of pain and burdensome symptoms.

Services offered through the Sunflower Pediatric Program can start at the time of a serious illness diagnosis and continue alongside disease-directed therapies, providing optimal support and symptom management during active treatment—even when cure is the goal. Care is closely coordinated with the patient's pediatrician or specialist to create a personalized plan of care.

sunflower **Pediatric Program**

A program of Hospice & Community Care



Learn about
the Sunflower
Pediatric Program.

“I was asked ‘why now?’ for hospice care. The answer is hard to put into words. Peace. I want my son to die peacefully. Hospice & Community Care helped me to let go of ‘Nurse Mommy’ and be just Mommy. I am truly thankful. Having a pediatric doctor available for home visits and nurses that understand kids is beyond helpful. They work hand in hand with [other pediatric programs] which is a dream come true because we already have a trust built in the hospital.”

~ Jean, Patient Family Member

Talking About Serious Illness and Death to Family Members



Children are often more resilient and flexible than adults give them credit for. If families do not talk to children about their loved one's life-limiting illness, children will pick up on the emotional intensity of the situation and fill in the gaps with their own imaginations and worry more. Often what they imagine is worse than what is actually going on. When adults are open and honest, they convey to children that they will get through this as a family. Being honest with children allows them to be less fearful and anxious. Caregivers who are not sure how to talk with children about the patient's serious illness, should talk with the Hospice social worker for assistance. We are here to help.



How to support children coping with illness and loss.

Communication is very important. Serious illness impacts everyone.

- Being open and honest with all family members, especially children, is critical.
- Pay attention and be sensitive to times when family members might feel scared or vulnerable.
- Offer support and be open to accepting it from others.
- Remember each person's personality, beliefs, and values are unique.
- Consider what you and your family need to cope as roles and responsibilities change.
- Conflict can arise when family members' opinions differ. Focus on what you share and value.

Our social workers are available to help in these situations.



Common questions about helping children when a loved one is seriously ill.

Signs and Symptoms to Look for and What to Do to Manage Them

Although it is difficult to predict exactly when, there are signs and symptoms that death is near. Not all signs will appear at the same time and some may never appear. However, all of the following are common:

- Increased sleeping and difficulty waking up.
- Unresponsive to people and things around them.
- New or increased confusion.
- Difficulty swallowing.
- Less interest in or not eating or drinking.
- Moaning sounds when breathing out.
- Changes in breathing, sometimes with long pauses followed by several quick, deep breaths.
- Urine output may be less and may turn darker in color.
- Blood pressure may gradually lower and blood flow to the hands and feet will decrease.
- Hands, arms, feet, and legs may feel cool to the touch.
- Body temperature may be irregular—switching from hot to cold.
- Dusky or dark discoloration around nose, mouth, fingers, or toes.
- Skin may appear waxy.
- Eyes may be open or slightly open, glassy or teary. Eyelids may not fully close. Gaze may become fixed.
- Restlessness may increase with pulling at bed linen or clothing, trying to “go” somewhere.
- Temporary increase in alertness, clarity, and energy.
- Speaking to people not present, talking about leaving or talking about a trip or journey.
- Social withdrawal or having little to say.

Tips

- Even if the patient cannot respond, it is possible that they can hear conversations going on around them and things said directly to them.
 - Try not to confuse withdrawal with rejection. The patient may not be able to carry on a conversation but may be comforted by a familiar voice or being read to from their favorite book. Soft, quiet music may be comforting if the patient likes music.
 - Do not startle them by shaking or speaking more loudly than usual.
 - Noisy breathing is not painful or distressing to the patient, but may be difficult for family and friends to hear. Putting the head of the bed the whole way down and turning them hard on one side can help reduce these noises.
 - Unresponsive people can still feel pain. Call our 24-hour phone number to report increased restlessness, grimacing, and/or muscle tension.
-

Grief

Grieving starts the moment a person receives a life-limiting diagnosis. Patients and family members grieve a variety of losses ranging from physical limitations to hopes and wishes for the future. Although it is a natural process, it can feel overwhelming at times. The key to getting through and coping with grief is to mourn.

Mourning is the outward expression of grief. It is how one manages what they do with their grief reactions and how they adapt to the current situation they are coping with. Everyone mourns differently. Some find it helpful to talk with others to process and cope with their grief reactions. Others may be more task oriented and may not feel comfortable talking about their feelings but rather prefer to keep busy to cope.

Throughout the course of care, support is available from Hospice chaplains and social workers. About 6 weeks after death, a counselor from the Pathways Center for Grief & Loss will reach out and continue to provide support for the next 16 months or more.

The Pathways newsletter, resource library, and individual and group support sessions are available to children, teens, and adults at no cost thanks to the generous support of the community.

**For more information, contact the
Pathways Center for Grief & Loss
at 1-(888) 282-2177 or
pathways@hospicecommunity.org**

PATHWAYS CENTER *for* GRIEF & LOSS



Visit our
family
support
video library.

Funeral Planning and Considerations

The Hospice team will ask if funeral arrangements have been made. Having these discussions will help ensure that the patient's wishes are met and help to alleviate making hurried decisions. Many funeral homes will help prepare the paperwork required to claim life insurance benefits.

The Hospice team wants to be sensitive to cultural and faith traditions. We strive to respect funeral practices that are important to the patient and family. Please tell us how we can support those traditions.

Below is information someone might need in preparation to meet with a funeral director:

- ☐ Social security number
- ☐ Date and place of birth
- ☐ Veteran information
- ☐ Father's name
- ☐ Mother's maiden name
- ☐ Names of spouse, siblings, and children
- ☐ Names of other immediate relatives
(maiden names, city, state)
- ☐ Grade level of education completed, graduation, year, and location
- ☐ Accomplishments and life's work
- ☐ Wedding anniversary date
- ☐ Life insurance policies
- ☐ Memberships—social or community organizations
- ☐ Hobbies and interests
- ☐ Name of faith organization and clergy
- ☐ Cemetery information
- ☐ Request for donations, memorials, and/or flowers
- ☐ Preferences for clothing, jewelry, make-up, etc.
- ☐ Which newspapers or social media to notify, including email addresses and phone numbers



Get a funeral pricing checklist.



Learn about shopping for funeral services.

After Death Survey Process

Our patients are very important to us. During the course of care please let us know if something is unclear regarding our services or the care the patient receives or fails to receive. Hospice & Community Care may also contact the patient, their caregiver or family at intervals to assess their satisfaction with the care and services we are providing. Your answers will help us to improve our services and ensure that we meet the needs and expectations of our patients and families.

After the death of the patient, the caregiver will receive a survey from our contracted vendor, HEALTHCAREfirst, who is approved by the Centers for Medicare and Medicaid Services (CMS) to perform mandatory Consumer Assessment of Health Care Providers and Systems (CAHPS) surveys. The survey considers the patient and the primary caregiver as a unit of care. HEALTHCAREfirst will contact the caregiver or family member by mail after death to evaluate the experience of care and services received from Hospice & Community Care.

During the course of care, we will not ask the same questions included in the CAHPS survey. Additionally, we are not permitted to contact the caregiver regarding CAHPS survey answers. Please reach out to us if there are any specific questions that need addressed.



We want to meet your expectations. If things aren't going as expected, call our 24-hour number to speak with a Hospice team member with questions or for guidance.

**1 (877) 506-0149
or 1 (855) 665-2273**

Medication Disposal Guidelines

Hospice & Community Care is committed to the safe disposal of prescription medications that are no longer required for the care of the patient. Our staff will assist you to identify effective disposal methods using the following two guidelines:

1. Drug Take Back Program OR

- This is the first choice in disposal for any medications.
- Find your local community drug take back location at www.ddap.pa.gov or
- Call the DEA Office of Diversion Control Customer Support Center at 1 (800) 882-9539 to find the closest location where you can drop off medications for proper disposal or
- Call municipal government household trash & recycling service for available programs in your community.



2. Disposal in the Home

- Check the drug label or patient information that accompanied the medication. Follow any specific disposal instructions included with the medication.
- Take the medications out of their original container. Use either the following flush or trash method.
- You may flush the following medications down the sink or toilet:
 - Morphine Sulfate (MS Contin®, Kadian®, Concentrated Liquid Morphine)
 - Oxycodone Hydrochloride (Percocet®, Percodan®, OxyContin®, Liquid Oxycodone)
 - Hydrocodone (Lortab®, Vicodin®, Norco®)
 - Fentanyl (Duragesic® patch)
 - Hydromorphone (Dilaudid®)
 - Methadone
- Any medication:
 - Mix with an undesirable substance such as used coffee grounds or kitty litter. (Hospice & Community Care will provide a container if needed.)
 - Put the mixture in a sealable bag or other container to prevent leakage.
 - Scratch out all identifying information on the prescription label and discard in the trash.
- If you have any questions about medication disposal please call us at 1 (877) 506-0149.

Making Your Healthcare Decisions

Patients receiving healthcare have certain rights. One of these rights is the right to accept, reject, or stop medical treatments. There may be times, however, when you might be too ill or too badly injured to tell your physician what you think about medical treatments, for example, whether certain treatments should be stopped or not started.

To help people know what you want in a situation where you cannot speak for yourself, you have the right to prepare an advance directive. This is usually a written statement, signed by you and explaining how you do or do not wish certain medical procedures or treatments be provided. An advance directive is also a document in which you can name someone you trust to make these decisions for you.

Hospice & Community Care does not base care or in any way discriminate against anyone according to whether or not an advance directive is written. Whether or not you prepare an advance directive is your choice. If you do have an advance directive, we encourage you to provide a copy to Hospice. If you provide a copy, it will be placed in your medical record so that Hospice staff can know and honor your wishes for care to the extent Pennsylvania law will allow.

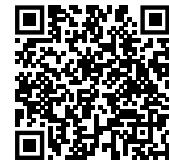
We encourage you to write an advance directive giving instructions about your decisions for medical treatments. If you are interested in completing an advance directive, your Hospice social worker can assist you in finding the document that is right for you. If you choose to write an advance directive, we encourage you to talk with your family, your physicians, your attorney, and anyone else whose advice and support in these decisions is important to you. A copy should be maintained in your home. If you have any

questions about the information, please call us.

Some people may also decide that they do

not want emergency personnel to attempt cardiopulmonary resuscitation (CPR) if their heart stops beating or they stop breathing. This is a decision allowed to some patients under Pennsylvania law. The law allows a terminally ill person (or their surrogate) to obtain an out of hospital do not resuscitate (DNR) order that directs emergency medical services (EMS) personnel not to provide CPR in the event that 911 is called. A physician issues an out of hospital DNR order. If this is a decision that you are thinking about, talk with the Hospice social worker or with your physician for more information.

Some people may have a POLST (Pennsylvania Orders Life-Sustaining Treatment). This is a medical order that allows a person to specify the types of medical treatments they wish to receive toward the end of life. The form must be signed by the person initiating it or their designated healthcare decision maker and also signed by a physician, NP, or certified physician's assistant. The goal of POLST is to effectively communicate the wishes of the seriously ill across all care settings. You have the right to complete a new POLST at any time.



Find advance care planning resources.

You can get additional info at <http://www.caringinfo.org>



To reach your Hospice team call 1 (877) 506-0149

For more information on volunteering or donating, call 1 (800) 924-7610 or info@hospicecommunity.org.

Volunteer

Volunteers make important contributions to the lives of our patients and their families every day. We provide all volunteers with the necessary training to prepare them for their volunteering journey. Depending on a person's skills and strengths, there are multiple opportunities to volunteer. Patient and family support options include Home Hospice (in patient homes), Senior Living Facility Visitors, Bereavement, and Hospice Inpatient Center volunteers. Other support options that are not with patients include office and foyer volunteers,



Learn more about volunteering.

as well as special projects, such as fundraising and community relations.

Join Our Special Events

Hospice & Community Care holds fundraising events throughout the year which raise funds to support care for our patients and families.

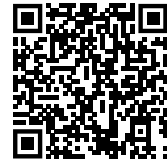


See a list of our special events.

Donate

Those who are touched by Hospice & Community Care through the care and support that they receive often ask about ways to honor their loved ones and to give back to those in need.

All gifts that Hospice & Community Care receives are used to provide medical, emotional and spiritual support for patients and families in our care. Donations from the community also provide for bereavement support for any adult, teen or child through the Pathways Center for Grief & Loss whether or not their loved one received Hospice services.



Here are ways to give back.

Follow Us on Social Media



Facebook

www.facebook.com/HospiceandCommunityCare



Instagram

www.instagram.com/hospicecomcare



LinkedIn

www.linkedin.com/company/hospice&communitycare



Twitter

twitter.com/HospiceComCare



ADLs – Activities of Daily Living

BK – Bowel Kit (pronounced BIC)

CHC – Continuous Home Care

CLM – Concentrated Liquid Morphine

CP – Chaplain

DME – Durable Medical Equipment

DNR – Do Not Resuscitate

Dx – Diagnosis

GIP – General Inpatient (including acute care)

HA – Hospice Aide

HIM – Health Information Management

HMB – Hospice Medicare Benefit

ICA – Initial Comprehensive Assessment

IPC – Inpatient Center

IDT – Interdisciplinary Team

LOC – Level of Care

LPN – Licensed Practical Nurse

OOH DNR – Out of Hospital Do Not Resuscitate

O₂ – Oxygen

PRN – As Needed (pro re nata)

POLST – Pennsylvania Orders for Life Sustaining Treatment

RHC – Routine Home Care

RN – Registered Nurse

SMK – Symptom Management Kit

SMO – Symptom Management Orders

SW – Social Worker



The Essa Flory Center
685 Good Drive, P.O. Box 4125
Lancaster, PA 17604-4125
(717) 295-3900

The E. E. Manny Murry Center
4075 Old Harrisburg Pike, Mount Joy, PA 17552

The Bob Fryer & Family Inpatient Center	Pathways Center for Grief & Loss
(717) 735-9661	(717) 391-2413

The Ann B. Barshinger Hospice Center
235 Saint Charles Way, Suite 250
York, PA 17402
(717) 793-2113