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Compassionate Care

*Committed to Quality of Life*

# Family Guide to Hospice Care at Home

# Home Safety Tips

Please review this page of home safety tips. It is always a good idea to consistently evaluate your home for safety. Upon admission, your Hospice nurse will do a safety assessment of your home with you and/or your family.

## Stairs

- Make sure there is adequate lighting
- The surface of the steps should be “slip-proof”
- Be sure handrails are sturdy and easy to grasp

## Bedroom

- Arrange all electrical cords to prevent tripping
- Try to limit use of multiple extension cords
- Make sure rugs are slip-resistant
- Put a light within reach of the person in bed
- Establish an evacuation plan with designated “fire exits” and do not block passageways with clutter
- Use all electrical equipment (blankets, pads, etc.) only as directed

## Kitchen

- Make sure towels, curtains, and flammable liquids are kept away from stove or any other open flame
- There should be at least one smoke detector on each level of the home. Batteries should be checked regularly
- Keep all electrical cords and appliances away from sink
- Clean up spills immediately to prevent slips and falls

## Living Areas

- All rugs and carpet should be slip-proof
- Keep passageways free from clutter
- Know your evacuation routes in event of a fire
- There should be easy access to a telephone with emergency numbers available

## Bathroom

- Use brushes and sponges with long handles to decrease bending and stooping in the shower
- A “grab bar” near the tub and/or toilet is a good idea
- Be sure hot water temperature is below 120°F
- Leave a “night light” on to prevent falls
- Check tub and floor mats for non-skid treads
- Use a shower bench/chair to rest if you tire or become short of breath

## Electrical Safety

- Remove cords from beneath furniture, rugs and carpeting
- Replace frayed cords
- Do not overload extension cords; check rating label on cord and appliance
- Do not use multiple outlet adapters on electrical outlets
- Use the appropriate size light bulb for lamp or fixture; do not exceed recommendation
- Know where your circuit breaker box is located and how to use it in an emergency

## Medication Safety

- Store all medications in properly labeled containers, away from children, and away from extreme temperature
- Limit access to medicines to the person who is “most knowledgeable” and has been taught by your hospice nurse
- If memory is an issue, using medication boxes labeled with day/time can be helpful
- Report any/all uncomfortable side-effects from medicines to the Hospice staff
- Never share, sell or loan medications
- Allow access for hospice nurse to monitor and track medications (Policy 2029.2)

## Fire Safety

- Heat your home safely: do not use gas stove burners or ovens
- Keep portable heaters at least 3 feet away from people and objects.
- Never dry clothes on heaters!
- Avoid smoking. It's best not to smoke, but if you do: Never light up when you're drowsy or when oxygen is being used
- Use large, deep ashtrays and never leave smoking materials unattended.
- Never throw out smoking materials that are still hot or burning.

### Follow general fire safety tips:

- Have smoke detectors on every level of your home: make sure one is located in the kitchen and where the fireplace and water heaters are located.
- Test smoke detectors once a month and change the batteries twice a year as the time zones change.
- Keep a whistle and flashlight at bedside to summon for help
- Plan at least 2 ways out of the home from each room.

***Emergency Preparedness makes good sense: take the time to make an evacuation plan that everyone in the home knows and follows. Practice evacuating!***

## Pain Management

The main goal of Hospice care is to provide for your comfort. We want to work with you and your caregivers to keep you as free of pain as possible.

Different people experience pain very differently. Some people feel it is a sign of weakness to have pain, and have learned to deny how badly they feel. Some feel that increased pain is a sign of worsening disease, and do not want to admit the pain being felt. It is very important that you be as forthright with us as possible in reporting your pain so we can provide the best possible help.

Your Hospice nurse will introduce you to “pain scales.” These scales help us identify pain and other symptoms that cause you discomfort. Some scales are the 0–10 and the faces. When talking with your Hospice nurse or doctor, be sure to tell them where the pain is located and how it feels (burning, stabbing, throbbing, intensity). Also describe how long the pain lasts and what helps to make it better. Your Hospice nurse and doctor will work with you to find the right combination of medications to help relieve your pain (and other symptoms). It is not always possible to completely eliminate pain, but in most cases the pain can be lessened and you will feel more comfortable. You will decide what you want your pain to be and we will work with the team to help you reach your goal.

### **A word about pain medicines:**

Many Hospice patients require strong pain medicines in the morphine family to get good pain relief. Some people fear that they will become addicted to the pain medication, so they try not to take the medicine, or they try to take less than is prescribed. It is important to take the medicine as your Hospice doctor has prescribed, and as your Hospice nurse has instructed you.

Addiction is **not a problem** with Hospice patients taking strong pain medications as prescribed: If the pain goes away, the medication can be easily tapered off. You also do not have to worry about becoming immune or tolerant to the strong medications. Medication doses can be increased whenever necessary: In Hospice, pain is what the patient says it is: What you describe is what helps us to treat it: For patients who cannot communicate their pain, we use other assessment findings to help.

## **Taking Medicines By Mouth**

1. **Use liquids:** Take pills with enough liquid. Unless otherwise instructed, it is OK to take pills with water, milk, juice, or soda. Be sure to get enough liquid to swallow the pills completely. Taking a few sips of liquid to moisten the mouth before putting pills in can help prevent the pills from sticking.
2. **To swallow tablets:** *Most* tablets that are too big to be swallowed easily can be crushed and mixed into a small amount of juice, pudding, ice cream or applesauce.

***Be sure to ask your Hospice nurse before crushing any tablets! Slow-release tablets must not be crushed (e.g., medicines with a SR, LA, SA, CR, etc. after their name)***

3. **To take capsules:** Some people have trouble swallowing capsules. *Some* capsules can be opened, and the powder inside mixed with a small amount of juice, pudding, ice cream or applesauce:  
***Be sure to ask your Hospice nurse before opening any capsules!***
4. **Learn the names** of your medicines and the reasons for taking them: Your Hospice nurse or doctor will answer any questions you may have about your medications.
5. **Take your medicines ONLY** at the times and in the amounts prescribed. Your Hospice nurse will give you a written schedule to help you know when and how to take your medicines. Be sure to mark the schedule sheet when you take the medications:
6. **Stop taking your medicines ONLY** on the advice of your Hospice nurse or doctor. Talk with your Hospice nurse or doctor if you think you are getting too much medication.
7. **Keep each medicine** in its own labeled container.
8. **Keep all medicines** in a safe place, **OUT OF THE REACH OF CHILDREN.**
9. **Do not allow anyone else** to take any of your medications. Each medication has been especially prescribed for you. They may be harmful to someone else.
10. **Review all changes in medications** with your nurse each visit. Your Hospice nurse will keep an updated medication sheet in your home.

## **Notify your Hospice nurse immediately if:**

- You are unable to take your medicine as ordered.
- You do not choose to take the medicine as ordered.
- You have any side effects from the medicine you are taking.
- You are not sure whether a new medication is the right one.
- You have any questions about what medicines you should be taking.

*Only medications listed as related to the terminal illness are covered by the hospice benefit. Medications that are not covered may be called to your local pharmacy. Our hospice nurse will obtain orders and call the medication to your pharmacy of choice. If you have any questions, please contact your primary nurse.*

## **Management and Disposal of Controlled Drugs in the Home (Policy No. 2029.2)**

### **Procedure:**

1. Upon admission and/or the time controlled drugs are ordered the clinician will provide a copy of the policy regarding management of disposal of controlled substances.
2. The nurse will provide instruction to the patient/family/caregiver regarding the medication regimen. This instruction will include:
  - (a) Correct administration – frequency, route and dosage;
  - (b) How the medication relates to disease process; and
  - (c) Side effects, contraindications and adverse reactions.
3. The nurse coordinates with the patient/family/caregiver for the safe storage of drugs.
  - (a) Medications should be stored in a separate container or protected location.
  - (b) Medications are to be kept out of reach of children, pets and confused or disoriented patients.
  - (c) Drugs requiring refrigeration are to be stored inside refrigerator in a well-marked and specified location.
4. The nurse will assess the ability of the patient/caregiver to administer medications and biologicals.
5. Each patient will receive handouts for specific medications he/she is receiving, which includes information on:
  - (a) Actions of medication;
  - (b) Potential side effects;
  - (c) Contraindications the patient should be aware of; and
  - (d) Any special instructions needed.
6. Controlled substances are distributed directly to the patient or representative. The dispensing pharmacist is responsible for monitoring the amount of drug issued and the length of time between renewals. The nurse is responsible to monitor medications in the home.
7. When a patient no longer has a need for a controlled substance, it is the responsibility of the nurse to dispose of the remainder of the prescription and document the clinical record.
8. If the nurse's attempt to make a home visit to dispose of controlled substances is unsuccessful, the patient/family/caregiver will be instructed to dispose of them. The primary nurse/case manager will document in the clinical record that the patient/family/ caregiver was instructed to dispose of the medications.

9. The nurse attending the death of a patient will dispose of any remaining controlled drugs. The nurse will document the disposal of the medications, identifying the drug and strength, the quantity and the method of disposal on the pronouncement of death note, and will be witnessed by a family member or designee.
10. If the family/caregiver refuses to allow the nurse to dispose of the prescribed medications, that information will be documented on the pronouncement of death note. The family/caregiver will then assume responsibility for those drugs.
11. To dispose of drugs, federal prescription drug disposal guidelines urge Americans to:
  - (a) Take unused, unneeded or expired prescription drugs out of their original containers.
  - (b) Mix the prescription drugs with an undesirable substance, like used coffee grounds or kitty litter, and put them in impermeable, non-descript containers, such as empty cans or sealable bags further ensuring that the drugs are not diverted or accidentally ingested by children or pets.
  - (c) Throw these containers in the trash.
  - (d) Flush prescription drugs down the toilet only if the accompanying patient information specifically instructs it is safe to do so.
  - (e) Return unused, unneeded or expired prescription drugs to pharmaceutical take back locations (if available) that allow the public to bring unused drugs to a safe location for safe disposal.

## Using Oxygen at Home

Oxygen can help the patient breathe more comfortably. Oxygen is ordered by the doctor. It is important to use oxygen in the home safely. The home oxygen system should be checked every day. Oxygen is a medication and can be dangerous if not used correctly.

### Supplies you will need:

1. Oxygen system
  - a. E tank – green oxygen metal cylinder with a valve knob used to turn it off and on
  - b. Concentrator – electrical, plug-in unit
2. Tubing – can be 7 to 25 ft. long
3. Water bottle and distilled water
4. Nasal cannula or face mask

### Safety Measures:

1. For your safety:
  - a. The medical equipment supplier will show you how the equipment works at the time it is delivered to your home.
  - b. Keep the oxygen equipment in a safe place, away from an area where you or the patient frequently walk. Be sure also that the oxygen system is at least 5 feet away from any heat source.
  - c. Do not smoke, light any matches or candles, or use any form of open flame in the room where oxygen is in use.
  - d. Avoid using flammable substances (body oils, alcohol, petroleum jelly, aerosol sprays or face creams) on or near the patient when oxygen is in use.
  - e. Use a grounded, three-prong plug for any appliances or equipment being used near the patient.
  - f. Do not use an electric blanket or heating pad on the patient.
  - g. Store all extra full tanks in a well-ventilated room and sitting upright. Secure them so tipping or falling will not damage or dislodge the valve stems.

2. For best results:
  - a. Check the oxygen liter flow. It should be kept at the setting told to you by your Hospice nurse. Check every morning and before bedtime.
  - b. Check the tubing for any kinks, obstructions (such as furniture on it or the patient lying on it), and/or loose connections.
  - c. Empty and replace the distilled water in the bottle **every** day.
  - d. Once every week clean the water baffle using a diluted solution of bleach in water, follow with warm soap and water, and rinse **very well**. Refill the cleaned bottle with distilled water.
  - e. Replace the oxygen tubing at least once a month.
  - f. Change the nasal canula or mask every two weeks.

Your nurse has access to these items and can assist you in changing them

*Notify your Hospice nurse if there is a problem with the oxygen system.*

## Infection Control in the Home

Cleanliness and good hygiene can help prevent infection. Proper disposal of medical supplies can prevent injury and the spread of infection. Certain illnesses and treatments can make a person more susceptible to infection.

It is important to report signs of an infection promptly to your physician or homecare nurse.

Signs may include:

- fever/chills
- sore throat
- cough
- painful urination
- pain/tenderness or swelling
- inflamed skin/rash/sores
- nausea/vomiting/diarrhea

You can help control infection by following these guidelines:

### Handwashing

Handwashing is the single most important step in controlling the spread of infection. Wash your hands before and after care to the patient, before eating or handling foods and after toileting. Hand washing should be done frequently and correctly:

- **Soap and water:** Use soap and water on hands that are visibly soiled. Remove jewelry, use warm running water and preferably liquid soap. Place hands under water and wash for at least 20 seconds paying attention to all areas. Rinse soap off dry with a clean towel or paper towel.
- **Waterless hand cleanser:** If hands are not visibly soiled an alcohol based hand rub is appropriate for use. To use place a dime sized amount in the palm of your hand and rub hands together covering all surfaces of hands and fingers.

### Disposable items and equipment

Disposable items such as diapers, wipes etc should be stored in a dry place and disposed of in plastic bags that are securely tied and placed in the trash.

## Non-Disposable items and Equipment

- **Soiled laundry:** Wash apart from other household laundry in hot water. Bleach may be used if viral contamination is present, 1 part bleach to 10 parts water is recommended.
- **Equipment:** Such as walkers, bath seats and wheelchairs may be cleaned with hot soapy water or using products recommended by your equipment supplier.
- **Thermometers** should be cleaned with alcohol before and after each use.

## Preparing for the Final Stage of Life

When a person enters the final stage of life, two different dynamics are at work. These dynamics are closely interrelated and interdependent. On the physical plane, the body begins the final process of shutting down, which will end when all the systems cease to function. Usually, this is an orderly and undramatic, progressive series of physical changes which are not medical emergencies requiring invasive interventions. These physical changes are a normal, natural way in which the body prepares itself to stop, and the most appropriate kinds of responses are comfort-enhancing measures.

The other dynamic of the dying process at work is on the emotional/spiritual/mental plane, and it is a different kind of process. The “spirit” of the dying person begins the final process of release from the body, its immediate environment, and all attachments. This release also tends to follow its own priorities, which may include the resolution of whatever is unfinished of a practical nature and reception of a permission to “let go” from family members. These events are the normal, natural way in which the “spirit” prepares to move from this existence into the next dimension of existence. The most appropriate kinds of responses to the emotional/spiritual/mental changes are those which support and encourage this release and transition.

When a person’s body is ready and wants to stop its functions, but the person is still unresolved or unreconciled over some important issue or significant relationship, he/she may be uncomfortable or debilitated. On the other hand, when a person is emotionally/spiritually/mentally resolved and ready for this release, but his/her body has not completed its final preparation, the person will continue to live until that shut-down process ceases.

**The experience we call death occurs when the body completes its natural process of shutting down, and the spirit completes its process of reconciling and finishing. These two processes need to happen in a way that is appropriate and unique to the values, beliefs, and lifestyle of the dying person.**

Therefore, as you seek to prepare yourself as the end of life event approaches, the members of your Hospice team want you to know what to expect and how to respond in ways that will help your loved one accomplish this transition with support, understanding, and ease. This is the great gift of love you have to offer your loved one as this moment approaches.

The physical and emotional/spiritual/mental signs and symptoms of impending death which follow are offered to help you understand the natural kinds of changes/events which you may observe and how you can respond appropriately. Not all of these signs and symptoms will occur with every person, nor will they occur in any particular sequence. Each person is unique and needs to do things in his/her own way. This is not the time to try to change your loved one. It is the time to give full acceptance, support, and comfort.

The following list of physical signs and symptoms is intended to assist you in understanding how the body prepares itself for the final stage of life:

## **Decreased Urine Output**

The person's urine output usually decreases during the end stage of life. It may also change color, becoming the color of tea. This is referred to as "concentrated urine." This is due to the decreased fluid intake as well as decreases in metabolism and circulation through the kidneys. Consult with your Hospice nurse to determine whether there may be a need to insert or irrigate an indwelling catheter.

## **Decreased Nutrition (Food and Fluid) Intake**

Your loved one may demonstrate a decrease in appetite and thirst, wanting little or no food and drink. This occurs because the body naturally begins to conserve the energy which is usually expended on these tasks. Do not try to force food or drink. To force the person or attempt to manipulate him/her to accept unwanted food/drink only makes him/her even more uncomfortable. Small chips of ice, frozen juices, or ice popsicles may be refreshing to the mouth. If the person is able to swallow, fluids may be given in small amounts by syringe (ask your Hospice case manager for guidance). Glycerine swabs may also help keep the mouth and lips moist and comfortable. A cool, moist washcloth on the forehead may also help to enhance physical comfort for your loved one.

## **Changes in Breathing**

Your loved one's regular breathing pattern may change with the onset of a different breathing pace and/or rhythm. It is not uncommon to witness irregular patterns with shallow breaths leading to periods of no breathing which may last for up to a minute or so. This is called "Cheyne-Stokes" breathing. The person may also demonstrate periods of rapid, shallow breathing similar to a "pant-like" respiration. These patterns are very common and generally indicate a decrease in circulation to the internal organs. Elevating the head and/or turning the person to one side or the other may help to bring comfort. Certain medications may be utilized under direction from your Hospice case manager. You may also sit with your loved one while holding his/her hand speaking in a calm, gentle tone.

The following list of emotional, spiritual and mental signs and symptoms with appropriate responses is intended to assist you in providing care to your loved one during the final stage of life:

## **Withdrawal**

The person may seem unresponsive, withdrawn, or in a coma-like state. This usually indicates the person is in preparation for release, becoming detached from surroundings and relationships, and beginning to "let go." Because the sense of hearing remains to the end, speak to your loved one in your normal tone of voice, identify yourself by name, hold his/her hand, and offer verbal reassurance in a manner that will help your loved one let go.

## **Seeing Visions**

Your loved one may see and speak (or claim to have spoken to) persons who have already died. He/she may also indicate having seen places not visible or accessible to you. This does not necessarily indicate the occurrence of a hallucination or a drug reaction. Instead, your loved one is beginning to detach from this life and is preparing for the transition at the end of life so it will not be frightening. Do not contradict, try to explain, demean, or argue about what the person claims to have seen or heard. Just because we cannot see or hear the same experience does not mean it is not real to your loved one. Simply affirm his/her experience. These experiences are common to all persons at the end of life. Reassure your loved one if the experience seems to frighten him/her.

## Coolness

The person's face, hands, arms, feet, and then legs may become increasingly cool to the touch. At the same time, skin color may change. This is a "normal" indication that the circulation of blood is decreasing to the body's extremities and being reserved for the more vital organs. You may keep the person warm with a blanket (non-electric) and/or warm clothing.

## Sleeping

The person may spend an increased amount of time sleeping and appear to be unresponsive, even difficult to arouse. This change in behavior is due, in part, to changes in the body's metabolism. Sit with your loved one, hold his/her hand, but do not shake it or speak loudly. Talk to him/her in a normal, soft tone. Be natural in your conversation. Do not talk about him/her in his/her presence. Never assume he/she cannot hear you. It is believed hearing is the last sense to be lost. Spend time with your loved one when he/she seems most alert and awake.

## Disorientation

Your loved one may seem to be confused at times about the time, their surroundings and/or the identity of the people around him/her including those who are very close and familiar. This is also due to changes in the body's metabolism. Identify yourself by name before you speak rather than ask the person to guess who you are. Speak softly, clearly, and truthfully when you need to communicate something important to the person's comfort such as letting him/her know when it's time to take medication. You should explain the reason for the communication and offer reassurance without trying to manipulate the patient to meet your own needs.

## Incontinence

Your loved one may lose control of bowel and/or bladder as the muscles in those areas begin to relax. You may discuss this with your Hospice nurse in order to determine what can be done to protect the bed and keep your loved one clean and comfortable.

## Congestion

The person may have gurgling sounds coming from his/her chest as though marbles were rolling around inside. These sounds may become very loud. This change is due to the decrease of fluid intake and the increasing inability of the patient to cough up normal secretions. Mechanical suctioning of the person usually only increases the secretions and causes sharp discomfort. Instead, gently turn the person's head to the side and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. The sound of the congestion does not indicate the onset of severe or new pain.

## Restlessness

The person may appear restless and make repetitive motions as pulling a bed linen or clothing. This often happens in response to the decrease in oxygen circulation to the brain and to metabolic changes. Do not interfere with or try to restrain such movements. Simply reassure your loved one using calm, quiet, natural tones in your speech, lightly stroking the forehead, reading from a favorite book, or playing soothing music in the background.

## **Restlessness**

Just as with physical causes, restlessness can also be a symptom of unresolved or unfinished issues which may disturb your loved one. Your Hospice team members can assist you in identifying what may be happening and help you to find ways to care for your loved one allowing him/her to find release from the tension or fear. Other things which may be helpful in calming your loved one are to recall a favorite place or experience, read something comforting, play music, and give assurance that it is all right to let go.

## **Decreased Nutrition**

When the person wants little or no food and drink, this may indicate a “readiness” for the final shut-down. Do not try to force food and/or drink. You can best help your loved one by giving permission to let go whenever he/she is ready. At the same time, you should affirm your loved one’s ongoing value to you and the good that you received from him/her that you will carry forward with you in your life.

## **Decreased Socialization**

Your loved one may only want to be with a very few or even just one person at a time. This is another sign of preparation for release. If you are not part of the “inner circle” of support at the end of life, it does not mean you are not loved or are unimportant. It simply means you have already fulfilled your role with your loved one and it is time for you to say farewell. If you are part of the final inner circle of support, the person needs your affirmation, support and permission to let go.

## **Unusual Communication**

Your loved one may make a seemingly “out-of-character” or non-sequitur statement, gesture, or request. This usually indicates that he/she is ready to say farewell and is testing you to see if you are ready to let him/her go. Accept the moment as a beautiful “gift” when it is offered. Kiss, hug, hold, cry, laugh, and say whatever it is you most need to say.

## **Giving Permission**

Giving permission to your loved one to “let go,” without imparting guilt for leaving or trying to keep him/her with you to meet your own needs, can be difficult. A dying person will normally try to “hold on,” even though it brings prolonged discomfort, in order to be sure those who are left behind will be “OK.” Your ability to release your loved one from this concern while giving assurance that you and other loved ones will be all right and giving permission to let go is one of the greatest gifts you have to give your loved one at this time.

## **Saying Goodbye**

When your loved one is ready to die and you are able to let go, then it is time to say “Goodbye.” This is your final gift of love, for it achieves closure and makes final release possible. It may be helpful to lay in the bed and hold your loved one, or to take your loved one’s hand and say everything you need to say. It may be as simple as saying “I love you.” It may include recounting favorite memories, places, and activities you shared. It may be saying “I’m sorry” for whatever you feel contributed to any tension or difficulties in your relationship with this person. It may also include saying “Thank you” for all those

things you and your loved one shared and consider important to your relationship. Finally, tears are a normal and natural response as a part of saying “Good-bye.” Tears need not be hidden nor apologized for ... tears outwardly express your inner love ... and help you to let go.

### **How Will You Know when Death Has Occurred?**

Although you may be prepared for the end of life process, you may not be prepared for the actual moment of death. It may be helpful for you and your family to think about and discuss what you would do if you were the one present at the moment of death. At first you may feel as though something should be done immediately, but the death of a Hospice patient is not a “medical emergency.” Nothing must be done immediately. You should, however, notify the Hospice team as soon as possible ... at anytime ... 24 hours per day, seven days per week. A Hospice Case Manager is always available to assist you.

The signs of death include such things as no response to touch or voice, no breathing, no heartbeat, release of bowel and bladder contents, eyelids slightly open with eyes fixed on a certain spot, no blinking, pupils unresponsive, jaw relaxed and slightly open.

Your loved one’s body does not have to be moved until you are ready. When you feel the time is right, you may call the funeral home to make arrangements for removal of the body. You should be sure to let the Funeral Director know your loved one is a Hospice patient. The Hospice Case Manager can assist you with this if you need help. You do not need to notify the police. The Hospice Case Manager will contact any authority requiring notification. In addition, the Case Manager will notify the patient’s physician.

### **With Our Appreciation**

The Hospice team thanks you for the privilege of assisting you with the care of your loved one during this important time. We commend you for all you have done to provide your loved one with understanding care, comfort and calm to enable him/her to leave this world with a special sense of peace and love. You have given your loved one the most wonderful and sensitive gifts we, as humans, have to offer.

# Compassionate Care Hospice

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