Hospice Caregiving Book
FOR URGENT QUESTIONS, CALL THE GILCHRIST NURSE HELPLINE
443.849.8200

YOUR GILCHRIST TEAM

Physician: ____________________________

Nurse: ________________________________

Social Worker: _________________________

Chaplain: _____________________________

Hospice Aide: _________________________

Team Manager: _________________________

Grief Counselor: _______________________

Volunteer: _____________________________

LOCATIONS

Corporate Office
11311 McCormick Road, Suite 350
Hunt Valley, MD 21031
443.849.8200

Howard County Office
5537 Twin Knolls Road, Suite 434
Columbia, MD 21045
410.730.5072

OFFICE LOCATIONS

Gilchrist Center Towson
555 W. Towsontown Boulevard
Towson, MD 21204
443.849.4700

Gilchrist Center Howard County
6336 Cedar Lane
Columbia, MD 21044
443.283.2700

Gilchrist Center Baltimore
828 North Eutaw Street
Baltimore, MD 21201
667.217.3300

INPATIENT CENTERS

OUR MISSION

To provide counseling, support and care to anyone with a serious illness, so they may live life to the fullest.

OUR VISION

We are deeply committed to giving people the clear information and loving support they need to make informed choices about their care.
INTRODUCTION

When facing a life-limiting illness, it is only natural to have questions about care, medications, safety and practical concerns. This Hospice Caregiving Book provides information to help answer these questions. Our team will review this book with you and help you use it as a guide to your care.

Our goal is to help you maintain control of your life and to live as fully and comfortably as possible, without pain. We will also help address your physical, emotional, social, financial and spiritual concerns, while addressing your loved ones’ needs as they care for you.
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YOUR HOSPICE CARE TEAM

PHYSICIAN
The physician of your choice may continue to provide care in collaboration with the hospice team, or you may choose to designate a hospice medical director or nurse practitioner as your primary clinician.

REGISTERED NURSE
The nurse provides hands-on care and education and offers options to best manage pain and other symptoms of illness. As “case manager,” the registered nurse (RN) also coordinates other needed services.

LICENSED PRACTICAL NURSE (LPN)
The LPN is a skilled member of the hospice team who works closely with the RN/case manager and visits patients whose condition is more stable.

SOCIAL WORKER
The social worker helps you and your family cope emotionally and communicate openly. Your social worker will also assist with accessing community resources, preparing Advance Directives and making alternative living arrangements.

CHAPLAIN
The chaplain will listen and help you reflect on what is most meaningful in life, while supporting your faith and beliefs. Along with your own clergy, the chaplain will provide support to help you and your loved ones find spiritual comfort.

HOSPICE AIDE
The hospice aide assists you with personal care, such as bathing, shaving, dressing and changing linens. The aide will provide companionship, while helping you maintain dignity and independence.

VOLUNTEERS
Volunteers serve as companions to you and your loved ones. They can relieve your loved ones of the constant demands of caregiving through a variety of support activities, such as sitting with you while your caregiver takes a break, listening and sharing things you enjoy most.

GRIEF COUNSELORS
Grief counselors, who are master’s prepared and licensed, are available to support you and your loved ones. They collaborate with your social worker and chaplain to meet your emotional needs. Grief counselors also offer a variety of grief support groups and events for those who have experienced loss.

In addition to the team members above, your Gilchrist Hospice Care team may include physical, occupational, speech and music therapists, as needed.
For questions or concerns related to your care, contact the Gilchrist Nurse Helpline at 443.849.8200.

COMPLEMENTARY HOSPICE CARE OFFERINGS

MUSIC THERAPY
Music therapy can help improve quality of life by reducing stress, anxiety and agitation while also giving individuals a way to express themselves, even if they can no longer communicate. Our board-certified music therapists use everything from listening to performing to writing and recording music in an effort to meet the social, emotional, spiritual and cognitive needs of the individual and family.

WE HONOR VETERANS
We Honor Veterans is a program designed to meet the unique needs of veterans and thank them for their sacrifice and service to our country. Gilchrist partners with the National Hospice and Palliative Care Organization and our local VA office to provide veteran to veteran outreach, pinning ceremonies and other initiatives to ensure that the contributions and needs of veterans are recognized and respected.

JEWSH HOSPICE
Gilchrist’s Jewish Hospice includes all of the components of hospice care, plus enhancements to ensure that our care is compatible with our Jewish families’ religious and cultural beliefs. The program is accredited by the National Institute for Jewish Hospice, and each team member has specialized training in Jewish customs and practices, as well as health care decision-making issues that may arise due to concerns with following Jewish law. A rabbi is available to families, if requested.
UNDERSTANDING YOUR CARE OPTIONS

ADVANCE DIRECTIVES

Advance Directives are legal documents stating the medical procedures you do and do not want in the event you are unable to communicate these wishes yourself. It is important that your wishes are clear should you not be able to make them known.

Advance Directives may include:

- A Living Will, which specifies the types of end-of-life care you desire if you are unable to verbalize those wishes at a later time.
- The Health Care Agent Designation, which gives another person the authority to make medical decisions for you if you are unable to do so.

MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT (MOLST)

A MOLST form states whether you want CPR (cardiopulmonary resuscitation) attempted, or the Limited Care or Comfort Care options. These options are detailed on the following page.

RESOURCES

ADVANCE DIRECTIVES

- Aging with Dignity: Five Wishes
  A form to help you document your wishes for end-of-life treatment
  www.agingwithdignity.org/five-wishes/individuals-and-families

- Maryland Advance Directive: Planning for Future Health Care Decisions
  A guide to Maryland law on health care decisions
  www.marylandattorneygeneral.gov/Health%20Policy%20Documents/adirective.pdf

- Maryland Advance Directive Planning for Important Health Care Decisions
  An additional resource for completing advance directives
  www.caringinfo.org/files/public/ad/Maryland.pdf

MOLST FORMS

- Maryland MOLST Form
  Printable Maryland MOLST forms and worksheets
  marylandmolst.org/pages/molst_form.htm

Need to Complete Advance Directives?

Tell your Gilchrist social worker. They will help you to complete the forms and answer questions.
UNDERSTANDING YOUR CARE OPTIONS

MOLST OPTIONS

Life-Prolonging Care: (Attempt CPR)

CPR tries to get your heart to beat again if it stops. This means pressing on your chest and using an electric shock to attempt to restart your heart. Most of the time in patients with an advanced disease, CPR does not work.

If you want CPR attempted, you will also agree to have a ventilator or breathing machine to keep breathing, if necessary. This involves putting a tube down your throat into your lungs and connecting you to a machine that pushes air into your lungs. You cannot eat or talk while on this machine. If you are on a ventilator, you will likely need very strong medicines. These are usually given in the intensive care unit (ICU). CPR will not cure your disease and in most patients with an advanced disease, CPR does not return you to your previous state of health. With the Life-Prolonging approach, you choose to have these procedures in exchange for the possibility of a longer life.

Limited Care: (intubate, Option A-1 or DNI/BiPAP, Option A-2)

With this approach, prolonging life is still important, but not if it means having CPR or being placed on a breathing machine. If you choose Limited Care, you may choose to have a breathing tube inserted (intubation) or a pressure mask (BiPAP) if needed, and agree to medicines for treatable problems that may arise such as fluid in the lungs or a urinary infection. This approach lets you have different medical treatments including hospital care, antibiotics, other medicines and fluids through a vein. You choose to avoid CPR and to allow death to occur naturally.

Comfort Care: (No CPR, Option B)

The main goal of this approach is not to prolong life; it is to maximize comfort, relieve symptoms and allow death to occur naturally. Treatments are only used if they help control uncomfortable symptoms such as pain, trouble breathing, or feeling sick to your stomach. It does not include CPR or breathing machines, nor does it normally include hospitalization—unless it is needed to provide comfort. If you choose Comfort Care, you will be treated at home, an inpatient hospice, a nursing home or other facility until death occurs naturally.

Already Have Advance Directives?

First, review them to make sure all wishes for nutrition, hydration, resuscitation and transportation have not changed. Second, have two copies of all written documents available. One will be reviewed by your Gilchrist team and the other will be added to your medical record.

For questions or concerns related to your care, contact the Gilchrist Nurse Helpline at 443.849.8200.
MANAGING YOUR SYMPTOMS

Symptoms may arise as your disease progresses or as a result of certain medications. Some of the more common symptoms are listed below, along with training on how you can manage them. Changes in your condition can occur at any time. We are here to support you whenever needed, day or night.

SHORTNESS OF BREATH
Breathing difficulties can cause anxiety and discomfort.

To reduce discomfort:

• Open a window or turn on a fan to promote air circulation.
• Raise the head of the bed or prop your head up on pillows.
• Use slow, calming breaths. Practicing meditation may help.
• Medical air or oxygen may be ordered to increase comfort, when appropriate.
• If medication has been ordered, make sure it is taken as directed.
• Pace activity to conserve energy.

CONSTIPATION
Constipation may cause pain and discomfort, and may be due to lack of activity, reduced food and fluid intake, general weakness or pain medications.

To prevent constipation:

• Take laxatives and stool softeners as prescribed by your physician.
• If possible, increase daily intake of fluids and high fiber foods (e.g., room temperature water, fruit juices, fresh raw fruits and vegetables).
• Increase activity as tolerated.
• Talk to your doctor before using over-the-counter medications or enemas.

NAUSEA, VOMITING, OR DIARRHEA
Gastrointestinal upset can be caused by your disease, certain foods, different treatments or medication.

To reduce discomfort:

• Take prescribed medications as early as possible when symptoms occur.
• Adjust food choices to reduce irritation (drink clear liquids, avoid caffeine, etc).
• Serve food at room temperature and choose bland options like popsicles or Jello.
• Maintain good mouth care (see page 25).
• Keep skin clean and dry to prevent skin breakdown and irritation.

For questions or concerns related to your care, contact the Gilchrist Nurse Helpline at 443.849.8200.
MANAGING YOUR SYMPTOMS

FATIGUE
You may feel like you run out of energy even when doing small activities. In addition to feeling tired physically, you may also feel tired emotionally and spiritually.

To help manage fatigue:
- Conserve energy by spacing out activities throughout the day.
- Talk to your doctor about reducing medications that are no longer working.
- Keep chairs nearby to lean on for support.
- Use a shower chair and a bedside commode for help with daily activities of living.

CHANGES IN FOOD OR FLUID NEEDS
The inability to eat and take fluids may be related to the illness, medication, difficulty swallowing, fears, or changes in the sense of taste or smell. A loss of appetite is normal and expected.

To reduce discomfort:
- Take pain and nausea medication 30 minutes before meals, as prescribed.
- Eat smaller portions and allow a relaxed diet with no restrictions.
- Consider eating together, even if it is not in the kitchen or at a table.
- Maintain frequent mouth care (see page 25).
- A decrease in urination may occur as less fluid is consumed. Expect the urine to become darker; a catheter may be needed to manage incontinence.

RESTLESSNESS AND AGITATION
Depending on one’s illness, restless and/or agitated behaviors can occur and may be very difficult on everyone in the care environment. Call your hospice nurse early when you notice changes in your loved one.

To manage restlessness and agitation:
- Avoid restraining arms and legs as this can cause heightened suffering.
- Speak in a low, calm voice and provide reassurance (e.g., “I am right here with you, Mom”).
- Reduce any external stimulation and manage the light or darkness of the room.
- Provide distractions that bring comfort, such as music, reading, guided imagery or light massage.
- Medications may be prescribed as needed or around the clock to help ease these symptoms.

ANXIETY AND SADNESS
It is normal to be anxious or have feelings of sadness during this journey, yet anxiety and sadness often go unreported or are undertreated. The whole team of hospice staff is equipped to meet you where you are and offer support to help you cope with these feelings.

To help manage anxiety and sadness:
- Discuss your fears and worries with our trained chaplains or social workers.
- Request Caring Touch from our hospice aides.
- Ask your nurse to contact your provider about medications or treatments that may help.
- Provide a calm, peaceful presence in order to encourage sharing.
- Utilize aromatherapy, guided imagery, meditation, journaling, storytelling, etc.
PAIN MANAGEMENT

Pain can keep you from being active, sleeping well, enjoying family and friends, or eating — all of which may lead to feeling afraid or depressed. If you are feeling pain, tell your Gilchrist nurse right away. Getting help for your pain early on can make pain management more effective. Gilchrist strives to control all complaints of pain within 24 hours.

ASSESSING PAIN

To assess pain, your Gilchrist nurse will ask these basic questions and possibly more:

1. Where is the pain?
2. How would you describe the pain (i.e., sharp, throbbing, tingling, aching, burning, cramping, etc.)?
3. What medicines or non-drug therapies have you used to relieve pain?
4. What makes the pain better or worse?
5. What number, on a scale of 0 to 10, is your goal for pain?

Use the pain intensity scale below to rate your pain before and after you take the medicine.

![Pain Assessment Tool](image)

*Faces pain rating scale modified from Wong DL: Whaley & Wong’s essentials of pediatric nursing, ed 5, pp. 1215-1216, St. Louis, 1997, Mosby.*

If a verbal response is not an option, we will assess non-verbal behaviors. Some non-verbal behaviors that may indicate pain, especially if two or more behaviors are present, are:

- Difficulty breathing
- A frown or sad face, furrowed brow or grimace, especially when care is being provided
- Moaning, groaning or crying
- Stiffening or withdrawing when care is attempted
- Agitation and restlessness

For questions or concerns related to your care, contact the Gilchrist Nurse Helpline at 443.849.8200.
PAIN MEDICATION

TYPES OF PAIN MEDICATION
The following are a few of the more common types of pain medication and their uses:

- **Non-opioids** – Ibuprofen or Motrin. Used for mild to moderate pain or bone pain.
- **Opioids** – Morphine or Oxycodone. Used for moderate to severe pain.
- **Antidepressants** – Nortriptyline. Used for nerve pain.
- **Anticonvulsants** – Neurontin or Dilantin. Used for nerve pain.
- **Steroids** – Decadron or Prednisone: Used to relieve bone pain and pain caused by inflammation (swelling).

TAKING YOUR PAIN MEDICATION
It is always best to call your Gilchrist nurse before administering the first dose of pain medication to ensure it is being given correctly. Most pain medicine is taken by mouth (orally). If it is hard for you to swallow or take a tablet or a liquid, ask your Gilchrist nurse about other ways pain medicine may be given.

To help your pain medicine work best:

1. Take on a regular schedule (i.e., same time of day). Taking medicine regularly and as directed by your physician or Gilchrist nurse will help keep pain under control.
2. Do not skip a dose of medicine or wait for your pain to get worse before taking pain medicine.
3. Some activities may make your pain worse, such as riding in a car. Ask your physician or Gilchrist nurse how and when to take extra doses of pain medication before activities that may cause you pain. The goal is to PREVENT pain. Once you feel pain, it is harder to get it under control.

QUESTIONS OR CONCERNS ABOUT THE USE OF PAIN MEDICATION
You may have questions or concerns about the use of pain medication. Below are answers to frequently asked questions about pain medication.

Can the use of morphine or other opioids cause death?
There will always be a ‘last dose’ of pain medication, but it is not the pain medication that causes death. It is the disease that causes death and often severe pain as the end of life approaches. Morphine is one pain medication that may be used to prevent suffering at the time of death.

Will the pain medication cause addiction?
As your body adjusts to a medication, your physician may need to increase the dose in order to get the same level of pain relief. That does not mean you are addicted to a medication. Using pain medication for pain relief is the right thing to do.

What if my pain medication does not help?
Be sure to talk to your physician or Gilchrist nurse if your medication is not relieving your pain. They will work with you to find the pain medicine and schedule that helps you the most. They may also recommend more aggressive pain management, coordinated with your doctor and the medical director, which would be accompanied with increased nursing visits and pain management education.
PAIN MEDICATION

PAIN MEDICATION SIDE EFFECTS
Below are common side effects of pain medication:

- **Drowsiness and confusion** – These are usually temporary and may only last a few days.
- **Constipation** – This happens to a majority of patients who take pain medication. Preventive measures like those on page 7 should be taken to avoid adverse effects from constipation. Please also share with your Gilchrist nurse what has worked for you in the past.
- **Nausea** – This may be troublesome for the first few days after pain medication is started. You will be instructed by your Gilchrist nurse in ways to prevent or control nausea. Please also see page 8 for some suggestions.
- **Itching** – Itching may be a side effect of certain pain medications. Talk to your Gilchrist nurse if you experience itchiness, as other medications can be prescribed.
- **Dry Mouth** – This is a common side effect many patients experience with pain medication use. Ice chips and good mouth care, such as the suggestions on page 25, can help.

CHARTING PAIN MEDICATION
It may be helpful to keep track of how your pain medicine is working before and after taking a dose. Making this a daily habit may make your treatment more effective. Your Gilchrist nurse will show you how to chart your pain and medication. A medication tracking chart is included on page 17 of this book.

NON-DRUG TREATMENTS FOR PAIN
There are many non-drug treatments available that may help relieve pain. You may use these treatments along with your regular medication, but inform your Gilchrist nurse if you begin, are currently using or would like more information on any treatments listed below:

- Biofeedback
- Breathing and relaxation, guided imagery or meditation
- Massage, pressure, caring touch, vibration or Reiki
- Hypnosis
- Acupuncture
- Aromatherapy
PATIENT SAFETY

Our goal is to keep patients safe and to prevent harm from falls, medication and oxygen use. Please read the following guidelines to help decrease the risks for injury and to create the safest environment possible.

FALL SAFETY

A fall is any event resulting in a patient coming to rest unintentionally on the floor or other lower level. While every patient is at risk for falling, the risk is even higher if falls have occurred within the last six months, regardless of the reason. Below are other fall risk factors.

Fall risk factors:

- Advanced age
- Disease progression
- History of falls
- Use of opioids (pain medication) or psychotropic medication
- Increased pain
- Weakness of body and of the limbs
- Increased clutter in the home (cords, throw rugs, toys)
- Pets in the home
- Restlessness or confusion
- Use of oxygen

Patients, families and your Gilchrist team have a shared responsibility for helping reduce injuries from falls in all settings. Patients may feel fine when sitting or lying in bed, but then fall as soon as they move to a standing position. Caregivers should remember to “Call before you fall” and work with your Gilchrist team to decide on ways to help reduce injuries from falls, such as the examples below.

WAYS TO HELP REDUCE INJURIES FROM FALLS:

- If weakness is a problem, provide support and assistance with walking and transferring. Ask the patient to call you when they need to get up for any reason.
- Leave a small bell or other object that makes noise or keep a room monitor within the patient’s reach.
- Keep frequently used items within reach.
- Have the patient wear non-skid footwear when walking.
- Keep the hospital bed in its lowest level with the wheels locked.
- Clean eyeglasses regularly and encourage use as prescribed.
- Keep the urinal, bedpan or bedside commode within reach.

WHAT TO DO IF A PATIENT FALLS

1. Call the Nurse Helpline immediately to report the fall and to receive further instructions: 443.849.8200.
2. DO NOT move the patient if they complain of severe pain. If any area looks strange or out of shape (possibly due to a broken bone) or if the patient is or has been unconscious, make sure they stay where they fell.
INFECTION CONTROL IN THE HOME

Hand washing with soap and water is the most important protection against infection.

Your Gilchrist team will wash their hands before and after providing care. When their hands are visibly soiled, they will ask for a convenient place with liquid soap and paper towels to clean them.

For your safety:

• Wash your hands before meals, before food preparation, after using the bathroom, after touching blood or bodily fluids, and after removing disposable gloves.
• Use soap, warm water and friction when washing hands. Rub hands vigorously for at least 20 seconds.
• If a Gilchrist team member forgets to wash their hands with either hand sanitizer or soap and water, remind them to do so.
• Prevent the spread of infection when you sneeze or cough by covering your mouth and nose with the bend of your elbow. Keep tissues handy. Be sure to dispose of used tissues and then clean your hands.
• If you are sick, avoid close contact with other people.
• Keep rooms well-ventilated to decrease the risk of colds, flu and other airborne communicable diseases.
• Wash soiled linen in hot soapy water as soon as possible.
• Mop or wipe up blood/bodily fluid spills with hot soapy water and then disinfect the area with a bleach solution (use one-part bleach to ten-parts water or another disinfectant). Wear gloves while cleaning up a spill.
• In addition to gloves, your Gilchrist nurse carries additional types of personal protective equipment (PPE) such as masks and gowns. If it is determined the patient has an infection that requires use of PPE, they will be provided.
• Masks may also be worn during care to protect patients at high risk for infection from everyday germs.
• Gowns may be used during procedures when the risk of splashing bodily fluids or blood is likely, such as wound care or suctioning.

THE FLU:

Gilchrist does not provide the flu vaccine. However, all Gilchrist staff are immunized. Please notify your Gilchrist nurse if you suspect a family member has symptoms of the flu. The CDC provides useful information and resources about the flu at www.cdc.gov/flu.
MEDICATION SAFETY

Your Gilchrist nurse will review your medications and how you are taking them at each visit. We encourage you to ask questions about medication use to promote safety.

**General guidelines to ensure safe medication use:**

- Only take medications labeled for your use. **Do not take medications** if the label cannot be read or if the medicine has changed color or appears broken or tampered with. Call your Gilchrist nurse before taking medication that appears different.
- Store medication away from children, in a central location. Your Gilchrist nurse will check your medication at least weekly to obtain timely refills.
- Unless instructed to place medications in a refrigerator, do not expose them to extreme cold or heat.
- Do not mix medicines in the same bottle. Use a pillbox to store and organize.

- Take all medicines as prescribed. Keep track of given and missed doses. Your Gilchrist nurse will use this information to help guide your care.
- Use your Medication List to keep track of all of your medications (prescription or over the counter) and supplements. Share this list with family, caregivers and all of your doctors.
- Inform your Gilchrist nurse of any changes or additions to medications, both prescription and over-the-counter, including nutritional supplements or natural/herbal remedies.
- Review all information including labels on medications delivered to your home. Be sure medication names and dosages match what you were told to expect.
- Many medications can cause unwanted side effects. We will work with you and your doctor to guide you in deciding which medications to continue taking.
- Dispose of medication properly. Your Gilchrist nurse will assist you in developing a proper disposal plan.
- **Fall risk:** Certain medications can increase your risk of falling. (Refer to the fall safety section on page 12 of this book.)
Name: __________________________  Birth Date: __________________________

Enter ALL prescription medicine (including samples), over-the-counter medicines, herbal and natural remedies, and dietary supplements.

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<th>Name (What Medicine)</th>
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<td>Pain; Shortness of Breath, etc.</td>
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Enter ALL prescription medicine (including samples), over-the-counter medicines, herbal and natural remedies, and dietary supplements.

- **When**
  - Morn
  - Noon
  - Eve
  - Bed

- **Dosage**
  - As Needed
  - As Needed

- **Reasons**
  - (What is it for)

- **Medication Covered?**
  - ☐ ☐ ☐ ☐ ☐
  - ☐ ☐ ☐ ☐ ☐
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*Enter All prescription medicine (including samples), over-the-counter medicines, herbal and natural remedies, and dietary supplements.*
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<tr>
<th>Medication:</th>
<th>Directions: Give (dosage/amount) every (number) hours</th>
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<td>Taken for:</td>
<td>Scheduled □ As Needed □</td>
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Please write-in ALL doses given below.

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<th>Date</th>
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Created: (date)

Other Instructions:
PATIENT SAFETY

EMERGENCY PLAN

Your Gilchrist team is prepared to help you plan for urgent events. Please ask a member of your team to discuss plans for you and your family in the event of an emergency (e.g., natural disaster, inclement weather, or other emergent event that might cause an interruption in service). There are community resources available to the public that can assist in your planning.

In an emergency situation, the Gilchrist team will call or visit you to ensure your safety and comfort. Please help your Gilchrist team set priorities by communicating your immediate needs. If you have concerns about an emergent event, please don’t hesitate to contact your Gilchrist team for support. Our staff is equipped with an emergency plan to assist caring for all patients in a timely and effective manner. **If you are experiencing a medical emergency that requires urgent attention, please dial 911.**

General preparation recommendations include having on hand:

- Working flashlight
- Battery powered radio or TV
- Extra food, water and medicine
- First aid supplies
- Fire extinguisher

ADDITIONAL SAFETY REMINDERS

- **Electric Heating Pads**: While an electric heating pad is usually regarded as safe, it can be dangerous if you have decreased sensation due to diabetes, spinal cord injuries or stroke, or if you are taking medication for pain or sleeplessness. Do not use a heating pad if you are receiving oxygen therapy.
- **Medical Equipment**: Report medical equipment that needs repair to Gilchrist. Do not use until replaced or repaired.
- **Emergency Numbers**: Keep emergency numbers posted on or near the telephone.
- **Smoking**: If your loved one smokes, it is possible they might light a cigarette and drift back to sleep. This poses an obvious fire risk. Try limiting smoking to times when they can be watched closely or limiting access to smoking materials to minimize fire risk.
- **Smoke Detectors/Fire Extinguishers**: We strongly recommend you have a functioning smoke detector and fire extinguisher, and someone in the residence who can correctly operate it. Check these safety devices monthly to ensure they remain in working order.
- **Emergency Evacuation Planning**: Ensure your evacuation route and alternate route are free of clutter and allow sufficient space for everyone to exit the residence safely.
PATIENT SAFETY

OXYGEN SAFETY

Oxygen can be beneficial when it is used correctly in a safe environment. However, in unsafe situations, the risk of starting a fire is real. Ensuring everyone’s safety while oxygen therapy is used is a shared responsibility.

The oxygen supply company will provide you with initial training when the oxygen equipment is delivered. Your Gilchrist team will monitor the effectiveness of the oxygen to make sure it meets your comfort needs. You are responsible for your own safety and for following the use and storage guidelines provided by the oxygen supply company and your Gilchrist team. Talk with your Gilchrist team about any concerns or questions you may have.

Your safety and the safety of those around you is our priority. If at any time your Gilchrist team observes or suspects unsafe behavior involving oxygen use or storage, we will work with you to remove the oxygen from your home and replace it with alternatives to oxygen therapy.

IMPORTANT OXYGEN SAFETY REMINDERS

- For your safety, smoking (including e-cigarettes) should not be permitted for patients using oxygen. Family members or caregivers should not smoke in the same room where oxygen is in use or stored, and should move outside and wait 10 minutes before smoking after being in contact with the person using the oxygen.
- DO NOT cook with a gas or electric stove while using oxygen.
- Keep ALL oxygen equipment at least 10 feet away from heat sources, including stoves, candles, space heaters, heating pads, hair dryers, electric razors, e-cigarettes, cigarettes or cigars.
- Oxygen equipment and cylinders should be stored upright in a cart or lying flat on the floor in a well-ventilated area, 8-10 inches from curtains or walls and never in a closet or car trunk.
- DO NOT use grease, oil-based, alcohol-based or petroleum-based products, or aerosol sprays on or near any oxygen equipment, including tubes and cannulas.
- Do not plug the oxygen equipment into extension cords or ungrounded or overloaded outlets.
- Place oxygen tubing in areas where it is less likely to pose a tripping hazard and maintain evacuation routes free of clutter to permit space for safe exit.
- Check smoke detectors and fire extinguishers monthly, notify your local fire department that you have oxygen in the home, and ensure someone in the home can correctly operate the extinguisher.
- Check the oxygen flow rate each morning, evening and each time the oxygen is turned on. Turn off oxygen equipment and valves when not in use, and wipe the cannula or mask with plain water if it becomes soiled.
- If at any time you find the oxygen does not provide relief, please contact Gilchrist so we can work with your physician to find a more effective treatment.
- The Gilchrist oxygen safety signs provided by your nurse should be displayed at all times.
- Fall risk: The use of supplemental oxygen increases the risk of falling. (Refer to the fall safety section on page 12 of this book.)
OXYGEN IN USE TENT CARD
An “Oxygen in Use, No Smoking” sign should be displayed on your front door and in the window of the room where the oxygen is stored. An “Oxygen in Use” tent card should be kept close to where the oxygen is in use as a reminder to others that safety precautions should be taken.

OXYGEN IN USE

No one should smoke in your home – the fire danger is too great.

Keep at least 10 feet from heat sources: pilot lights, electric appliances, candles, etc.

Avoid the use of alcohol-based and petroleum-based products: lip balms, lotions, oils, grease.
PRESSURE SORES
Broken skin may occur as a result of pressure, changes in nutritional status or contact with bodily fluids. Pressure sores are common at the end of life.

What to look for:
- Red areas on the skin that do not go away, even if the pressure is removed.
- Cracked, blistered, scaly and broken skin.
- An open sore involving the skin surface or deeper tissue.
- Yellowish stains on clothing or sheets.
- Complaints of pain.

To help prevent pressure sores:
- Change position frequently.
- Use pillows to “bridge” any potential pressure areas, particularly heels and lower back (sacral) areas.
- Use the therapeutic surfaces provided by Gilchrist.
- Clean promptly after bowel movements and urinary incontinence.
- Change the patient’s clothing or bed linen as soon as you notice soiling.
**WOUND CARE GUIDE**

**Keys to good wound care:**
comfort, pressure relief, keeping it clean and dry, and preventing infection

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<td>Location #4:</td>
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</table>

**STEPS TO CLEANING WOUND(S):**

1. Give pain medication(s) 30-60 minutes before cleaning.
2. Wash hands.
4. Put on gloves.
5. Remove old dressing and put in trash.
6. Change gloves.
7. Apply treatment as ordered above.
8. Apply cover dressing.

**Important!**
CALL GILCHRIST AT 443.849.8200 IF YOU NOTICE ANY OF THE FOLLOWING:
- PAIN
- ODOR
- BLEEDING
- WOUND LOOKS WORSE
- YOU HAVE ONE WEEK'S WORTH OF SUPPLIES LEFT.

**Treatment #1:**
**Treatment #2:**
**Treatment #3:**
**Treatment #4:**
**Treatment #5:**

**Change dressings:** AND AS NEEDED

DEC'17
WOUND CARE GUIDE

Keys to good wound care: comfort, pressure relief, keeping it clean and dry, and preventing infection

Location #1: ____________________________
Location #2: ____________________________
Location #3: ____________________________
Location #4: ____________________________
Location #5: ____________________________

Treatment #1: ____________________________________________________________
Treatment #2: ____________________________________________________________
Treatment #3: ____________________________________________________________
Treatment #4: ____________________________________________________________
Treatment #5: ____________________________________________________________

Change dressings: ________________________________________________________ AND AS NEEDED

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DEC’17
CAREGIVING

BATHING
Frequency of bathing may vary considerably. For some, only two or three times a week is necessary, with only a partial bath on other days. As the patient becomes weaker, bathing can be difficult. Hospice aides are available to assist with bathing and other personal care.

To ease difficulties with bathing and promote safety:
- Place a chair or stool inside the tub or shower.
- A sponge bath may be taken sitting beside the sink.
- If these methods are difficult, give the bath in bed.

SKIN CARE
Maintaining skin integrity is key to comfort and safety. It is important to keep skin clean, dry and moisturized.

To provide preventive skin care:
- Keep skin soft with water-based lotion to help prevent cracking of the skin.
- Keep sheets as clean and wrinkle-free as possible.
- Reposition patient frequently to protect pressure points. Areas that are prone to pressure are the hips, elbows, shoulder blades, heels, ankles, back of the head, and ears.
- Use a folded flat sheet under the midsection to pull the patient up or reposition.
- Avoid leaving wet clothing or bed linen on or under the patient.

MOUTH CARE
Good mouth care is important to prevent problems and to reduce discomfort caused by dryness, infection and open sores.

To provide routine mouth care:
- Use a soft toothbrush every morning, after eating and at bedtime.
- Remove and clean dentures every day. Avoid wearing them if they fit poorly.
- Keep the lips moist with water-based lubricants to avoid cracking.
- Rinse mouth, as needed, for comfort.
- Use of toothettes may be helpful.
PLANNING AHEAD

There are several practical concerns you may want to consider prior to the death of your loved one. Attention to these issues now allows your loved one to communicate their wishes while they are still able and prevents future stress and hardship on the family. Your Gilchrist social worker is available to help with some of these issues.

FINANCIAL PLANNING

- Contact the Social Security Administration regarding disability and retirement benefits to determine eligibility.
- If the patient is a veteran, ask about Gilchrist’s We Honor Veterans program. We will assist with veteran benefit information.
- Make sure the titles to assets are as the patient wishes.
- Consider designating a Power of Attorney if the patient is not able to manage finances.
- Review the will to ensure financial assets and personal effects will be distributed as the patient wishes.
- Check the designation of beneficiaries for life insurance, pension plans, retirement and other accounts to ensure they are as the patient wishes.
- Contact your lawyer or financial planner for assistance.

PLANNING FOR CHILDREN

Who does the patient wish to serve as guardian of minors? Consider establishing a financial trustee for children.

PLANNING FOR FINAL ARRANGEMENTS

- Decide which funeral home or cremation service will handle final arrangements. We advise you to consult a licensed funeral director to help with final arrangement options and pre-planning.
- If considering organ donation or donating the body to science, plan ahead. The patient’s signature may be required.
- Meet with your clergy to plan for the funeral or memorial service. If you do not have a clergy member to perform the service, a Gilchrist chaplain may be able to do it for you or your funeral director may recommend another celebrant.
- Consider designating a charity to receive donations in lieu of flowers.

Helpful items for making final arrangements:

- Locate important papers and passwords for deeds, bankbooks/online banking, stock certificates, birth and marriage certificates, deed to the cemetery lot, veteran’s papers (DD214 Service Separation papers) and passwords to frequently used accounts.
- Know the date of birth and birthplace of your loved one.
- Know the full name of the father and maiden name of the mother of your loved one.
- Know your loved one’s Social Security number.
- Gather information for the obituary.
- Locate the life insurance policy or the policy numbers.
WHEN DEATH OCCURS

The moment of death will likely be jarring, even if you have spent weeks or months preparing for the loss. Your Gilchrist team will help guide you so you can know what to expect and what to do when death occurs.

WHAT TO EXPECT WHEN DEATH OCCURS:

- After your loved one has died, call Gilchrist first at 443-849-8200, any time of day or night.
- A Gilchrist nurse will be sent to the residence for further support and guidance.
- If you would like a visit from your Gilchrist social worker or chaplain, let us know during your initial call.
- If you have any concerns about the timing of the death or the circumstance, please discuss with the nurse during the visit.
- During the visit, Gilchrist team members will help prepare your loved one’s body for the funeral home or for those who have been chosen by the family to claim the body for burial, cremation or other arrangements. We ask that you have final arrangement information on hand.
- Gilchrist will notify the durable medical equipment (DME) company when equipment pick-up is needed. Then a representative of the DME company will call you to make the pick-up arrangements.
- Gilchrist will also offer information on our Counseling and Support services. Please provide the names and contact information of family members or friends you think might also benefit from grief support.
- Within a few days of this visit, expect a call from your Gilchrist team, offering their support and condolences. Expect another call from Counseling and Support staff a few weeks later.

DISPOSING OF MEDICATION

Your Gilchrist nurse will assist you by safely disposing of all prescription medications when they are no longer needed or at the time of death. For those living in residential communities, your medications will be safely discarded by the residential community nursing staff. Gilchrist follows state and federal agency guidelines for the safe disposal of medications and we will partner with you, with your authorization, to perform this service for you.

For more information, please refer to Policy #2-542 Disposal of Controlled Substances and Other Unused Prescription Medications at Home, provided in your Admission folder. Feel free to discuss any questions or concerns with your Gilchrist nurse at any time.
PATIENT RIGHTS & RESPONSIBILITIES

BILL OF RIGHTS

Patients of Gilchrist Hospice Care or their guardians have the right to, and Gilchrist caregivers have the responsibility to provide:

1. Information regarding Gilchrist Hospice Care’s philosophy of care and a description of the scope of hospice care services and specific limitations of those services.

2. A choice of care providers and the ability to effectively communicate with those providers. The ability to request a change in care provider(s) at any point during the patient’s care.

3. Information at the time of acceptance of these rights and of all rules and regulations governing patient responsibilities as evidenced by the patient’s written acknowledgment.

4. A choice of an attending physician who will provide the medical direction for their hospice care and to change that physician at any point during their care with us. The attending physician chosen may be a hospice physician.

5. In our inpatient and residential units the medical staff is limited but every attempt will be made to assure that the hospice attending physician is agreeable to the patient. In the event that the attending physician in the inpatient unit is out, the patient or representative will be notified of the name of the covering physician daily.

6. Information at the time of admission regarding services under the hospice benefit and related charges, including any charges for services for which the patient or a private insurer may be responsible.

7. Information regarding all changes in services and to be informed within 15 working days of when the agency becomes aware of a change in coverage.

8. Information regarding one’s health condition, unless medically contraindicated. Initial and regular assessments of one’s condition and level of comfort, including one’s pain level and participation in the planning of services, including treatment measures, management of pain, end-of-life decisions and referrals to other agencies.

9. Information about diagnosis, prognosis and treatment, including the nature and purpose of any proposed procedures. Communication that is in understandable terms regarding the benefits, risks and effects of the proposed procedures so that an informed decision can be made regarding consent for care.

10. Effective pain management and symptom control from the hospice for conditions related to the terminal illness.

11. The option to refuse treatment to the extent permitted by law and to be informed of the medical consequences of such refusal.

12. The option to refuse to participate in experimental research/treatments.

13. A copy of the organization’s written policies and procedures regarding Advance directives, including how such rights are implemented by Gilchrist Hospice Care.

14. The option to make Advance Directives under Maryland state law (e.g., medical orders for life-sustaining treatment [MOLST], living wills, health care treatment directives, durable power of attorney).
15. The option to have confidential treatment of personal health information as outlined in the GBMC/Gilchrist Hospice Care Notice of Privacy Practices.

16. The option to have individual values and beliefs considered in the provision of care including privacy in treatment and personal care.

17. The option to have care that is given without discrimination as to race, color, creed, sex, sexual orientation, disability, religion, ability to pay or national origin.

18. The option to attend or not attend religious services as the patient chooses, and receive visits from members of the clergy.

19. The option to be involved in the resolution of any conflict that may arise regarding care or service decisions.

20. Education to the patient and family regarding the treatment required so that the patient can, to the extent possible, help himself or herself, and the family or other party designated by the patient can understand and help the patient.

21. Admission to services only if the agency has the ability to provide safe, professional care at the level of intensity needed. Patients have the right to reasonable continuity of care and to be referred elsewhere if denied service for any reason.

22. Freedom from verbal, physical, mental, sexual and psychological abuse, including injuries of unknown source, and misappropriation of patient property.

23. Freedom from mistreatment, neglect, involuntary seclusion and exploitation, and to have person and property respected.

24. Freedom from physical and chemical restraints.

25. The option to manage personal financial affairs.

26. The option to maintain legal counsel.

27. The option to register a grievance regarding treatment or care that is, or fails to be, furnished and a lack of respect for property by anyone who is furnishing services on behalf of the hospice, and to not be subjected to discrimination or reprisal for exercising his or her rights.

28. To utilize live streaming video to maintain contact, but may not video record or audio record Gilchrist staff, volunteers or treatments.
GILCHRIST HOSPICE CARE RESPONSIBILITIES

The patient has a right to expect that Gilchrist Hospice Care will:

1. Protect and promote the patient’s right to exercise his or her rights.
2. Ensure that all alleged violations involving mistreatment, neglect, or verbal, mental, sexual and physical abuse, including injuries of unknown source, and misappropriation of patient property by anyone furnishing services on behalf of Gilchrist Hospice Care, are reported immediately by hospice employees and contracted staff to the hospice administrator.
3. Immediately investigate all alleged violations involving anyone furnishing services on behalf of Gilchrist Hospice Care and immediately take action to prevent further potential violations while the alleged violation is being verified.
4. Take appropriate corrective action in accordance with state law if the alleged violation is verified by the hospice administration or an outside body having jurisdiction.
5. Ensure that verified violations are reported to state and local bodies having jurisdiction within five working days of becoming aware of the violation.

INPATIENT CENTER RIGHTS

In addition to the above rights, patients admitted to any Gilchrist inpatient or residential facility have the right to, and Gilchrist caregivers have the responsibility to provide:

1. Privacy, including the right to have a staff member knock on the patient’s door to announce his or her presence before entering.
2. Private meetings or visits with any individual the patient chooses in accordance with patient and facility safety.
3. Unlimited contact with visitors and others, and to restrict contact with visitors and others not directly involved in the patient’s care.
4. The use of a private telephone within the facility.
5. Access to and use of personal clothing and possessions, and reasonable security for those effects in accordance with the facility’s security policies.
6. An environment that preserves their dignity and contributes to a positive self-image.
PATIENT RIGHTS & RESPONSIBILITIES

PATIENT AND FAMILY RESPONSIBILITIES

1. To give accurate and complete information about current complaints, past illnesses, hospitalizations, medications and other matters relating to the patient’s health, as well as advance directive documentation, living will information and who has been chosen to make decisions for the patient should the patient not be able.

2. To assist in developing and maintaining a safe environment by reporting perceived risks in their care and unexpected changes in their condition.

3. To provide information to Gilchrist Hospice Care about service needs and expectations.

4. To ask questions when care, treatment and service, or instructions are not understood.

5. To participate in the development and update of the Plan of Care. To consult with Gilchrist Hospice Care prior to making additions or changes to the care plan.

6. To follow the care, treatment and service plan developed. If concerns arise regarding the Plan of Care, to express to Gilchrist Hospice Care the concerns and the ability or willingness to adhere to the Plan of Care. To understand that the anticipated care outcomes may not be achieved if the care plan is not followed.

7. To follow established Gilchrist Center rules and regulations.

8. To show respect and consideration toward Gilchrist Hospice Care staff and property.

9. To meet financial obligations as agreed in the Gilchrist Hospice Care Service Agreement.

10. To inform Gilchrist Hospice Care when appointments cannot be kept.

11. To provide Gilchrist Hospice Care the name of the attending physician desired to manage their hospice care. This may include a hospice physician.
COMPLAINTS

Our goal is to assist you to meet your physical, psychosocial and spiritual needs during your time in hospice. If you are not satisfied or have a complaint, please discuss it with your nurse or the team manager. If it is not resolved, the following options are available to you:

To register a complaint or patient safety concern with Gilchrist Hospice Care’s President, call 443-849-8200; TTY: 1-800-735-2258.

Written Grievances to OHCQ can be sent to:

Office of Health Care Quality
Maryland Department of Health and Mental Hygiene Spring Grove Center
Bland Bryant Building
55 Wade Avenue
Catonsville, Maryland 21228

To register a grievance with the State of Maryland, Office of Health Care Quality (OHCQ), without fear of reprisal or discrimination, patients and families may call 1-800-492-6005. The Office of Health Care Quality is available to answer questions related to the agency’s Medicare and/or licensure status, or to receive complaints. This service is in operation 24 hours a day, 7 days a week. Normal working hours are 8 a.m. to 4:30 p.m. After 4:30 p.m., calls are taken by an answering machine.

Written grievances to CHAP can be sent to:

Mail: CHAP
Attn: Complaints Department
1275 K Street NW, Suite 800
Washington, DC 20005

Email: complaints@chapinc.org
Fax: 202-862-3419

To register a grievance with the Community Health Accreditation Partner (CHAP), patients and families may call 800-656-9656, 24 hours a day.

An investigation will be conducted by Gilchrist Hospice Care of complaints made by the patient or the patient’s family or guardian regarding treatment or care and Gilchrist Hospice Care will document the existence of the complaint and the resolution of the complaint.
NOTES

Gilchrist on Social Media

facebook.com/gilchristcares
thegilchristblog.com
@Gilchrist_News
linkedin.com/company/gilchrist
For urgent questions, call the Gilchrist Nurse Helpline at 443.849.8200