Our Lady *of* Peace

# HOSPICE & HOME HEALTH GUIDE

***Here When You Need Us Most…***
***Wherever You Call Home.***

# Gill Brothers

FUNERAL SERVICE & CREMATION

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# Our Lady *of* Peace

The end of life is full of challenges and emotions. Our Lady of Peace is here to help patients and their families explore all the options and answer the difficult questions.

It's important to know you and your family have a choice in hospice care providers—regardless of where a patient received previous medical care.

## OUR MISSION

*Called by God, Our Lady of Peace gently comforts and cares for those most in need near the end of their lives, wherever they call home, regardless of means.*

## OUR VISION

*We are compassionate, faith-based end-of-life care leaders.*

## OUR VALUES

*Compassion, Dignity, Inclusivity, Presence, Peace, Diversity, Excellence, Stewardship*

### HOME HEALTH CARE

651-789-5030
nancyl@ourladyofpeacemn.org

### HOSPICE

651-789-5030
nancyl@ourladyofpeacemn.org

### RESIDENTIAL HOSPICE

651-789-5031
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2076 Anthony Ave, St. Paul, MN 55104

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## CONTENTS



## OUR STAFF

### KINDNESS. COMPASSION. EXPERIENCE.

Our staff is comprised of skilled, experienced people who care deeply about carrying out the important mission of Our Lady of Peace. We work together to keep our organization running smoothly and providing the best possible care to our patients and their loved ones.

**Joe Stanislav** / *President & CEO*

Joe's tenure with Our Lady of Peace has seen much change, from the development of the first long-term care-based hospice in Minnesota to the transformation of St. Mary's Home to an all private room nursing facility. His unwavering dedication to our organization ensures our important mission can continue.

**Kim Webster** / *Chief Operating Officer*

Kim brings 40-years in the senior health services field, with a focus on administration, healthcare, social work, marketing and food service. She has served within nursing homes, hospitals, and assisted living communities, most recently as COO for an assisted living organization with eight communities in MN, IA and OH. She has a love for hospice and home care and knows personally and professionally how important hospice services are to providing dignity, respect and compassion to patients at end of life, and their loved ones

**Dr. Michael Pinchback** / *Director of Medicine*

Michael Pinchback MD is the Chief Medical Officer and Medical Director of Our Lady of Peace Residential and Hospice. He joined in 2016. Originally graduating from the University of Arkansas School of Medicine, he finished his residency at the Mayo Clinic Graduate School of Medicine. He is certified by the American Board of Family Medicine and the Hospice Medical Director Certification Board.

**Matthew Stafford** / *Director of Nursing for Residential Hospice*

Matthew has devoted over 30 years to caring for patients at Our Lady of Peace. He received his RN degree from the University of Minnesota. His knowledge and compassion are invaluable to those we serve.

**Nancy Larson** / *Director of Nursing for Hospice and Home Health Care*

Nancy has worked in the field of hospice and home care for over 18 years in California, Wisconsin, and Minnesota. She received her BSN from UW Oshkosh. She has been with Our Lady of Peace since 2007 and enjoys working as a team with other disciplines across hospice care.

**Lisa Sweeney** / *Director of Development*

From her background in elementary education to her experience with Alzheimer's patients at the Marian Center in St. Paul, Lisa brings an unparalleled passion for helping those in need to Our Lady of Peace.

**Paula Fischer** / *Director, Highland Block Nurse Program*

Paula Fischer has been the Director of Highland Block Nurse Program since 1992. She has a Bachelor's Degree in Social Work and a Certificate of Pastoral Ministry. Paula feels blessed to work with elders and their caregivers, providing services to help them remain in the homes and neighborhood they love and being part of Our Lady of Peace's mission of quality care to the community.

## OUR BOARD OF DIRECTORS

Each of our board members brings a diverse collection of personal and professional experiences as caregivers to their role with Our Lady of Peace. Their guidance has been invaluable in creating the organization we are today, as well as providing a vision for what we might be in the future.

### OFFICERS

**Jim Miller** / *Chair*
**Opened** / *Vice-Chair*
**Angie Swetland** / *Secretary*
**Mark Meyer** / *Treasurer*
**Joe Stanislav** / *President & CEO*

### BOARD OF DIRECTORS

Annastacia Belladonna-Carrera
Douglas J. Bruce
Richard Easton
Dennis Flaherty
John Kupris
Fr. John Malone
Stephen E. Otto
Deborah Paone
Carrie Treptow
John Zobel

## OUR STORY

### RESIDENTIAL HOSPICE

The Dominican Sisters of Hawthorne opened a humble care center in St. Paul to provide free care for terminal cancer patients who were without means. Our Lady of Peace has since expanded its mission to include adult non-cancer patients regardless of their social, religious, or economic status.

### IN-HOME HOSPICE

Our Hospice program was formerly known as St. Mary's Hospice, located in Highland Park and run by the Franciscan Health Community. It is a community-based hospice headquartered at the Our Lady of Peace Residential Hospice campus, serving the 7-county metro area. The staff provides care to patients wherever they call home—their private homes, nursing homes, group homes, etc.

### HOME HEALTH CARE

The Home Health Care program, formerly Franciscan Home Health Care, serves the 7-county metro area and provides in-home therapies, post-operative care, palliative care, and assistance with daily living.

### HIGHLAND BLOCK NURSE PROGRAM

The goal of the state-funded Highland Block Nurse Program, housed at the Our Lady of Peace campus, is to help older residents stay healthy and live safely in their homes in the Highland Park neighborhood of St. Paul.


## OUR HISTORY

### 1941 — OUR LADY OF GOOD COUNSEL

On December 7th, 1941 the Dominican Sisters of Hawthorne, NY came to St. Paul, MN and started Our Lady of Good Counsel Home, a free end of life care facility to serve the "cancer poor."

### 2001 — HOSPICE

The Hospice program was introduced, allowing patients to receive hospice care wherever they call home.

### 2004 — HOME HEALTH

Home Health services began, serving older adults in their homes.

### 2009 — FRANCISCAN HEALTH COMMUNITY

The operation of the home was transitioned to the Franciscan Health Community.

### 2015 — OUR LADY OF PEACE

Our facility licensure changed from Long Term Care to Residential Hospice. The corporation name changed under new licensure to Our Lady of Peace and is currently a non-profit Catholic organization.

### 2016 — CELEBRATING 75 YEARS

We have been serving our community with end-of-life care for 75 years, serving tens of thousands of patients from all walks of life.

## WHAT IS HOSPICE?

Hospice is not a place, it is a philosophy of healthcare that focuses on providing comfort and quality of life for individuals with a life-limiting illness. Whether living in a personal residence, the home of a loved one, assisted living, or a skilled nursing facility, hospice teams provide care to patients wherever they may call home. Hospice care does not seek to hasten or prolong the dying process, but instead strives to help patients truly live until they die, encouraging them to take part in activities they enjoy or that bring fulfilment, to allow them to live their life to the fullest.

Here at Our Lady of Peace, we treat the person, not the disease, and advocate for the patients and their families to be the decision makers. Together, we will formulate a personalized Plan of Care to focus specifically to the patient's individual needs. We provide expert pain relief and symptom management care for the patient, emotional and spiritual counseling, if desired, as well as grief support for the family.

## WHEN TO CONSIDER HOSPICE CARE?

Admission to hospice may occur when there is a prognosis of six months or less, should the disease or illness runs its normal course. At this stage, with acute aggressive treatment no longer a viable option, the primary focus is on comfort care and symptom management. Common illnesses which may require admission to hospice care includes, but is not limited to, the later stages of Alzheimer's Disease and other dementias, Cancer, Heart Disease, Lung Disease, AIDS, ALS, and many others.

Hospice care might be considered if one or more of the following exist along with a terminal diagnosis:

- Multiple admissions to the hospital in a short period of time
- Multiple Emergency Department visits
- Unexplained weight loss
- Trouble eating and swallowing
- Severe weakness; lethargy; spending most of the time in a chair or bed
- Shortness of breath while sitting, lying down, or following minimum exertion
- Multiple falls within a 6-month period
- Recurrent infections, such as pneumonia or urinary tract infection
- Symptoms, including pain, have become problematic

## WHO IS ELIGIBLE FOR HOSPICE SERVICES?

To qualify for Hospice services, the following criteria must be met:

- The patient has a life-limiting illness for which cure is no longer probable.
- The patient likely has a life expectancy of six months or less, if the disease or illness runs its normal course.
- Emphasis of treatment is on symptom control and comfort care rather than curative therapy.
- Patients may continue to qualify for hospice even after 6 months of service as long as physical decline is still evident.

**Should you have any questions, or wish to speak with us regarding a possible admission to hospice, please do not hesitate to contact us.**

## WHO PAYS FOR HOSPICE CARE?

The Hospice Benefit provides coverage for palliative, comfort-oriented care and services, provided by Medicare, Medicaid, and some private insurance companies. Please speak with our hospice staff to see if you are eligible for benefit.

Medicare Part A and Medi-Cal services pay 100% of Hospice services. Most private insurances have a Hospice Benefit component that often does not require any funds from the patient. However, some insurance companies require patients to pay for a portion of the hospice benefit, therefore a co-pay may be required, in which case you or your loved one will be responsible.

If you or your loved one lives in a nursing home, the following benefits may apply:

- If you have Medicare coverage, and are paying privately for a room and board, you are eligible for the Hospice Medicare Benefit and will continue to pay privately for the nursing home room and board.
- If you have Medicare coverage and Medicaid pays for room and board charges, you are eligible for the Hospice Medicare Benefit. Medicaid will continue to pay the nursing home room and board and you will continue to be responsible for paying the patient liability portion of the room and board charges, if applicable.
- If you have Medicaid coverage only, you are eligible for Medicaid Hospice Benefit. Medicaid will continue to pay the nursing home room and board and you will continue to be responsible for paying the patient liability portion of the room and board charges, if applicable.

## MYTHS VS. REALITIES

There are a lot of myths surrounding Our Lady of Peace and the services we provide at our Medicare-Certified Residential Hospice. Here, we aim to correct those misconceptions and clarify our important mission.

**MYTH:** Patient must be Catholic.
**REALITY:** All are welcome, regardless of their beliefs.

**MYTH:** Cancer diagnosis required.
**REALITY:** All terminal diagnoses are considered for adult admissions.

**MYTH:** Patients must be actively dying.
**REALITY:** We generally serve those in their last 4–6 weeks of life.

**MYTH:** The application process takes weeks.
**REALITY:** Patients may be admitted within 24 hours or less if all appropriate documentation is submitted.

**MYTH:** Patients cannot leave once admitted.
**REALITY:** Patients may leave on a pass with a responsible party.

**MYTH:** There are never any openings.
**REALITY:** On average, we admit 30+ patients per month.

**MYTH:** Only patients with serious financial hardship are admitted.
**REALITY:** We admit patients based on caregiver referrals and level of need.

**MYTH:** Patients need to be signed up with a community-based hospice prior to admission.
**REALITY:** No need to be signed up with a previous hospice. We are here to help.

**MYTH:** Our Lady of Peace charges a fee.
**REALITY:** We provide care at our Residential Hospice at no cost to patients and families.

## MENU OF SERVICES

Here at Our Lady of Peace, we recognize that dying is a normal and natural process that all of us will experience some day. We provide a service to anyone with a life-limiting illness that maximises comfort and manages pain effectively to allow the patient to live as fully and comfortably as possible.

We also recognize our patients and their loved ones as one unit of care, therefore the services are not limited only to the patient. We provide services for the families that are also affected by the illness.

### BELOW IS A MENU OF SERVICES THAT WE OFFER TO HELP YOU IDENTIFY YOUR NEEDS AND TO HELP US HELP YOU FORMULATE YOUR PERSONALIZED PLAN OF CARE:

- Pain relief or relief from other difficult-to-manage physical symptoms
- Wound care
- 24-hour access to a registered nurse and/or social worker
- Medication management and/or home delivery of medications
- Help from a certified nursing assistance with bathing, grooming or dressing
- Education and equipment to safely move the patient
- A hospital bed, bedside commode, wheelchair, walker or other medical equipment in the home
- Portable oxygen
- Help with changing linens and/or ensuring the patient's environment is safe and organized
- Education on being a more effective caregiver to the patient
- Emotional support for the patient or for the caregiver
- Help children to cope with change and/or loss
- Assistance / advice about finances and medical insurance issues
- Assistance with Advance Care Planning
- Spiritual guidance or support
- Volunteers to help with the burdens of care giving
- Access to a registered dietician to discuss nutritional concerns
- In-patient care at hospice facility for symptom management as an alternative to a hospital stay
- Short-term respite care at hospice facility to give the family caregiver a break
- Music therapy
- Massage therapy
- Story Keeping (recording the patient's life story)
- Help to care for the family pets (through the Pet Peace of Mind program)
- Honoring of the patient's service to our country (through the We Honor Veterans program)
- Hair grooming and styling at home
- Family photographs
- Pediatric hospice or palliative care
- Help to make every day special and joyful

## YOUR HOSPICE TEAM

The goal of the hospice team is to promote a pain-free life for the patient, and to support their loved ones. At Our Lady of Peace, we have a team of highly skilled professionals available to work with you and your family.

### DOCTOR AND ATTENDING PHYSICIAN:

The Hospice Medical Director and Attending Physician of your choice, if you have one, will be available to consult with the hospice team on your Plan of Care. They will direct your care in regards to symptom management, preparing the most effective and appropriate treatment options for end-of-life symptoms. They will also order your medicines, treatments and hospice services. The hospice team will keep your doctor informed about your condition.

### NURSES:

A registered nurse will be responsible for coordinating all phases of your care. They will assess and monitor your condition and physical status, provide care for your pain and symptom management, and help you and your caregiver learn how to best manage your care. Although continuous assistance may not be required, an on-call nurse will be available 24 hours a day, seven days a week for emergencies.

### HOSPICE AIDE:

A hospice aide provides personal care such as bathing, skin and mouth care, personal grooming, assistance dressing, toileting, incontinence care, repositioning bed bound patients, assistance with walking, linen changes, or a shower, tub bath or bed bath. They may on occasion perform additional duties as required to ensure the patient's immediate needs are met, and will report any identified needs to the hospice nurse.

### MEDICAL SOCIAL WORKERS:

It can help to talk with someone trained and knowledgeable about the kind of stresses you are facing. Medical social workers provide education and counseling, for both the patient and their family, and can help identify other community resources that may be available and of benefit to you.

### CHAPLAIN:

The chaplain is available to assist you in drawing on your own belief system and/or reconnecting you to your faith and religious tradition. This service may help you cope with the impact of your illness.

### VOLUNTEERS:

Our volunteers are on hand to provide companionship, prepare light meals, offer respite time for your caregiver with short visits, reading, lending emotional support, and to help with many other tasks that can help maximise comfort and fulfilment for the patient. All our volunteers undergo a diligent application, interview and vetting process, followed by an extensive orientation and specialized training program which includes understanding hospice, confidentiality, working with families, listening skills, loss and grief support, and bereavement assistance.

### BEREAVEMENT:

Services offered by bereavement counselors include individual counseling, group support and timely written information to assist in understanding the grief process for both the patient and their family.

### OTHER THERAPIES:

In addition, every patient has access to these essential therapies to match their personal needs: Music Therapy, Massage, Healing Touch, and Pet Therapy.

**"AT THE END OF LIFE, WHAT REALLY MATTERS IS NOT WHAT WE BOUGHT, BUT WHAT WE BUILT; NOT WHAT WE GOT, BUT WHAT WE SHARED; NOT OUR COMPETENCE, BUT OUR CHARACTER; AND NOT OUR SUCCESS, BUT OUR SIGNIFICANCE. ...**

**LIVE A LIFE OF LOVE."**

**- UNKNOWN**

## FREQUENTLY ASKED QUESTIONS

### MY PHYSICIAN SUGGESTED HOSPICE - WHAT NOW?

If hospice treatment is considered, your physician will carry out an evaluation order. We will meet with the patient and family at a suitable location to explain the benefits, answer questions, and to sign a set of consents, which are a Medicare and/or Insurance Company requirement. This will allow us to obtain medical records for the nursing staff.

Should hospice care be an appropriate route for the patient, based on the Medicare Criteria for Hospice Guidelines, admission to the hospice may be granted. The admission team will assess the patient and family's needs, where the hospice team will assist in developing a Plan of Care.

Over the first few days under hospice care, our interdisciplinary team will contact the patient and the family to co-ordinate a schedule for regular nursing visits, personal care, emotional support and spiritual assistance as agreed within the Plan of Care.

### WHO WILL PROVIDE THE CARE?

Our interdisciplinary hospice team, consisting of nurses, hospice aides, social workers, chaplain and volunteers, will review the Plan of Care with the patient and family on a routine basis to ensure the care needs are kept up to date and are always being met, to adhere to the patient's changing needs and wishes. The regularity of the visits may fluctuate during the course of the illness where the patient's condition and goals of care change.

### IS HOSPICE AVAILABLE AFTER HOURS?

Yes. Hospice care is available seven days a week, 24 hours a day. Our nurses are available to respond at any hour should assistance be required.

### CAN I BE CARED FOR IF I LIVE IN A NURSING FACILITY OR LONG-TERM CARE FACILITY?

Yes. Hospice services are provided to the terminally ill, wherever they may live. They may receive visits from hospice nurses, home health aides, chaplains, social workers, and volunteers, along with other services provided by the facility itself. The hospice and the facility will co-ordinate the Plan of Care in accordance to the patient's needs and wishes.

### WHAT HAPPENS IF I CANNOT STAY AT HOME DUE TO MY INCREASING CARE NEEDS?

Although Medicare considers this type of care to be custodial care, and is therefore not included under the Medicare Hospice Benefit, nor under most private insurance, we may assist in making arrangements with inpatient residential centers/skilled nursing facilities, or Board and Care homes, so that care can continue at a higher level. If custodial care is not covered by insurance, typically the patient is responsible for payment.

### ARE HOSPICES INSPECTED AND EVALUATED BY STATE AND FEDERAL REVIEWERS?

Yes. Hospices periodically undergo inspection to ensure federal and state regulatory standards are met. These inspections are required in order to be approved for reimbursement by Medicare.

### WHAT HAPPENS AFTER MY LOVED ONE DIES?

If a team member is not present at the time of death, one will arrive soon after being notified. At this point, a hospice nurse will make a visit and pronounce the patient, make necessary phone calls to the pre-chosen mortuary/funeral home, prepare the body for pick-up and support the family as needed.

## PAIN MANAGEMENT

Medications for pain management has in recent years developed significantly to permit us to control pain well to provide long-term relief. The goal of hospice is to ensure the patient is comfortable and free of pain, and we achieve this by administering pain medication regularly, not just when the person is feeling pain, overlapping the doses so that the effectiveness does not wear off. This ensures that the patient remains comfortable and pain free.

Some people fear that the medication, if administered regularly, will not be as effective when "really" needed. Experience has shown that these concerns, however, are unwarranted.

**Potential side effects may occur as a result of pain medicines. These can include:**

- Drowsiness/lethargy – people often worry that "strong" medication may make the patient drowsy or lethargic. This may occur, however this usually gets better within 1-3 says of starting or increasing dosage.
- Constipation - commonly occurs when pain medication is taken routinely where laxatives and/or stool softeners are not taken on a regular basis.
- Nausea – can occur with or without vomiting, and will often pass in 2-3 days as the body adapts to the effects of the medication.
- Dry mouth – additional fluids, sugarless hard candy and/or artificial saliva can alleviate the problem.
- Increased heart rate – this may slow within a few days of starting medicine or changing dosage.

Although these symptoms can sometimes occur, adjusting the medicine accordingly thus minimizing side effects can often control them. Our hospice team will provide you with adequate training to ensure you know which side effects to look out for from your pain medication. Should you find that the pain relief is ineffective, experience any of the above side effects, or have any questions regarding dosage and/or medication changes, please consult the Hospice nurse.

The following table can be used to keep a log of when, where and how much medication is taken, and with a pain scale included, it allows us to see how the pain medication can be altered to minimize episodes of pain.

## SUGGESTIONS FOR PAIN MANAGEMENT

1. Take your medication exactly as prescribed and do not wait until pain is intense before taking your pain medicine. If the directions say to give one or two doses and you have only taken one and still have pain after 30-45 minutes, take the second dose. If the pain continues 30 minutes after your second dose, let your nurse know.

2. Ensure you have a 3-day supply of pain medicine available at all times.

3. Report your pain accurately.

    - When did the pain start?
    - Is it a new pain?
    - Where is the pain located?
    - How you would rate your pain on a scale of 1-10?
    - Is there anything that makes the pain better or worse?
    - When did you last take your pain medication?

4. The caregiver should watch for signs of pain in patients who might not be able to verbalize what they are feeling. These signs might include:

    - Frowning
    - Moaning
    - Restlessness
    - Short rapid breathing
    - Muscle tensing
    - Resistance to turning or positioning

5. Relax and limit visitors. Ensure the temperature is comfortable, lights are dimmed and clothing is loose. Try to change your body position and avoid sitting or lying in the same position for more than two hours.

6. Try relaxation breathing – breathe slowly and deeply through your nose, expanding your belly with air, and breathe out through your mouth, emptying your belly and allowing it to relax.

7. If being touched helps, ask someone to gently massage your hands or feet.

8. Try to focus on something besides the pain. Taking your mind away from the pain and focusing on a movie or music, for example, can help reduce the feeling of pain.

9. Applying heating pads or ice packs, with a light cloth between the pack and skin, can be used over the area of pain for 15-30 minutes. Ensure you check the skin frequently. Do not use the heating pad at its highest setting or while sleeping.

## PAIN LOG

| DATE | TIME | PAIN SCALE 1-10 | MEDICATION TYPE AND AMOUNT | LOCATION / DESCRIPTION | RESPONSE TO MEDICATION | INITIALS |
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## NUTRITION

Both physical and emotional changes can influence the ability or desire to eat. This might be alarming to the caregiver, however these changes are common experiences for persons with an advanced illness. As our bodies near the end of life, the brain releases a chemical that makes the body no longer feel hunger or thirst, therefore reducing our appetites. Changes in sense of taste or smell, bouts of diarrhea, constipation, nausea or vomiting, and difficulty swallowing may also contribute to a loss of appetite. This can be frustrating for a caregiver, often pleading with the person to eat, however feeding a patient at this point might actually make them more uncomfortable. Gentle, positive encouragement is more efficient than trying to force the patient to eat.

### THINGS TO CONSIDER:

1. Smaller meals and snacks throughout the day may be better tolerated than three regular meals. The patient is often the best judge of appropriate amounts. Taking plenty of time to eat may increase enjoyment.

2. Be sensitive to strong or unpleasant smelling foods or odors. Reducing cooking times by using a microwave may help cut down on cooking odors.

3. Due to taste changes, pleasant tasting foods and foods served at room temperature may make foods more appealing.

4. Where swallowing is an issue, changing consistencies and textures of solids and liquids may ease swallowing ability. Please notify the hospice nurse if the patient experiences difficulty swallowing or soreness in the mouth.

## OXYGEN SAFETY

Oxygen itself does not burn, although it does make things burn much faster. If you are using oxygen at home, you must take extra care to stay safe. Oxygen can feed a spark and cause a large fire in seconds. To be safe at home, follow these oxygen safety guidelines.

### IN THE HOME:

- If you move around the house with your oxygen, you may need more than one fire extinguisher. Make sure you have a working fire extinguisher in your home.
- Put a 'NO SMOKING' sign in every room where oxygen is being used. Do not smoke or allow anyone to smoke in the room where oxygen is being used.
- Keep oxygen, or children with oxygen, away from the stovetop and oven. Avoid open flames.
- Watch out for splattering grease. It can catch fire.
- Cooking with a microwave is safe.
- Keep oxygen at least 6 feet away from:
    - Toys with electric motors
    - Electric baseboard or space heaters
    - Wood stoves or fireplaces
    - Electric blankets
    - Hairdryers, electric razors, and electric toothbrushes (unless battery powered). Hair dryers should be used on a cool setting only.
- Avoid static electricity or things that are likely to cause static electricity e.g. nylon or woolen clothing.
- Use a humidifier in winter to add moisture to dry air in your home.

### OTHER SAFETY TIPS:

- Do not store your oxygen in a trunk, box, or small closet. Secure oxygen cylinders in an upright position with a chain as arranged by your home care therapist. Keep out of direct sunlight and away from heat.
- Keep liquids that may catch fire away from your oxygen, including products that contain oil, grease, alcohol, or other liquids that can burn.
- Do not use Vaseline or other petroleum-based creams and lotions on your face or upper part of your body unless you talk to your respiratory therapist or doctor first. Aloe Vera and other water-based products such as K-Y Jelly are okay to use.
- Avoid tripping over oxygen tubing.

**IF A FIRE OCCURS IN YOUR HOME, GET OUT, STAY OUT, AND CALL FOR HELP**

## HOME SAFETY

There are numerous ways to minimize risks for the patient wherever they may be living to ensure the patient lives comfortably and without worry.

### TO PREVENT THE SPREAD OF INFECTIONS:

1. Wash hands before and after patient care.
2. Wear latex gloves when handling body fluids or materials with body fluids on them.
3. Flush body fluids into the regular sewer system. Dispose of blood-contaminated items in plastic bags and put in the garbage.
4. Disinfect areas that have been contaminated with body fluids.
5. Use liquid soaps in place of bar soaps.
6. Keep areas well ventilated.
7. Store medical supplies in original packaging or a sealed container.
8. Line linen baskets and trash cans with plastic bags.
9. Wash linens in washer and dry them on a high setting.
10. Wash dishes or eating utensils in hot, soapy water or in the dishwasher.

### TO ENSURE MEDICATION SAFETY:

1. Store medications in original packaging or a sealed container, securing all caps on medication bottles.
2. Keep medication in a cool, dry area and out of the reach of children yet easily accessible to the patient.
3. Follow instructions on labels and/or as directed by a physician or hospice nurse.
4. Do not take medications intended for another person.
5. If needles are used, dispose of used needles with the caps off in a puncture-proof receptacle provided by hospice. Keep needles and syringes out of reach of children and out of sight of visitors.
6. Hospice staff will properly dispose of any unused medication. Do not flush or pour down the drain.

Should you have any questions about your medications, please do not hesitate to contact your hospice nurse.

### TO ENSURE ENVIROMENTAL SAFETY:

1. Avoid tripping / slipping hazards (e.g. keeping cords out of the line of traffic or taping them down, removing all small rugs unless they have non-skid backing, removing clutter etc.)
2. Keep a telephone and other frequently used items within reach of the patient.
3. Arrange furniture for easy navigation, removing all furniture that is not stable or steady.
4. Light the way to the bathroom using a night-light.
5. Install secure grab bars near the toilet and in shower/tub.
6. Use non-skid material in the bathtub. Check water temperature with hand before entering tub.
7. Mobility and safety aids may be helpful to prevent falls (e.g. walker, cane, wheelchair, elevated toilet seat etc.)

Please report any falls to the hospice nurse, not only to ensure that the patient is okay, but also to help prevent any future falls.

### TO ENSURE FIRE SAFETY:

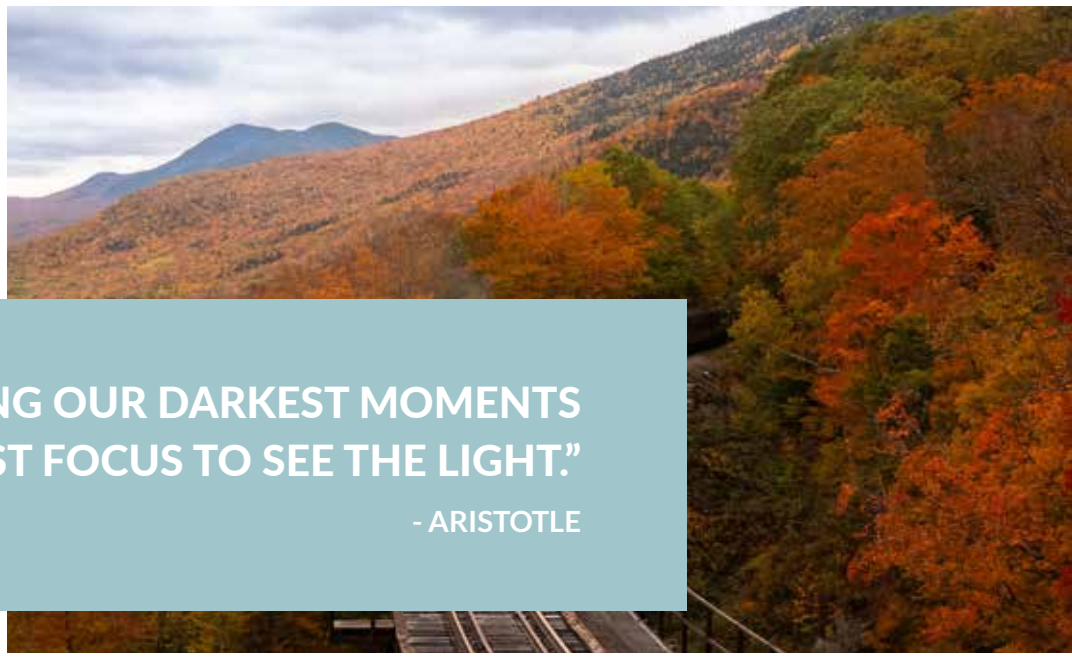
1. Use smoke detectors on every floor of your home and near all bedrooms. Check batteries every 3 months.
2. Check cords for damage, fraying or knots.
3. Do not overload extensions cords.
4. Establish fire escape routes for various areas within the home and practice evacuation in the event of a fire.
5. Avoid smoking in bed.
6. Call 911 if there is smoke or a fire.

## PREPARING FOR DEATH

As the body nears death, many emotional and spiritual changes may occur, and it is at this time that we may take the opportunity to reflect on our lives together. There are signs and symptoms that generally indicate that the body is nearing death, although not all individuals will show every symptom, nor are all the signs of approaching death present in every case. They can also depend on the type of terminal illness.

### PRE-ACTIVE PHASE OF DYING (MONTHS/WEEKS BEFORE DEATH)

- The patient may begin to withdraw as they begin to separate physically and emotionally from their loved ones.
- The patient may sleep more and become increasingly difficult to arouse, spend time with their eyes closed, or stare into space.
- The patient may become angry about unfulfilled hopes and dreams.
- The patient may become increasingly confused about time, place, and the identity of close and familiar people. They may also talk of going home or planning a journey, or talk to others we cannot see or reach for people or things we cannot feel.
- Sometimes referred to colloquially as the "death rattle", as the muscles start to relax in the throat, the patient may speak in rambling words.
- The patient may experience shallower and/or irregular breathing, or appear not to breathe for short periods of time during sleep or rest (apnea).
- Lower blood pressure may make the patient become dizzy when sitting or standing.
- The patient may gain less control of bowels and bladder.
- The patient may refuse all food and drink. Loss of appetite and thirst can occur, as the body no longer requires it, and may result in weight loss.
- Changes to skin color may occur (pale, yellow or bluish around lips, ears and nails) and arms, feet and legs may develop splotches or areas of reddish-blue or purple.
- The body cools and may become cool to the touch as blood circulation slows down.
- Increased swelling (edema) of either the extremities of the entire body may occur.



**"IT IS DURING OUR DARKEST MOMENTS THAT WE MUST FOCUS TO SEE THE LIGHT."**

**- ARISTOTLE**

## ACTIVE PHASE OF DYING (DAYS BEFORE DEATH)

- The eyes may look glassy.
- Breathing may stop for longer periods of time, sometimes between 15-45 seconds (known as apnea). There might be cyclic changes in breathing pattern, such as slow progressing to fast breathing and then slow again, and breathing may become louder. The patient may breath with a wide open mouth.
- The patient may experience restlessness and start picking at clothing or bedding.
- Inability to arouse the patient at all (coma), or to arouse them only with great effort, the patient may exist in a severely unresponsive state (semi-coma).
- The patient's body may be held in a rigid, unchanging position.
- The patient may start speaking in riddles or of events to come, and may ask to "go home".
- The splotching moves from the arms, legs and feet to the body.
- Urinary or bowel incontinence may start to occur in a patient who was not incontinent before.

It is natural, when facing a life-limiting illness or nearing death, that the dying person may begin to reflect on key spiritual issues, for example, questioning their purpose in life, how their beliefs and values may impact them during this time, and questioning what happens after death. These questions are completely normal in the process of life transition. They may take this opportunity to reflect on and to be thankful for the people that they have been able to spend their lives with and events that they have experienced. It might become a time to express love and gratitude, or perhaps to ask for forgiveness or to forgive old hurts. The support of the chaplain at this time can allow for a peaceful end of life as they prepare to say goodbye to the people they're leaving behind.

A dying person will normally try to hold on in order to ensure their loved ones will be all right. Your ability to release the dying person from this concern, to provide them with the assurance that it is all right for them to go when they are ready, is one of the greatest gifts you can give your loved one at this difficult time. A dying person may be waiting for your permission to pass from this life. Always remember, your loved one can hear you until the very end, even when they may not be able to respond by speaking. Your presence at this time can be a great expression of your love and support and may help them to be more at peace at the time of death.

Saying goodbye is your final gift to your loved one. You may want to lie in bed with them, to take their hand and to say everything you might want or feel compelled to say. It might be as simple as "I love you", or to apologize for things left unsaid. You might want to thank them. Tears do not need to be hidden from your loved one or apologized for. Our loved ones deserve our tears. If tears don't come naturally to you, this does not mean that you don't love your loved one. You may show your love in others ways. Saying goodbye brings closure and makes the final release possible.

**Cardiopulmonary Resuscitation (CPR)**
May involve chest compressions to circulate blood throughout your body, or inserting a tube down your throat or placing a bag over your nose or mouth to force air into your lungs.

**Do Not Resuscitate (DNR) / Allow Natural Death (AND)**
If your heart stops beating or you stop breathing, no attempts would be made to revive you and you will be allowed to die "naturally".

If you choose not to sign a DNR/AND, CPR will be performed by emergency medical services staff (911).

## WHAT TO DO WHEN DEATH OCCURS

It is important to prepare yourself for the dying process of a loved one, however the actual death moment is harder to prepare for. It may be helpful for you and your family to sit down and discuss what you will do if you are the one present at the time of death to ensure all appropriate measures are carried out with sensitivity and effectively, with as little complication as possible.

Death is not an emergency. Nothing needs to be done immediately; however, there are time constraints for organ and tissue donors. When you think death has occurred, call the hospice nurse, regardless of the time of day or night. DO NOT CALL 911. The hospice nurse will come to the home. If you are alone, we would encourage you to call a friend or family member to be with you at this time. If your loved one has died, the hospice nurse will call the funeral home.

The body does not have to be moved until you are ready. If you or another family member wants to assist in preparing the body by bathing or dressing, this can be arranged. The funeral home will come to receive the patient. You may wait to go to the funeral home until a later time.

### IMPORTANT PEOPLE TO CONTACT:

**Name** / Relationship:

Telephone:

**Name** / Relationship:

Telephone:

**Name** / Relationship:

Telephone:

**Name** / Relationship:

Telephone:

**Name** / Relationship:

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## IMPORTANT NOTES

## IMPORTANT NOTES

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