

Patient & Family Guide to Hospice Care



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To All,

For over ten years New England Hospice has provided quality services to patients and families who face a life limiting illness. Choosing hospice care is an important decision that can greatly benefit the quality of life for a patient and provide support to a patient's family during a difficult time. We are dedicated to providing your loved one with quality of life and comfort in the time they have left.

Our commitment is to provide education, nurturing support and guidance to assist patients and families during this time. We extend our care, support and services to our patients, families and the communities in which they reside. Our team works together to provide patients and their loved ones with expert medical care and emotional and spiritual support.

We maintain that hospice is about life and the quality of time we have left. The decision to choose hospice is never easy. We are honored that you have chosen to invite us into your lives in such an intimate way. We are committed to exceeding your expectations.

Thank you very much for allowing us to be part of your lives.

Gregg Estey, Administrator

Our Pledge to You:

- Encourage and support care and services that are safe, patient-centered, effective, efficient, timely, and equitable.
- Uphold high standards of ethical conduct in advocating for the rights of patients and their family caregivers.
- Preserve and promote the inherent potential for growth within individuals and families during the last phase of life.

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Information for Getting Started

Understanding Hospice Care

Hospice is a concept of caring for the terminally ill that dates back to the 1960's. The founder of modern hospice, Dr. Cecily Saunders, introduced the concept of caring for a patient's physical, emotional, social and spiritual needs.

With a philosophy of compassion and dignity, hospice utilizes a team of healthcare professionals and volunteers who provide ongoing support for both the family and the patient.

Focusing on improving the quality of life and not a cure, hospice attempts to ease the emotional, spiritual and physical pain often associated with terminal illness.

By recognizing dying as a part of life, hospice will support the patient and family in maintaining control of end-of-life choices and through the bereavement period.

Patients will remain in the familiar, comforting surroundings of home.

What We Mean By Hospice Care

Hospice care refers to end-of-life care in which the goal is comfort, symptom management, and quality of life, as opposed to finding a cure. Hospice is coordinated and provided by an interdisciplinary care team. Your team will include the your physician, nursing, social work, pastoral care, volunteers and companions. Hospice care generally isn't considered an option until a person is terminally ill, with a probable life expectancy of six months or less. Hospice will serve the patient and family's needs.

What Services and Support Does Hospice Care Include?

New England Hospice is dedicated to providing:

- Care that focuses not just on the patient's medical condition, but also on the emotional, social, and spiritual needs of both the patient and the patient's family
- Care that is directed, as much as possible, by the patient, working together with the family and the hospice staff
- Care provided by an interdisciplinary team that includes physician, nurse, social worker, therapists, chaplain, and trained volunteers
- Nursing support available for patients and primary caregivers on an on-call basis, 24 hours-a-day, seven days a week
- Care directed at effective pain and symptom management
- Care at home, wherever that may be for the patient
- Bereavement support for up to 13 months after death.

When Should Hospice Care Begin?

The decision to stop curative treatment and choose hospice is never easy, but here are some basic guidelines:

1. When curative treatment no longer makes sense. Often working on extending life through treatment has the opposite effect and is painful.
2. When the emphasis of treatment changes to comfort, symptom control and enhancing the quality of life left.
3. Hospice care is for patients who have a terminal illness which is anticipated to result in a life expectancy of six months or less.
4. To get the most out of hospice care, it should not be put off until a point at which much of the opportunity to benefit from a focus on comfort care and quality of life has passed. However, even when death is imminent, there is still benefit in hospice support.

The Hospice Team

Hospice care is patient centered, which means that the patient makes care decisions and participates in care planning as much as possible. The patient's primary home caregiver is also an important part of the hospice team. So is the patient's physician, who continues to direct medical aspects of the patient's care. In addition, a hospice team typically includes:

Hospice nurse – The hospice nurse will visit with you and your family to determine your individualized needs and work out what services you are interested in receiving. The nurse's primary goal is to provide symptom management and comfort. Responsibilities include:

- assessing comfort level and any symptoms which may need attention, such as pain, nausea, etc.
- working with the physician to manage symptoms
- educating the caregiver
- helping coordinate needed equipment, supplies, and services
- explaining the effects of illness and treatment, answering your questions, and offering support.

Social worker – The social worker will explain the hospice philosophy, goals, and services. A hospice social worker works closely with the patient and family to create and maintain a supportive, in-home care setting that will work in terms of the patient's safety and comfort. The social worker is also available to help patient and family deal with personal, financial, emotional and care planning issues that come up. A hospice social worker may also help by:

- identifying available resources in the community
- determining eligibility for state and local assistance programs
- providing information on advance directives (living will, health care directive, health care proxy, etc.)
- listening to concerns, answering questions, and providing emotional support.

Chaplain or spiritual counselor – is available to visit, listen, and provide support to both patient and family. Chaplains take a non-denominational approach, and can also connect you or your loved one with someone representing a preferred religious faith or tradition. The hospice chaplain can:

- meet with you or your loved one to share hopes, fears, dreams and concerns
- support you in your exploration or struggles with spiritual and/or emotional issues
- provide spiritual counseling, while respecting your personal beliefs
- pray with you, if requested
- assist you in planning a funeral, memorial service, or other similar gathering.

Therapists – including physical, occupational, speech and Reiki therapists. They often play a role during hospice care in promoting the independence, quality of life, and safety of the patient and family. The hospice nurse can help determine if a referral to one of these therapists might be helpful. Therapists may:

- assist in identifying and filling medical equipment needs, such as a hand-held shower, bath seat, walker, etc.
- help identify any safety hazards in the home
- help the patient improve strength and mobility through the use of equipment and exercise programs
- evaluate leisure interests and teach skills and activities that improve quality of life
- demonstrate safe patient transfer techniques
- teach exercises for a bed-bound person that can relieve pain and discomfort caused by lack of mobility
- evaluate communication or swallowing difficulties and recommend ways of handling these.

Hospice aides – Aides will help with personal care needs and may visit as needed.

Hospice aides help with:

- bathing
- shampooing
- grooming and shaving
- changing bed linens
- wound and skin care
- assistance with toileting
- light homemaker tasks
- support for physical activity and relaxation
- teaching caregivers good personal care techniques.

Hospice volunteers and Companions –are an important part of the hospice care team.

Hospice volunteers receive in-depth training before being assigned to a patient and family. Depending on your needs and wishes, a hospice volunteer may be able to help by:

- staying with the patient so the caregiver can rest
- providing companionship – spending time with the patient in conversation, playing a few hands of cards, or sharing things of interest to the patient
- running small errands
- doing light housework, running a load of laundry, or preparing a meal
- spending time with children in the home, so the caregiver can have some private time.

Bereavement or grief counselor – provide education, counseling and support for dealing with grief and loss. This member of the hospice team helps by:

- providing counseling and support both before and after the patient’s death
- identifying other resources available in the community, such as a grief workshop or support group
- following up, typically for at least 12 months after the patient’s death, to see how the family is coping with their loss.

Paying for Hospice Care

If you are eligible for the Medicare or Medicaid Hospice Benefit: Under this benefit the following are covered:

- intermittent home visits by the hospice staff
- medications related to the hospice diagnosis
- certain supplies
- medical equipment that is normally covered by Medicare
- short-term respite care
- some lab tests
- procedures to manage symptoms.

However, to be covered, these services must be:

- Related to the patient's terminal illness;
- Authorized by hospice as comfort care and part of the patient's plan of care; and
- Obtained through a provider approved under the program.

Office visits to see the primary physician will be covered in the same way as before election of the Medicare Hospice Benefit.

Here are two points to remember if you are receiving care under the Medicare/Medicaid Hospice Benefit:

First, if you access care independently without consulting the hospice team, neither the hospice program nor Medicare (or Medicaid, if applicable) will pay for those services; and

Second, if you decide to change from comfort care to active treatment that seeks a cure, you will need to revoke your Medicare (or Medicaid) Hospice Benefit and revert to your regular Medicare or Medicaid benefits, since your goals would then be different from the goals of hospice care.

If you have private insurance: Hospice staff will work with you to determine the scope of your coverage and arrange for payment by your insurance plan.

If you have limited or no insurance coverage for hospice care: Hospice staff will work with you to determine your eligibility for financial aid and/or set up a reasonable payment schedule.

Information on Rights and Responsibilities

Patients' Rights

Hospice patients have certain rights that are described in the packet given to you upon admission and discussed with the patient when hospice care first begins. Be sure to read carefully the detailed description of patients' rights you receive and ask questions if there is anything you do not understand.

As an overview, each hospice patient has the right to:

- Pain management and symptom control
- Be involved in developing their hospice plan of care
- Be treated with respect & receive quality end of life care
- Receive spoken & written notice of their rights and responsibilities in a manner they understand during the assessment meeting with hospice
- Refuse care or treatment
- Receive information on advanced directives
- Voice concerns and not be discriminated against for doing so
- Choose their attending physician
- Have their clinical record kept confidential
- Be free of mistreatment, neglect, verbal, mental, sexual or physical abuse
- Receive information about what is covered under the hospice benefit.
- Receive information about the scope and limitations of hospice services.

Maintaining quality hospice care depends on good patient and family feedback. If you have questions, please ask them. If you are aware of something you don't like or you think is inconsistent with quality, respectful care, let your hospice know right away. If you are comfortable doing so, discuss your concerns directly with the person or persons involved. If that feels awkward or does not resolve your concerns, contact the hospice manager, director, or administrator.

Patient and Family Responsibilities

Along with patients' rights, your hospice program will let you know what it expects of the patients and families it serves. Patient and family responsibilities include such things as providing accurate information, keeping the hospice team informed of changes, keeping the home where care is being provided clean and safe, and learning and following basic steps for preventing the spread of infection, especially hand washing.

HIPAA Compliance – Privacy and Confidentiality

Hospice patients are covered by the Health Insurance Portability and Accountability Act of 1996, or “HIPAA.” Information on HIPAA policies and procedures can be reviewed at the end of this booklet. If you have questions or concerns about privacy or confidentiality, ask a member of the hospice team.

Healthcare Decisions and Advance Directives

Hospice patients are entitled to make their own healthcare decisions as much as possible and for as long as possible. When a patient is no longer able to understand the medical options and make decisions, the patient’s representative steps in and makes them on the patient’s behalf.

Advance directives play an important role in this by letting a person say ahead of time how and by whom care decisions should be made, if the patient later loses the ability to make them. Advance directives are legal documents that vary from state to state, but typically there are two kinds. One is a health care directive or living will, a document in which you state your wishes for treatment near the end of your life. The other is a durable power of attorney for health care, sometimes called a healthcare proxy (or “DPOA”), in which you name a close relative or friend to make decisions for you, if you later lose the ability to make them yourself. If you name someone as your health care back-up decision maker, it’s a good idea to discuss with that person how you would like decisions made if that becomes necessary.

Another healthcare planning document you may hear about is called a Medical Order on Life-Sustaining Treatment (a “MOLST” form) or a do-not-resuscitate (or “DNR”) order. These are orders a physician enters in a patient’s medical record after discussion with the patient or patient’s representative. They notify emergency response personnel and other healthcare providers that cardiopulmonary resuscitation, or “CPR,” should or should not be started if this person’s heart or breathing were to stop.

The hospice social worker can answer questions about advance directives, and a member of the hospice team will discuss these issues with you when hospice begins.

Information and Skills for Caregivers

Keeping a Care Log and Communicating Effectively

One of the first things a caregiver needs to get in the habit of doing is keeping a care log. It doesn't have to be fancy.

Keeping a care log is your way of tracking changes in the patient's condition and needs. This information will be important for keeping the rest of the care team informed, and for making adjustments to the care plan. In the care log, record the following information at least once a day, and more frequently if symptoms change:

- The date and time of your observations
- Frequency of bowel movements
- The name and dose of medications the patient has taken.

The hospice nurse will go over the care log and what you should include. Depending on the patient's medical situation, you may be asked to record such things as the patient's temperature, skin color, fluid intake, pain level, or frequency of urination and urine color.

As part of your notes, write down any questions you may want to ask the hospice team during their next visit. There is no such thing as a dumb question when it comes to taking good care of your loved one. So, make a note when you don't understand something, and ask for clarification.

Managing Pain and Other Symptoms

Pain

Fear of pain is common for patients and their families. It is important to listen to patients when they say they are experiencing pain. For patients, pain may be both a physical and an emotional experience. Only the patient can best describe the pain and its intensity. There are many ways to manage pain effectively, and the hospice team will work with you to provide the best treatment.

The nurse and doctor need a clear understanding of the patient's pain level, the type of pain he or she is experiencing, and how well medications are or are not controlling it. They will often ask the patient to rate pain on a scale of

0 through 10, with “0” meaning no pain, and “10” meaning the worst possible pain. The hospice nurse will ask what level is acceptable.

How does the patient describe the pain he or she is experiencing? Here are some words often used to describe different levels of pain? Ask the patient to use the words that best fit.

*sharp shooting aching stabbing pulsing crushing
tingling dull cramping itching burning cutting throbbing*

The type of pain is as important as its intensity in determining the best medications for the patient. Other medications may be prescribed, in addition to the regular pain medication, to better control a particular type of pain. These additional medications may be more familiar to you as treatment for other problems, such as depression, muscle tension, anxiety, or inflammation. However, they may also be used to manage pain.

Non-Verbal Signs of Pain

There are a variety of reasons that patients may be unable to verbalize pain, such as sedation, dementia, and delirium.

This can make it difficult to assess, and treat appropriately. When dealing with a patient like this, a first attempt should be made to elicit a self-report from the patient. If this is not possible, discussions with caregivers and family should be used to identify changes in behavior or actions that could be attributed to pain. As a supplement, non-verbal indicators of pain can be used, including:

- **Body movements:** writhing, restlessness, irritability, agitation
- **Sympathetic activation:** Hypertension, tachycardia, diaphoresis
- **Facial expressions:** grimacing, squinting eyes, tense face, tears
- **Reactions to physical exam and movement:** combativeness, immobility

Non-Verbal Pain Scale:



A hospice patient may have concerns about pain medications. Here are some examples, along with points to keep in mind:

“The pain medication makes me too sleepy.” Some pain medications can make you feel drowsy. This sleepiness usually goes away after a few days. If you have lost sleep because of pain, you may sleep more the first few days after beginning your new medication, because your body is finally relaxing. The medications can be adjusted to decrease sleepiness but maintain comfort.

“The pain medicine makes me constipated.” Constipation is a common side effect of many pain medications and may not go away even after a patient becomes used to a medication. Other factors may also be contributing to constipation, such as decreased activity, decreased appetite, or a disease process. Constipation may be treated or prevented by balancing the effects of medications and decreased appetite and activity with stool softeners and laxatives.

“If I take pain medicine now, what will I do if the pain gets really bad?” Medication dosages may be increased or the medication can be changed to keep pain managed effectively. Keep your nurse informed about your level of pain and your goal.

“Will I become addicted?” Taking medications to treat pain is entirely different from abusing drugs. In a hospice situation, the goal is an important one: alleviating pain and maximizing quality of life.

If “addiction” is a concern for you or your loved one, discuss pain management with the hospice team so that pain is dealt with in a timely, medically appropriate way.

You or your loved one may have other questions about the pain medication schedule. If you do, be sure to ask your hospice nurse.

Taking prescribed pain medication regularly as directed can help manage pain effectively and minimize the need for additional medication. Pain may contribute to other problems, such as nausea and vomiting, irritability, confusion, loss of sleep, and immobility. Most people have a better quality of life when they are pain-free or experiencing low levels of discomfort.

Pain and discomfort can also be managed by other methods. For example, meditation, music, or guided imagery can reduce pain by helping a person to relax. Using cool or warm packs, or changing position may also help in soothing aches. Massage may help decrease discomfort by increasing circulation and relaxing muscles. Your hospice team may be able to assist you with these techniques or direct you to other resources.

Dizziness

Dizziness is a symptom that may have several different causes. Patient safety – in particular, avoiding falls – is a primary concern. Here are some steps to reduce problems with dizziness:

When getting out of bed or a chair, go slowly. For example, let your feet dangle at the side of the bed first, before standing. Often, dizziness will go away after a minute or two.

Change positions slowly, and use a cane or walker if available.

Keep the environment, especially traffic areas, clean and free of clutter.

If you or your loved one feels unsteady, ask for assistance. If they are tolerated, increase fluids – drinks such as Gatorade or Pedialyte can be especially helpful.

Nausea and Vomiting

Many patients experience nausea and vomiting. Here are suggestions that can help:

- Eat small, frequent meals.
- Avoid liquids at mealtime — drink them an hour after meals.
- Eat dry foods such as toast and crackers.
- Avoid spicy, fried, and fatty food, red meat and food with a strong odor.
- Pay close attention to mouth care.
- Take anti-nausea medication when prescribed (regularly or prior to meals)
- Unless instructed not to, take medications with small amounts of food or milk.
- Serve food cold or at room temperature to decrease its smell and taste.

Nausea caused by pain medication can feel like motion sickness. If this happens, try resting quietly. If you suspect your pain medicines are making you nauseated, tell your nurse.

Constipation

When people are very ill, many things can affect how their bowels function. Change in diet, activity, and the use of some medications can produce constipation. This is because the narcotic in the pain medicine slows down the bowel, allowing too much water to be absorbed from the waste matter. The result is a sluggish bowel with hard, dry stool.

Treatment is aimed at speeding up (stimulating) the bowel and/or putting more water into the stool. Medications to prevent constipation should be taken routinely, as directed by your doctor or nurse. You can also increase fluid intake and activity, as tolerated, to help decrease constipation. The goal is to have a bowel movement at least every three days.

Bowel problems to report to the nurse include:

- Very hard, difficult to pass stool
- More than three days without a bowel movement
- Constipation followed by diarrhea
- Constantly passing only smears of stool or liquid stool
- Blood with the stool
- Abdominal pain.

Your nurse may advise you to use a fruit paste recipe, such as the following:

Anti-Constipation Fruit Paste (Dose: 1-2 tablespoons per day)

| | |
|---------------------------------|-------------------|
| ¼ pound prunes | ¼ cup brown sugar |
| 1 ounce senna tea | ¼ pound figs |
| ¼ pound raisins or pitted dates | ¼ cup lemon juice |

Prepare the tea using ¾ cup boiling water. Steep for 5 minutes. Strain the tea and pour ½ cup into a large pot. Add fruit and boil for 5 minutes. Remove from heat, add sugar and lemon juice. Allow mixture to cool. Using a hand mixer, food processor, or blender, turn fruit mixture into a smooth paste. Spoon into jar or airtight container and place in freezer. Note: the fruit paste does not freeze solid but keeps indefinitely in the freezer.

Serving ideas: on toast, on hot cereal, in ice cream, yogurt, etc. Senna tea can be found in health food stores, grocery stores, and pharmacies.

Dry or Sore Mouth

Good mouth care is very important. Decreased fluid intake, some medications, or physical conditions can leave a hospice patient's mouth dry and/or sore. Here are some ways to help relieve mouth discomfort:

For dry mouth:

- Avoid smoking, drinking alcohol, and eating spicy foods. Try popsicles, shakes, yogurt, pineapple chunks, gum, sugar-free citrus drops, or hard candy such as lemon drops.
- Drink plenty of fluids or use ice chips.
- Rinse your mouth frequently.
- Take good care of teeth and gums by flossing and brushing regularly. A soft toothbrush may be helpful if the mouth is sore.
- The nurse may also have “toothettes,” which are sponges on a stick. They can be used with water to moisten the mouth and for general mouth care. Avoid the use of lemon glycerin swabs because they can dry the mouth.

For sore mouth:

- Avoid acidic foods like orange juice, tomato juice, and citrus fruit.
- Use a straw to prevent liquids from coming in contact with sores.
- If dentures are too loose, have them adjusted and remove while sores on the gums are healing.
- Some people get white patches of yeast in their mouths. If this happens, ask the nurse about using medication to ease the discomfort.

Food and Eating

It is common for people to lose their appetite when ill. This may be caused by disease, treatments, medications, pain, or simply changes in the way food tastes. The body's need for calories and protein rich foods is altered because of decreases in activity, exercise, and general metabolism. Here are suggestions for encouraging eating when appetite is diminished:

- Eat frequent, small meals.
- Drink liquid breakfast drinks, canned supplements such as Ensure, or homemade high-calorie shakes.
- Add dried milk or dried protein powder to liquid or soft foods to add calories.
- Use fruit juices, such as prune or apricot nectars, to add calories.
- Eat and drink favorite foods.
- Give liquids in other forms, (Jell-O, pudding, popsicles and ice cream).
- Avoid using straws, which may cause swallowing of air, leading to burping or nausea.
- Follow instructions on dietary supplements for storage, use, and expiration date.

When our bodies are able to heal, we need proper nutrition to regain strength. However, when our bodies are not able to heal (for example, during the last stages of a terminal illness), food can become an unnecessary burden and a source of discomfort.

When this happens, decreased appetite can create anxiety and tension for both the patient and caregiver. Attempting to force oneself to eat may drain precious energy and lead to nausea and vomiting at a time when the body is saying “no” to food or fluids. As a caregiver, you may feel guilty or inadequate or frustrated if your loved one is no longer taking much food or fluids.

If so, talk about your concerns with the hospice nurse.

Dehydration

A person who is very ill may become dehydrated, especially if a fever develops or the person can no longer swallow. Ice chips, lip balm, artificial saliva, mouth swabs and frequent mouth care can be used to promote comfort. To help prevent dehydration when the patient can still swallow, give sips or spoonfuls of fluids frequently over a 4-hour period. Check with your hospice nurse regarding fluid requirements in your situation.

Skin Problems

Skin sores (also called pressure ulcers or bed sores) develop when a person lies too long in bed in one position. These sores can be uncomfortable and can be a medical problem if they become infected. It's much better to prevent them in the first place. Here's how:

- The patient should change positions in bed by turning from side to side every two to four hours.
- If the person is able, help them move occasionally; for example, from bed to chair.
- Gently rub the skin with lotion to increase circulation and moisturize.
- Keep skin clean and dry.
- Change soiled or wet linens and clothing as needed to keep patient dry.
- Clean the skin regularly of any drainage, blood or urine.
- Use pillows to support the leg and back when the person lies on his or her side.
- Use a special mattress on the bed, such as an egg-crate foam pad or air mattress.
- If recommended by the nurse, apply protective pads around affected areas to reduce contact and relieve pressure.

The hospice team may have other suggestions depending on the situation. If you notice any redness, sores or bruises on the patient, let the hospice nurse know.

Emotional Withdrawal

It is common for someone who is terminally ill to begin withdrawing from familiar activities, such as work, hobbies, relationships, and so on. Active communication with others may seem less important. This may mean that touch and just being physically present will play a larger role than normal conversation in supporting your loved one.

Withdrawal is often used by patients to conserve energy and for self-reflection. Life review may become an important task. Hospice staff, especially the social worker and chaplain, can help.

Disorientation; Using Symbolic Language

One or two weeks prior to death, the patient may begin to sleep most of the time. It becomes difficult for the patient to keep his or her eyes open. Patients may become disoriented to time and place. They often become confused, talking or gesturing to people who are not present or who have already died.

In the last stages of their illness, they may speak in what is often referred to as “symbolic language.” An example might be, “I’ve got to cross the bridge now.” This is normal and can be reassuring, calming, and meaningful to the person. What a loved one can do is be affirming, understanding that disorientation and use of symbolic language are common and normal among persons nearing death.

Practical Caregiver Skills

Rule Number One: Take Good Care of Yourself

During hospice care, the patient isn’t the only one who needs care. If you are a primary caregiver, your emotional and physical well-being are also important, and often difficult to maintain. Only by taking good care of yourself will you be able to care for your loved one.

Small things you do for yourself can make a big difference. Here are some suggestions:

Focus on your strengths. Think about what others are going through – and know that you, too, will have the inner resources to cope. You’ve been through tough times before and survived. You will cope with this, as well.

Keep to your routine as much as you can. If you’re used to stretching and walking in place for half an hour each morning, stick to that routine every morning you can. Do you have a cup of tea in the middle of the afternoon? You’ll find you enjoy it even more now, even if you have to juggle your responsibilities to squeeze it in.

Be willing to accept help. Friends, family, hospice volunteers, and hired helpers can provide much-needed backup. Being open to accepting their help is a gift – to yourself, but also to them. In accepting help, be honest and specific about your needs. Ask someone to run an errand, mow the lawn, bring food, or sit with the patient while you go for a walk or take a nap.

Take time for yourself. A few quiet moments can be renewing. A walk with an old friend can help you keep your perspective. A bath, while someone else cares for the patient, can ease the aches of body and soul. It is important to make time for yourself and identify pleasurable activities as a part of your caregiving routine. Try to set a goal of at least one outing per week.

Pay attention to your own physical needs. You may become so busy being a caregiver that you forget about yourself. Eating properly, getting enough sleep and rest, exercising regularly – these are the basic building blocks. Healthy frozen dinners, meals prepared by a friend, a nap to offset missed sleep, and a short walk around the block to clear your mind can all play a role in keeping you grounded and giving you the emotional and physical reserves you need.

Practice simple relaxation techniques. Count breaths or focus on pleasant images while sitting in a relaxed state in a quiet place. Try this especially when someone else is providing the patient’s care – for example, when a member of the hospice team visits. Don’t forget, too, that laughter and keeping your sense of humor are as important as ever.

Renew or grow in your faith and spirituality. If you are part of a faith community or religious tradition, reserve some time each day for living and growing in your faith. If you are not, you may still find renewal and inspiration in spiritual reflection or readings.

Caring for Someone in Bed

As a person becomes weaker, he or she spends more time lying in bed or sitting in a chair. Moving becomes more difficult. Yet changing positions becomes more important than ever – to prevent bed sores and reduce pain and discomfort.

Repositioning a patient in bed – before you begin:

- Start by explaining to the patient what you are doing before you actually do it; if they can help, let them know how.
- Providing pain medication beforehand may help if repositioning has been causing pain.
- If someone is available to help you with repositioning, it will be easier on your back.
- Keep any tubing free, so it does not become tangled or get pulled.

Repositioning a patient in bed – protect your back by using good body mechanics:

- Never twist your back or trunk; instead use your legs and feet to turn your whole body.

- Lift with your legs, not your back.
- Bend or flex your knees; use legs and stomach muscles.

Repositioning a patient in bed – how to use a “drawsheet”

- A folded sheet (“draw” sheet) placed under the body (neck to buttocks) can be used to move the patient around in the bed. It assists in maintaining the patient’s body alignment during movement.
- To place a draw sheet under a patient, stand next to the patient at the side of the bed, roll him onto his side so that half of the bed is exposed. Lay the sheet open on the exposed half of the bed, tuck half the sheet up against the person’s back. Then go to the other side, roll the person the other way onto the sheet, and pull out and straighten out the tucked half of the sheet.
- Always support the head if the patient is unable to.
- Two people can move a patient up in the bed by rolling both sides of the sheet up close to the patient’s hips and together sliding the patient up in the bed. The patient may be able to help by flexing at the knees and pushing up with feet and knees.
- One person can use a draw sheet to move a patient up in bed by going to the head of the bed, grabbing the top end of the draw sheet, and pulling it and the patient up toward the head of the bed. One person can also use a draw sheet to move a patient from one side of the bed to the other.
- To remove the draw sheet, just reverse the side-to-side steps.

Repositioning a patient in bed – other suggestions:

- Raise the bed to a comfortable height level so you aren't bending over so much.
- When moving the patient to the near side of the bed, begin with the head then the shoulders, trunk, legs, and feet.
- When moving from side to side, it can be helpful to bend or flex the knees. This helps the rotation of the hip; the body will follow.
- When the person is in the new position, support the arms and legs with pillows or rolled up towels, especially when the person is lying on his side.
- If the person isn't able to communicate, imagine yourself in that position. Check that the person is not lying on a shoulder or arm.
- Rearrange pillows. Pillows can be placed for support under the person's head, between the knees, or under hands or arms.
- Keep skin clean and dry. Keep linen and clothing dry and wrinkle-free.
- Reddened areas or opened areas of skin need to be checked by the nurse. Apply lotion and massage the skin to promote circulation and general comfort.

Safely Moving a Patient from One Place to Another

There are time-tested techniques for safely moving a frail patient from wheelchair to bed, or from bed to chair. A member of the hospice team can demonstrate the basics, help you practice them, and answer your questions.

Here is one scenario: transferring a patient from bed to chair:

- First, take a moment to plan what you are going to do and the safest way to do it.
- Let the patient know what you'll be doing and how he can help.
- Always assist the patient to his strong side if he has one.
- Always lock/secure the bed, the wheelchair, and/or chair to prevent movement.
- Place the chair close to the bed, equalizing heights as much as possible; normally you will want the bed in a low position, with the head raised to a sitting position, if possible.
- Help the person to a sitting position; raising the head of the bed makes this easier.
- Give the person time in a sitting position to be sure that any dizziness subsides before helping him stand up.
- Stand in front of the person being transferred, with your feet apart – this broadens your base, improving your balance and control.
- Absorb any strain with your knees and legs, not your back – keep your back straight.
- Flex your hips slightly.
- Stand in front of the person and put your arms around their body, placing your hands on their ribs in back.
- Ask the person to place their hands on your shoulders, not around your neck.
- Make sure the person places his feet on the ground.
- Using your weight to balance, and keeping your knees slightly bent, gently rock the person into a standing position. Coaching the patient may help: “1, 2, 3, Up.”
- To turn, continue to counterbalance with your weight and maintain a wide-based stance; pivot on your feet, slowly turning your whole body, not twisting your trunk.
- Gently lower the person into the chair by bending your knees.

Giving a Patient a Bath in Bed

When using the bath or shower is no longer possible, the option is to give the patient a bed bath. A bed bath is about more than just being clean – it involves movement and exercise, stimulates circulation, helps prevent pressure sores, promotes relaxation, and gives the caregiver an opportunity to check the patient’s skin for breaks, redness, or areas becoming irritated.

Have these supplies ready:

- Towels and washcloth
- Clean clothes
- Soap (oatmeal soap can help with itching)
- Basin
- Lotion (containing lanolin)

General “how to” principles:

- Give pain medications one hour before bathing, if movement is painful.
- Suggest toileting before beginning.
- When giving a bath, encourage independence when possible.
- Provide privacy and prevent drafts.
- Adjust the bed to a comfortable position.
- Bathe only a small area at a time, keeping the person covered with a towel or blanket to avoid chills.
- Change the water frequently when it is dirty, soapy, or cool.
- If the person is unable to tolerate a full bath, offer to wash the face, hands, back and perianal (crotch and groin) area only.
- Avoid powders. Cornstarch is a good substitute for powder and can be lightly sprinkled on linen.

The steps to follow:

- Fill the basin two-thirds full with warm water.
- Wash one area at a time, starting with the face—drying the person as you move from one area to another.
- Wash the eyes from the inner to the outer corners, using water only, rinsing the cloth after each eye.
- Wash and rinse the face, neck, and ears.
- Work from the head down with long, circular motions, washing, rinsing, and drying thoroughly.
- Roll the person onto her side.
- Wash, rinse and dry the back.
- Wash the feet; sometimes it's comforting to place feet in a basin of warm water.
- Apply deodorant and lotion, and put on clean clothes, gown, or pajamas.

Cleaning the Perineal (Groin) Area

The patient may wish to wash this area by him- or herself. But if this is not possible, proceed this way:

For females, separate the labia with one hand and cleanse the area with downward strokes.

For males, clean the penis with circular motions. Pull back the foreskin of the uncircumcised male to clean this area. Wipe from front to back, changing location with each wipe. Daily washing of this area and after toileting is important to prevent infection and skin breakdown. There are skin protecting lotions which can be applied.

Mouth Care

Good mouth care can be easy to overlook, but it helps prevent sores, improve appetite, and promote general comfort.

Have these supplies ready:

- Soft toothbrush
- Towel
- Toothpaste
- Small bowl

General “how to” principles:

- When giving mouth care, have the person sit up in an upright position, if possible.
- Place the towel under the chin.
- Brush teeth and gums gently with toothpaste.
- Try to remove all food particles and crusted materials.
- To prevent gagging, avoid putting the toothbrush too far back in the person’s throat.
- Rinse the mouth out with cool water.
- If the person has dentures, remove and clean them. (Cleaning dentures after meals may also help. When people lose weight, dentures may no longer fit properly. This may be caused by a change in the shape of the jaw. Poorly fitting dentures may result in mouth sores. Some people choose to leave dentures out and eat softer foods.)
- If you notice mouth sores, tell the nurse – there are medications that may help.
- After finishing mouth care, apply a moisturizer to the lips and the corners of the mouth to prevent cracking.

Changing Bed Linens

For most people, clean sheets are one of life’s under-rated pleasures. When we’re sick, we appreciate them even more. Change sheets when they become soiled, wet or sweaty. They may need to be changed as often as several times a day, or as infrequently as once a week.

Changing bed linens is obviously easier if the person can get out of bed. But if that is too difficult, follow these easy steps:

- Have the clean linens available and near before you begin.
- Untuck the top sheet.
- Roll the person to one side of the bed; be careful the person doesn't slip off the side.
- Position yourself at the side of the bed farthest from the patient.
- Loosen the bottom sheet along the near side of the bed and roll it up along the person's back.
- Position the clean bottom sheet on the open side of the bed and tuck it in.
- Roll the rest of the clean sheet up close to the patient.
- Help the person roll back over both sheets and onto the clean sheet.
- Pull away the dirty sheet carefully and tuck the clean one into the bed.
- Help the person back into the middle of the bed in a comfortable position.
- Replace and tuck in the top sheet and cover.
- Change the pillowcases.

Confused / Anxious / Agitated Patients

Sometimes patients become forgetful and confused. They may move about in ways that could injure themselves or others. If this is a risk you feel you are dealing with, talk it over with the patient's physician or the hospice nurse. The hospice team will help you plan for patient safety.

In many cases, there are steps you can take to deal safely with a situation. For example:

Make the person more comfortable with:

- Repositioning frequently
- Food or drink
- A back rub
- Toileting
- Appropriate clothing
- Glasses, hearing aid, dentures

Increase activity level:

- Walking
- Recreation/social activity
- Exercise

Make environmental changes:

- Reduce noise
- Adjust lighting
- Aid mobility (cane, wheelchair)
- Change of location
- Use electronic bells/signals
- Use baby monitors
- Make the home safe (clear pathways, remove loose rugs, etc.)
- Play soft, familiar music
- Personalize space (with familiar objects)
- Have patient in supervised area (not left alone)
- Confine patient to a safety-proofed area

Provide psychosocial stimulation:

- One-to-one attention
- Reality orientation (for example: stating what day it is, the time, location, and who is present)
- Something to hold (gives sense of security)
- Relaxation techniques (massage, warm bath, touch).

Preventing the Spread of Infection

Infections are caused by germs that spread from one person or location to another. Some germs, like colds and flu, spread when you come in contact with a contaminated surface. Washing your hands the right way and at the right times is the main way to preventing these kinds of infections.

Other infections, like HIV (the virus that can cause AIDS) and Hepatitis B, are found in blood and other body fluids. The key to stopping these types of infection is to prevent unprotected contact with blood and other body fluids. Still other infections, like Tuberculosis, are carried on tiny particles in the air.

Helping prevent the spread of infection is one of the major responsibilities of being a caregiver. Infections can cause disease and serious complications for the patient, the caregiver, and others visiting or living in the home.

So, what are your “must do” steps for stopping the spread of infection? Here are five of the most important rules to know and follow:

1. Get in the habit of washing your hands both before and after: providing care; eating, drinking, or handling food; using the toilet; covering a cough; or blowing your nose. If washing with soap and water isn't possible in a particular situation, use an alcohol-based sanitizer hand gel, then wash your hands as soon as you are able to. (The reason for always washing with soap and water is that some potential sources of infection are not killed by sanitizers and must be removed through hand-washing.)

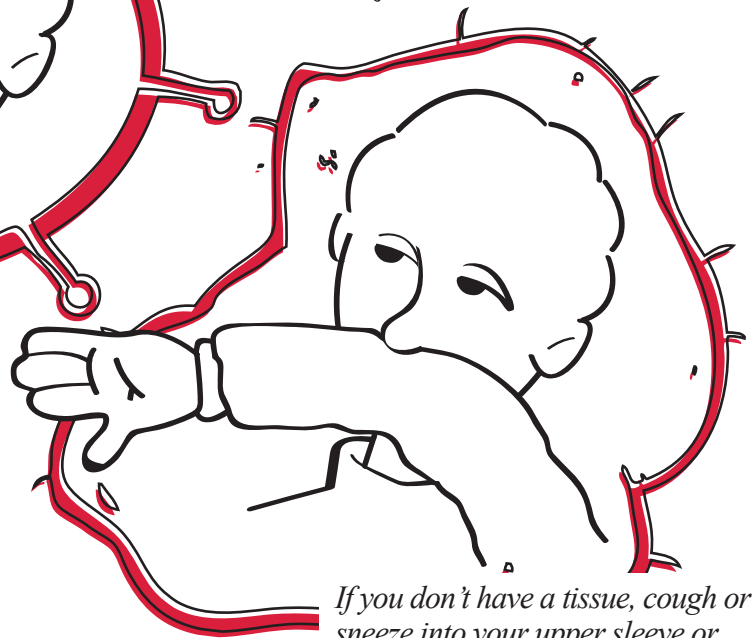
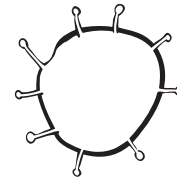
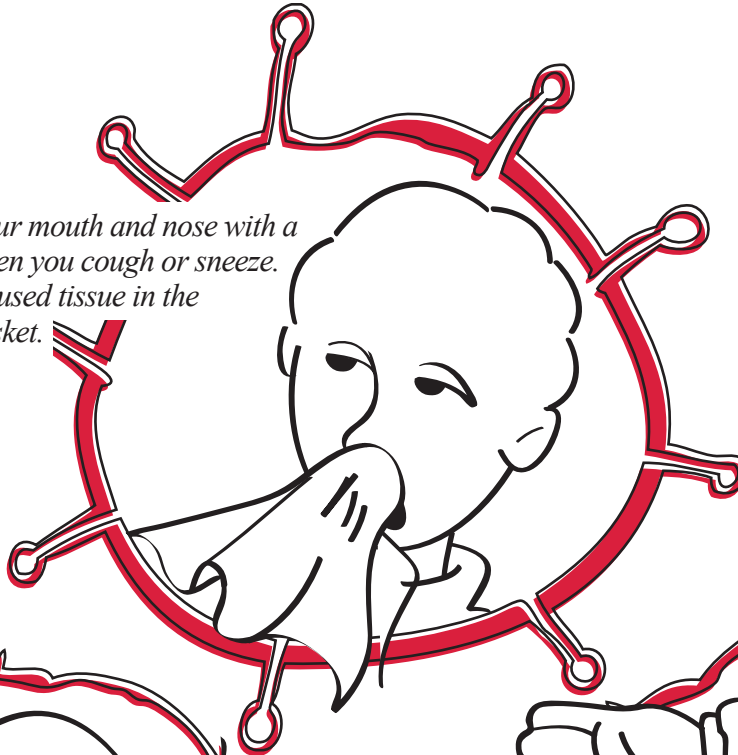
When you wash your hands, take the time to do it correctly. Follow these steps:

- Push up your sleeves and rinse with warm water.
 - Work your hands together with soap for at least 20 full seconds (about the time it takes to sing the “Happy Birthday” song twice).
 - Get under your nails and cuticles.
 - Rinse well.
 - Dry your hands using a clean paper towel, then use a dry paper towel to turn off the faucet; it is good practice to not share a cloth hand towel.
2. **Use extra caution around blood, body fluids, and any sharp objects** (like used syringes). Ask the hospice team what special safety precautions they recommend.
 3. If **personal protective items**, such as gloves or masks, are recommended or specified by the hospice team, be sure you learn how to put them on and take them off correctly, and then use them as directed.
 4. Maintain a **clean caregiving environment**. If there is a spill of blood, avoid direct contact with blood during clean-up. Ask the hospice team about correct disposal of used syringes, bandages, and other contaminated items. Follow the directions they give you.
 5. Finally, **include others in the work** of preventing the spread of infection. Make it clear to others involved in care, and to guests who visit, what is expected, especially the how and when of hand washing.

Cover Cough

— *Stop the spread of germs that can make you and others sick!* —

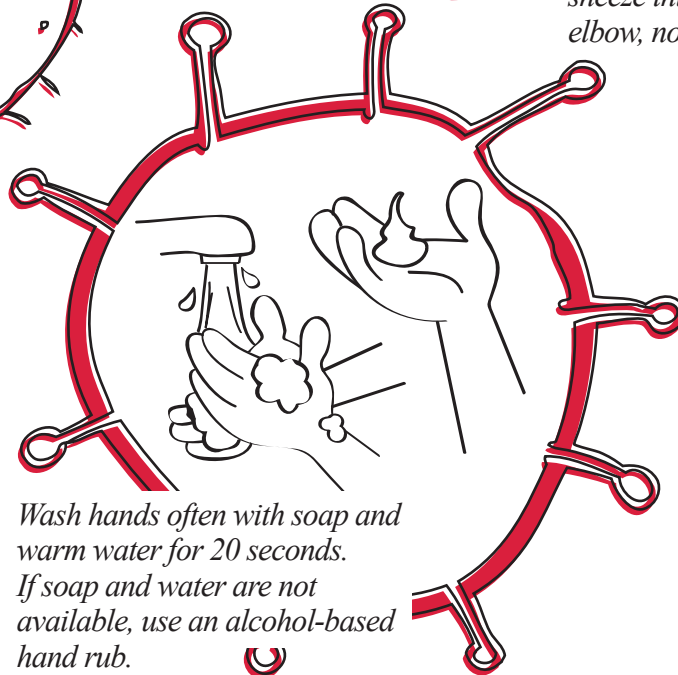
Cover your mouth and nose with a tissue when you cough or sneeze. Put your used tissue in the waste basket.



If you don't have a tissue, cough or sneeze into your upper sleeve or elbow, not your hands.



You may be asked to put on a facemask to protect others.



Wash hands often with soap and warm water for 20 seconds. If soap and water are not available, use an alcohol-based hand rub.



Using Oxygen Safely

Safe use of oxygen is important. Basic points for using oxygen safely include:

- The prongs of the nasal cannula must be in the patient's nose.
- If using a face mask, it must fit snugly on the person's face.
- Small pieces of cotton or pads between tubing and skin can lessen irritation if it occurs.
- Understand how to use the equipment and any backup system.
- Oxygen is a drug and must be used only as prescribed by your physician. Treat it just like any other medication your loved one takes. Don't change the amount unless instructed to do so. Oxygen needs vary with activity.
- Never use petroleum products (e.g., oil or grease) if oxygen equipment is being used, because of the risk of combustion. Vaseline is a petroleum-based product and should never be used for nasal irritation. Instead, use a water-based moisturizer such, as K-Y Jelly.
- Make certain that the delivery device (cannula, mask, etc.) is clean, to reduce potential infection and to assure adequate oxygen delivery.
- Oxygen tubing should be no longer than 50 feet, to avoid decreasing the amount of oxygen received.
- Check with your oxygen provider or hospice team regarding safety restrictions on smoking and the presence of any open flame (such as a candle, wood stove, or fireplace) in the home. It is essential that everyone visiting or living in a home where oxygen is in use knows and follows these restrictions to the letter.

Types of Oxygen Delivery Systems—Precautions, Instructions

There are different ways that oxygen can be provided:

Concentrators—These machines take the air and concentrate it into oxygen.

- Place concentrators away from curtains, heating units, or open flame.
- Remove any frayed electrical wiring. Do not use extension cords. Concentrators draw as much as 5-6 amps; be careful not to overload circuits.
- Do not use aerosol sprays in the vicinity of the concentrator, as they may clog the filter.

Liquid Systems

- Store in a cool, well-ventilated place at least ten feet from outlets, open flames or other heat sources.
- Do not touch the fill adapter (the area that frosts over) after filling the portable.
- Special precautions are required when traveling with liquid oxygen, especially during hot weather when car temperatures may exceed 200° F. Windows must be left open for ventilation and the car's electrical system must be in good working order to prevent sparks from igniting in a highly combustible atmosphere.

Tank Oxygen

- Store away from heat sources. The pressure inside the tank increases as cylinder temperature increases.
- Secure tanks to the wall, stand, or other stabilizing device to prevent them from falling over. Because of high pressures inside the tank, damage to the tank or regulator can be dangerous. Do not store in hot, unventilated areas, such as trunks of cars, closets, storage units, etc.
- Tanks that are not secured need to be laid on their side.

Remember: both liquid and cylinder oxygen must be secured with a seatbelt when traveling by car.

Other Home Safety Recommendations

Perform a home safety check up to be certain your home is a safe place in which to provide hospice care. Check to make sure there are no conditions that are “accidents waiting to happen.” Here are some practical tips on home safety:

General:

- Be sure the phone works and is within reach.
- Keep a list of key people and their phone numbers next to the phone.

Fire Safety:

- Install working smoke/heat alarms.
- Have fire extinguisher available.
- Avoid smoking in bed.
- Practice and discuss what to do in case of fire or if you smell gas or something burning.

Electrical:

- Do not overload the circuits.
- Do not use frayed cords or faulty switches.
- Do not stretch cords across pathways.

Accident Prevention

- Remove throw rugs or secure them to the floor.
- Keep exits/entrances free of clutter.
- Make sure traffic areas have adequate lighting.
- Wear shoes that will not slip.
- Use non-skid mats.
- Set hot water heater below 120°.
- Consider adding grab bars to the bathroom.
- As walking becomes more difficult, using a bedside commode, walker, and wheelchair may become necessary.

Don't Overlook Emergency Readiness

In the unlikely event of an emergency or disaster, your hospice team will do everything it can to continue providing care and support. But natural or other disaster could prevent that from happening and mean that for a time you will be on your own.

So, spending some time on emergency readiness is always a good idea.

Loss of power is often the first concern. If your loved one's health status depends on electrical equipment, planning ahead is critical and essential. Register any life-sustaining equipment with your power company and ask if there is a center designated to provide emergency power access in your community.

Here are some additional recommendations:

- Know the locations of shut-off valves for your household utilities (gas, electricity, water) and how to use them; if they require a special tool, have it nearby and ready to use.
- Disasters may come as fire, flood, hurricane, tornado, earthquake, winter storms, extremes of hot or cold weather, or prolonged power outages; some of these depend on where you live, so learn what the major risks in your area are, and prepare accordingly.

- Have readily available a list of emergency phone numbers, or in the case of phone outages, a plan with family/neighbors to obtain assistance.
- Designate an out-of-area emergency contact, in case local phone service is disrupted. Make sure others know your emergency communication plan. It is helpful for them to know that you are with a hospice program.
- Use an emergency supplies checklist to pull together both the supplies you would need to be on your own for several days while you “shelter in place” and a “grab and go” bag containing supplies for evacuating safely.

Conversations Near the End of Life

The greatest gift we can offer one another is our undivided attention. This is especially true when a person is seriously ill with a life-threatening disease. The person you’re taking care of – loved one, friend or neighbor – may express anxiety, sadness or fear about the future or regret about the past. The person may express a wish to “make right” broken relationships.

Try to listen without judgment or an agenda of your own. You don’t have to be a licensed health care professional to listen respectfully and to share feelings openly and honestly. Expressing these emotions is part of the “work” of dying; listening is part of the work of a loving caregiver. The process also has a strong spiritual element for many people. Your loved one may talk about what life means, or feelings about people or events that have been part of his or her life.

Questions About Living

When there is only a short time left in life, there are often choices to make in order to use one’s remaining time well.

- What do you still want to accomplish?
- What do you need to do to get your affairs in order?
- Who are the people with whom you want to spend time?
- Are there letters you want to write, conversations you’d like to have, matters you need to resolve?
- What will bring pleasure to this part of your life?

It is healthy and natural to think about these questions, and to talk about them with family and friends. Those who know they are going to die soon often experience high quality of life, resulting from the freedom to focus energy on what is really important.

Questions About Dying

Death is a mysterious journey for all of us. It is natural to have questions about the process and what it means. Such questions may include:

- What do I believe about what happens to a person during and after death?
- Are there ways to prepare spiritually for dying?
- What will make me less sad or afraid?
- How do I sum up my life, make peace with who I have been and who I am?
- What kind of funeral, memorial service, or other remembrance do I want after my death?
- Who do I want with me when I die?

These questions and others like them can be painful, but they can also bring great joy and a sense of inner peace. Each of us is different, of course. But many who are experiencing a terminal illness need and welcome persons who do not close off such conversations, but instead encourage them, listen supportively, and offer to share their own ideas and life experience, when that is helpful.

Who Can Help?

Over the past few decades, our culture has become more open in acknowledging dying as a normal stage of life. We now have professionals with special training to help those at the end of life ask the questions and find the answers that will make a difference to them.

Priests, ministers, rabbis, other leaders of spiritual communities: These people can be a significant resource for persons nearing the end of life, and for their loved ones. Every religious and philosophical community has its own beliefs around death and dying. To talk with someone who can both sensitively listen and also articulate a particular faith position can be a real gift. Many religious leaders are happy to extend themselves, even to those who are not officially a part of their church, synagogue, or other faith community. Don't be afraid to ask.

Chaplains, pastoral care counselors and grief counselors: A chaplain, pastoral care professional or volunteer, or grief counselor may be available. They are trained to be helpful to people across a wide spectrum of spiritual beliefs and are available to both patients and their families.

Private therapists: Especially when a person or family faces thorny issues—such as unresolved family conflicts—a private counselor or therapist can help. In finding a therapist, you can ask people you know for referrals. It's usually a good idea to have a “get acquainted” phone conversation with the therapist you are considering to make sure he or she is someone with whom you would be comfortable.

Support groups: Sometimes, it helps to talk with others who are in the same position as you. You can share insights, find humor where others may not, and support one another. Ask your hospice team about support groups available in your community. Online support groups are also becoming popular.

Friends and family: Family and friends probably do not have special training. They may not even have previous experience being with one who is dying. But if they are emotionally able to get past any discomfort they have talking openly about death and dying, they can be the very best resource available.

Preparing for Approaching Death

When a person enters the final stage of the dying process, two different dynamics are at work which are closely related and interdependent.

One is the physical process, in which the body begins the final process of shutting down, which will end when all the physical systems cease to function. Usually, this is an orderly and undramatic, progressive series of physical changes which are not medical emergencies requiring anything other than comfort measures. These physical changes are the natural way the body prepares itself for death. You can aid in this process by keeping the person as comfortable as possible.

The other dynamic at work is the spiritual and emotional process patients go through at the end of their lives. They begin to release themselves from a lifetime of attachments and often feel moved to resolve unfinished business. This may include tying up loose ends in their relationships or looking for permission to die from their family members.

Patients sometimes linger on in their dying process when important issues remain unresolved. Dying cannot be rushed. The person will continue to live until the body has physically shut down. Working through these emotional and spiritual events which simultaneously occur with the deterioration of the body is the normal and natural way a person prepares to die.

Family members can help this spiritual and emotional process along by following the patient's lead. If he wants to communicate with you, be ready to do so. Maintain an open, affectionate heart for whatever way the patient wants to work. For instance, it may be more beneficial to surround the patient with pictures of whatever religious figures he requests, rather than family photos. This can aid the patient in the sense of transition out of this world into the next. This is not the time to attempt to change your loved one. Instead, it's a time to offer unconditional acceptance, support and comfort.

A Natural Process

The physical signs of impending death which follow are offered to help you understand the natural way this event occurs and what you can do to help. Not all these signs and symptoms will occur with every person. Although you may be prepared for the death process, you may not yet be prepared for the actual moment of death. It may be helpful for you and your family to think about and discuss what you will do when this moment occurs. The death of a hospice patient is not an emergency as we usually define it. There is no rush. Nothing must be done immediately.

Physical Signs of Approaching Death and Appropriate Responses

Coolness: The person's hands, arms, feet and legs, may be increasingly cool to the touch and at the same time the color of the skin may change. The underside of the body may become darker and the skin may become mottled. This is a normal indication that the circulation of blood is decreasing to the body's extremities and being reserved for the most vital organs. Keep the person warm with a blanket, but do not use an electric blanket. Fluctuations in body temperature are a sign of approaching death. This is normal. A cool washcloth on the forehead or under the arms can feel good to a patient who has a high temperature.

Sleeping: The person may spend an increasing amount of time sleeping and appear to be uncommunicative or unresponsive, and at times be difficult to arouse. This normal change is due in part to changes in the metabolism of the body. Sit with your loved one. Hold the person's hand. Do not shake the hand or speak loudly, but speak softly and naturally. Plan to spend time with the person when he or she is most alert and awake. Do not talk about the person in his presence as though he is not there. Speak to your loved one directly as you normally would, even though there may be no response. Never assume the person cannot hear; hearing is the last of the senses to be lost.

Disorientation: The person may seem to be confused about the time, place and identity of people nearby, including close and familiar people. This is also due in part to the metabolism changes. Identify yourself by name before you speak, rather than have the person guess who you are. Speak softly, clearly and truthfully when you need to communicate something important for the patient's comfort, such as, "It's time to take your medication." Explain why you are asking something – for example, "So you won't begin to hurt."

Incontinence: The person may lose control of urine and/or bowel matter as the muscles in that area begin to relax. Discuss with your hospice nurse what can be done to protect the bed, and keep your loved one clean and comfortable.

Congestion: The person may have gurgling sounds coming from the chest as though marbles were rolling around inside; these sounds may become very loud. This normal change is due to the decrease of fluid intake and an inability to cough up normal secretions. Suctioning usually only increases the secretions and causes sharp discomfort. Gently turn the person's head to the side and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. Raise the head up with pillows to ease breathing. Medications are available that may help dry up secretions. The sound of the congestion does not indicate the onset of severe or new pain, and is usually more disturbing to the caregiver than to the patient.

Restlessness: The person may make restless and repetitive motions, such as pulling at bed linen or clothing. This often happens, and is due in part to the decrease in oxygen circulation to the brain and to metabolism changes. Do not interfere with or try to restrain such motions. To have a calming effect, in a quiet, natural way lightly massage the forehead, read to the person, or play some soothing music.

Fluid and food decrease: The person will likely experience decrease in appetite and thirst, wanting little or no food or fluid. The body will naturally begin to conserve energy which is expended on these tasks. Do not try to force food or drink into the person, or try to use guilt to manipulate them into eating or drinking something. To do this only makes the person more uncomfortable. Small chips of ice, frozen Gatorade or juice may be refreshing in the mouth. If the person is able to swallow, fluids may be given in small amounts by syringe (ask the hospice nurse for guidelines). A cool, moist washcloth on the forehead may also increase physical comfort.

Urine decrease and change in color: The person’s urine output normally decreases and may become tea colored — referred to as concentrated urine. This is due to decreased fluid intake, as well as a decrease in circulation through the kidneys. Consult with your hospice nurse to determine whether there may be a need to insert or irrigate a catheter.

Change in breathing: The person’s regular breathing pattern may change with the onset of a different breathing pace. A particular pattern consists of breathing irregularly, i.e., shallow breath with a period of not breathing of five to thirty seconds and up to a full minute. This is called Cheyne-Stokes breathing. The person may also experience periods of rapid shallow pant-like breathing. These patterns are very common and indicate decrease in circulation in the internal organs. Elevating the head and/or turning the person on the side may bring comfort. Hold the person’s hand. Speak gently. Cheyne-Stokes breathing is a normal part of the process. It is not uncomfortable for the patient and is an indication that the patient is close to dying.

When Death Occurs

People wish to handle the time of death and the events that follow in different ways. The hospice team’s first goal is to help you prepare, so you will know what to expect. Here are the typical steps when death occurs:

- Call the hospice office. A hospice nurse or other team member will speak with you and may come to your home. Check with them concerning appropriate notices to your doctor, medical examiner or coroner, etc.
- It may be helpful to have a friend or family member come to be with you.
- If you wish, the nurse will call the funeral home for you after the death. The funeral home usually arrives within an hour after the call. You may choose to wait several hours or longer before the funeral home comes if you wish to spend time with your loved one’s body or want to wait for other family members or friends to arrive.
- If you have any concerns or fears, call the hospice nurse.

Signs That a Person Has Died:

- No breathing
- No heartbeat
- No response to communication
- Eyes fixed on a certain spot

Practical Issues When Your Loved One Dies

Notifying Others That Your Loved One Has Died

When a loved one dies, some names will come to you immediately as persons who should be contacted. Close family; good friends; the person's minister, priest, or rabbi; their lawyer and physician. Some calls you will want to make yourself. Other calls have to be made, but you do not need to make them yourself.

When a death occurs, both your friends and your loved one's friends, as well as other family members, will want to help. It makes sense to let others help in passing the word. With friends, for example, or a church or community group, often you can make only one call and ask that person to organize informing others from that circle of acquaintances.

If there are many calls to be made, keep a list of who has been contacted. That way, there is less chance of overlooking someone important.

Working With the Funeral Home

Normally, within 24 hours of your loved one's death, you should be in contact with the funeral home to set up an appointment with a funeral director. Funeral homes offer a wide range of services at the time of death.

These usually include:

- Transporting the body from the place of death to the funeral home
- Preparing the body for burial, arranging for a casket and other necessary items for burial, or arranging for cremation
- Working with the family and, if desired, a priest, rabbi, or minister for a funeral or memorial service
- Providing time and space for visitation and a funeral or memorial service
- Assisting in the preparation of an obituary and funeral notice for the local newspapers
- Completing the necessary paperwork for the death certificate, and obtaining certified copies of the death certificate for the family. (Be sure to ask for an adequate number of certified death certificates. You will need one for each life insurance policy or pension the person had, and several more for processing the person's Last Will and Testament and other financial business. (A good rule of thumb is to request at least ten copies.)

- Transporting the body and family members (if desired) to the funeral or memorial service and/or to the cemetery.

Some funeral homes also offer support groups and bereavement counseling for family members of the person who has died.

Most funeral directors are professionally trained persons who provide their service with compassion and integrity. The role they play in a community is a necessary one, and most do their work sensitively. However, it is important to realize that funeral directors deal with people who are in an especially vulnerable state. When someone you love has just died, if pre-arrangements have not been made, you need to make quick decisions on painful issues.

These issues include whether the person will be buried or cremated, what kind of casket to buy, where to buy a burial plot, what kind of service to have. Some of these decisions may involve the outlay of significant amounts of money and may also be emotionally charged, so they become more complicated.

The following suggestions will minimize the risk of making decisions you later regret:

- Never send one family member alone to see the funeral director. If possible, have two or three family representatives go, one of whom should be more detached from the pain of the loss than a spouse, or sometimes even an older child.
- Most funeral homes offer a basic minimum service package. Additional services beyond that are charged individually. Make sure you understand what is included in the basic service, and what will be charged as additional services. Have the funeral director spell out the charges in writing. If you have questions about whether you want or need some of the services offered, go home and think about it, then call back with your answer.
- Remember, money does not equal love. Many people think they must buy an expensive casket or provide a lavish funeral to show their love. This is not true. Buy only what seems reasonable and appropriate in your situation.

The appointment with the funeral director is usually a part of the business of death that people dread. Arranging for caskets and funeral notices is no one's favorite chore. Try to schedule your visit far enough after your loved one's death that you and significant others have had a night's sleep and have had some time to talk among yourselves about the kinds of arrangements that seem best to you.

If your loved one has joined a memorial society or entered into some other form of prepaid funeral plan, you and other family members will have fewer decisions to make. However, you will also have less control. If you are uncomfortable with the arrangements that have been made, you may have little choice but to accept them and understand that they represent your loved one's wishes.

Planning a Funeral or Memorial Service

After one they love has died, most people find it helpful to participate in some structured ritual of celebration, remembrance, and letting go. Depending on the religious tradition and individual tastes of the deceased person and his or her family, this might range from a formal religious service followed by an elaborate wake, to setting a time for family members and friends to gather informally to talk about the one who has died. Such services, both formal and informal, can be a source of comfort and strength, gathering together the community of grief to laugh and cry and remember together.

Below is a list of questions which will help you in planning a funeral or memorial service for a close friend or relative that has died.

- Did your loved one leave any specific instructions about the kind of service that he would want? Did those instructions include specific requests for readings, music, a person to preside, or a place where the service should be held?
- When will it be convenient for the service to take place? Do close family and friends have schedules which have to be worked around in planning the time and place of the service? Do religious beliefs determine the timing?
- Where will the service take place? If the person belonged to a church, synagogue, or other religious community, when can it schedule a service?
- Who will officiate at the service? Will it be a minister or other religious leader, a family member, or friend? Do you want an organist, soloist, or other provider of music, and how will those arrangements be made?
- Are there readings, music, pictures, or any other elements which you think would be especially meaningful to you and others as part of the ceremony?
- Do you want to choose someone to deliver a formal eulogy? Do you or other friends or family members wish to offer some personal words of remembrance at the service?

- Do you wish to have visiting hours (a time when people can see the body, say a private goodbye, and speak with the family) before the service? This custom varies from community to community.
- Will there be any kind of reception or other informal gathering of friends and family after the service? Where will it be held?

If you work through a church or other religious community, your contact in that community will undoubtedly have other questions to ask you about the service. However, it is best to think about the questions outlined above before you meet with the person who will be in charge so that you have some idea about what you want.

Other Practical Issues

Along with the major issues of dealing with the death when it occurs—talking with the funeral director, and planning for a funeral or memorial service—there are other practical tasks large and small which should be attended to in the days and weeks following your loved one's death.

- You will want to contact the person's lawyer regarding the content of his or her will, if one exists, and any other legal business which needs to be attended to.
- Whoever has been appointed personal representative or executor under your loved one's last will and testament will need to contact the person's bank, financial planner, pension administrator, life insurance company, and any others with whom the person had significant financial dealing to inform them of the death.
- You should remember to cancel club memberships and magazine subscriptions and have mail delivery stopped or transferred.
- Outstanding bills need to be collected and paid, but this should always be coordinated with other aspects of handling the estate.
- For many families, one of the difficult things to do is to go through their loved one's personal possessions—clothing, papers, mementos, furniture. If there is a personal representative or executor, he or she will coordinate this task. Like visiting the funeral home, sorting through belongings is something that's usually much easier when two or more family members share the load.

Taking care of all the business that needs to be sorted out after a death can take weeks or even months, depending on how the person's affairs were organized. It is tiring and emotionally draining work. If you can,

share the responsibilities with other family members, do hard tasks with another person, and don't take on too much at one time. It is normal to feel overwhelmed at times with the finishing up of things.

Experiencing Grief and Loss

Anticipatory Grief

Watching someone you love decline in health is a painful process. When death is anticipated, both the patient and loved ones may experience a normal form of grief. It is called anticipatory grief and is similar to the process of grief following a loss.

Some of the aspects of anticipatory grief that you may notice include:

- Heightened fear, anxiety and depression
- Increased concern for the well-being of the terminally ill person
- Imagining the actual event of the death
- Attempts to adjust to the changes that may occur after the death.

Although anticipatory grief is a painful process, having some warning prior to the death can allow for several things:

- Absorbing the reality of the loss over a period of time
- Saying goodbye and completing other unfinished business with the dying person
- Reassigning the family roles of the dying person
- Gradual withdrawal of emotional energy invested in the dying person.

There are many ways that you can care for yourself during your loved one's illness that can lessen the negative aspect of anticipatory grieving. Plan to have some time for yourself every day. Seek out ways to nurture yourself, including eating well, sleeping enough, exercising, and spending time with a friend for hugs and laughs.

The Grieving Process

A wide variety of feelings and behaviors can be experienced in the grief process. Not everyone will respond to loss in the same way. It is helpful to know that the following characteristics can be a normal part of the grief experience:

Feelings. Feelings that are part of the grieving process can include shock, numbness, a sense of unreality, anger, irritability, guilt, self-reproach,

sadness, depression, anxiety, fear, hysteria, helplessness, vulnerability, low self-esteem, loneliness, relief, feelings of being crazy, mood swings and increased intensity of all feelings.

Physical sensations. Physical sensations experienced during grief can include hollowness in the stomach, tightness in the chest and throat, dry mouth, over-sensitivity to noise, dizziness, headaches, shortness of breath, weakness in the muscles, lack of energy, fatigue, excess of nervous energy, heart pounding, heavy or empty feeling in body and limbs, hot or cold flashes, skin sensitivity, stomach and intestinal upsets and an increase in physical illness.

Thought patterns. Grief-related thought patterns can include disbelief; a sense of unreality; preoccupation; confusion; lack of ability to concentrate; seeing, hearing or feeling the presence of the deceased; thoughts of self-destruction; problems with decision making.

Behaviors. Behaviors while experiencing grief include appetite and sleep disturbances, absent-minded behavior, social withdrawal, avoiding reminders of the loss, dreams of the loss, searching and calling out for the deceased, restlessness, sighing, crying, visiting places that are reminders of the loss, treasuring or carrying objects that belonged to the deceased, change in sexual activities, need for touch, hugs, contacts with others, increased sensitivity to positive and negative attention, assuming the mannerisms of the deceased, and exhibiting symptoms of the deceased's illness.

Social changes. Social changes brought on by a grieving process can include: either an increased desire for support of close friends or a withdrawal from friends and family; increased dependency on others; a need for acting normal around others; a need for relationships apart from those related to grief; being self-absorbed (no energy for or interest in others); marital difficulties — especially with the death of a child; role changes; role reversals; change in social patterns and status; hypersensitivity to topics of loss; and the need for rituals.

Suggestions for Coping With Grief

Allow yourself to feel your feelings. Someone close to you has died. Many emotions may arise. It's okay to feel angry, depressed, or even feel a sense of relief at the time of death.

- **Access your support system.** Reach out to people who are supportive to you. Family, friends, support groups, clergy or a therapist may be helpful.
- **Share your feelings of grief.** Talking about your feelings can be a relief. Don't hide your emotions from those who care about you.
- **Educate yourself about grief issues.** Reading literature about grief can help you understand what you are experiencing.
- **Take care of your physical self.** Remember that your emotional state can be affected by your physical state. Attempt to eat balanced meals, get adequate sleep, and do some form of exercise each day.
- **Avoid alcohol and other substances not prescribed by your physician.** Although they may numb the emotional pain initially, drugs and alcohol may prolong, delay and complicate your grief.
- **Give yourself permission to say "no."** Try not to rush or take on new responsibilities.
- **Be patient and gentle with yourself.** Healing from grief takes time. Your grief may not look like the grief of others around you. Respect your own individual grief style.

Helping Children Deal with Their Grief

Children process grief and loss differently than adults do. For example, they may be repetitive in dealing with their loss. As they reach each new level in their own growth, they use their newly acquired skills and maturity to gain further understanding of their grief. The child's history of loss and coping strategies, as well as the child's age and developmental stage, will affect how they experience their loss and the grieving that goes with it.

It's also true that children grieve not only in their own right, but also as part of a family. When a loved one is diagnosed with a terminal illness, it affects the way in which the family functions. Family roles and responsibilities may adjust to accommodate the new needs in the family structure.

Children may grieve not only for the dying loved one, but also for the secondary losses which result – for example, changes in routine, decreased attention from parents, increased individual responsibilities, etc.

If there are children involved in your hospice situation, feel free to discuss their needs with the hospice social worker.

When Your Caregiver Role Ends

Whether your role as hospice caregiver lasted for days, weeks or months, you will no doubt end your journey with questions. Should we have accessed hospice earlier? What could I have done better? How do I move from an all-consuming focus on being a caregiver to dealing with my own grieving process? What have I learned from this that may one day apply to my own end-of-life care?

As you look back and reflect on the experience you've just been through, remember that you cared for your loved one—spouse, parent, grand-parent, sibling, or other relative or friend—with compassion and skill. You served in an intimate and timeless role, at the moment your loved one needed you. Your being there didn't change the fact that the person died. Nothing could have. But it did fundamentally change the way the person died. You contributed by helping manage pain and other symptoms, by making the person as comfortable as possible, by helping maintain the person's dignity, and, most of all, by just being with the person when he or she needed you.

Many who serve as a caregiver to a loved one who is dying feel a sense of let-down and emptiness when their responsibilities draw to a close. This is a normal reaction after a time of extreme demands and unusual stress. You may have a range of emotions about the experience you have been through—from relief that it's over, to sorrow that you were powerless to alter the outcome, to anger that your loved one has died.

More than anything, remember that you have done your best. And, really, that is all that can reasonably be asked of any of us. So, be gentle with yourself. Treat yourself with the same care and compassion you have shown others. Just as there were resources available to help you as a family caregiver, there are resources available now to help you make sense of your experience and move on to the next chapter in your life.

Funeral or Memorial Service Planner

Name: _____

Date: _____

Type of Service Preferred

Funeral—open casket

Religious

Funeral—closed casket

Non-religious

Memorial service

Family only

Other

Open

Arrangements

Location of service: _____

Time of service: _____

Do you wish to hold visiting hours before the service? _____

When? _____ Where? _____

Do you wish to have a reception after the service? _____

When? _____ Where? _____

Content of Service

Organ or other instrumental music Soloist

Hymns or songs for congregational singing

Musical selections: _____

Scripture readings/other readings: _____

Eulogies/personal statements or recollections: _____

Other important elements: _____

Participants

Person(s) of citing: Musicians:

Speaker(s):

Pallbearers/honorary pallbearers:

Ushers:

Other notes:

Levels of Care

Routine Care

When symptoms are well managed, patients require less intensive care. This level of care is generally provided in your home or in a setting of your choice. However, Medicare and other insurance plans do not cover room and board costs.

General Inpatient: (Acute Care)

Admission or transfer into General Inpatient Care Unit may be required to control a patient's pain or other acute symptom management. The team's efforts are directed toward resolution of the symptoms that prompted the admission. This level of care must be in an inpatient setting where more physician and nursing care is available.

General Inpatient Unit is for patients whose condition necessitates an inpatient setting. These stays are most often viewed as transitional, to control symptoms until the patient can return home or can be cared for in a less acute setting.

Services provided are consistent with the philosophy of the Hospice and are coordinated by a team of professionals. The team consists of a physician, skilled nurses, certified nursing assistants, medical social workers and spiritual counselors.

Transfer Planning

The inpatient interdisciplinary team assesses the level of care of patients daily. Once a patient's symptoms are managed, the social worker discusses care and options for transfer out of the acute care. Hospice services will follow patients to the setting of their choice. Continuity of care is assured through a plan of care involving the patient, family, physician, unit staff and home care staff to facilitate a transfer to one of the following:

- Back Home
- Routine bed available in a Care Center
 - Long Term Care Facilities
 - Assisted Livings
 - Group Homes

Continuous Care

To maintain a patient at home this level of care may be needed to achieve acute symptom management during a medical crisis. This period is generally limited to a short period of time. This level of care requires a minimum number of skilled care during a 24 hour period.

Respite Care

Respite care in an inpatient unit is to provide a rest for family or those persons caring for the patient at home. The Hospice Medicare respite benefit allows up to a five-day stay for this level of care.

Guidelines for Medication Disposal

New England Hospice believes that the proper destruction of medication is one way we can contribute in protecting our environment.

You may have heard about how medication that is not disposed of properly can be accidentally taken by someone else. It also has the potential of contaminating the environment and our water supply. The disposal of unused medication down sinks and toilets is no longer recommended.

The following are guidelines that we compiled for you from the US Food and Drug Administration (FDA) Pharmacies and other entities that regulate medication disposal.

The following guidelines were developed to encourage the proper disposal of medicines and help reduce harm from accidental exposure or intentional misuse after they are no longer needed:

- Follow any specific disposal instructions on the prescription drug labeling or patient information that accompanies the medicine. Do not flush medicines down the sink or toilet unless this information specifically instructs you to do so.
- Take advantage of programs that allow the public to take unused drugs to a central location for proper disposal. Call your local law enforcement agencies to see if they sponsor medicine take-back programs in your community. Contact your city's or county government's household trash and recycling service to learn about medication disposal options and guidelines for your area.
- Transfer unused medicines to collectors registered with the Drug Enforcement Administration (DEA). Authorized sites may be retail, hospital or clinic pharmacies, and law enforcement locations. Some offer mail-back programs or collection receptacles ("drop-boxes"). Visit the [DEA's website](#) or call 1-800-882-9539 for more information and to find an [authorized collector](#) in your community.

If no disposal instructions are given on the prescription drug labeling and no take-back program is available in your area, throw the drugs in the household trash following these steps:

1. Remove them from their original containers and mix them with an undesirable substance, such as used coffee grounds, dirt or kitty litter (this makes the drug less appealing to children and pets, and unrecognizable to people who may intentionally go through the trash seeking drugs).
2. Place the mixture in a sealable bag, empty can or other container to prevent the drug from leaking or breaking out of a garbage bag.

PATIENT BILL OF RIGHTS AND RESPONSIBILITIES

Observance of these rights and responsibilities contributes to effective patient care and increased satisfaction for the patient, as well as the agency. The rights are respected by all agency personnel and integrated into all agency programs.

If a patient has been adjudged incompetent under state law by a court or proper jurisdiction, the rights of the patient are exercised by the person appointed pursuant to state law to act on the patient's behalf. If a state court has not adjudged a patient incompetent, any legal representative designated by the patient in accordance with state law may exercise the patient's rights to the extent allowed by state law.

1. The patient has the right to exercise his/her rights as a patient of the hospice
2. The patient has the right to considerate and respectful care.
3. The patient has the right to receive services regardless of race, color, sex, sexual orientation, religion, disability, national origin, age, or payment source.
4. The patient has the right to appropriate, professional and high quality services, rendered within the federal, state and local regulations and accepted standards of practice.
5. The patient has the right to receive effective pain management and symptom control from the hospice for conditions related to the terminal illness
6. The patient has the right to complete information concerning his/her diagnosis, treatment, and prognosis, alternatives and risks in terms and language the patient can reasonably be expected to understand.
7. The patient has the right to a description of available services, unit charges and billing mechanism and any changes in such to be given orally and in writing as soon as possible but no later than thirty working days from the date the agency becomes aware of the change.
8. The patient has the right to expect his/her person and property will be treated with respect and he/she will not be subjected to mistreatment, neglect or verbal, mental, sexual and physical abuse, including injuries or unknown source.
9. The patient has the right to information necessary to give informed consent prior to the start of any procedure or treatment, routine or experimental.
10. The patient has the right to receive a prompt response from the agency to questions regarding services, plan of treatment and/or medical record.
11. The patient has the right to be treated by the physician of his/her choice and to communicate with the physician and others planning care without restriction.
12. The patient has the right to participate in the development of the plan of care, the disciplines that will furnish care, the frequency of visits proposed, changes in the care to be furnished, the person supervising the care and the manner in which that person can be contacted.
13. The patient has the right to be informed, both verbally and in writing, in a reasonable time of anticipated termination of service and to participate in developing the discharge plan.
14. The patient has the right to refuse service or treatment within the confines of the law, to be informed of the consequences of the action, and to be treated thereafter without being subjected to reprisal or discrimination.
15. The patient has the right to formulate advance directives without fear of retribution.
16. The patient has the right to have his family or guardian exercise his rights if he is adjudicated to be incompetent.
17. The patient has the right to have a legal representative exercise his rights to the extent permitted by law even if he has not been adjudicated to be incompetent.
18. The patient has the right to have all clinical records, communications and services maintained confidentially in accordance with federal, state, and local laws and regulations; and disclosure would require a medical record release of information statement signed by the patient or a verifiable legal guardian.
19. The patient, or his designated representative, has the right to be fully informed of his health condition unless contraindicated by a physician in the clinical record.
20. The patient has the right to access his medical record unless contraindicated in the medical record.
21. The patient has the right to receive effective coordination and continuity of care if one or more services and/or organizations are involved in providing care.
22. The patient has the right to be informed upon admission, verbally and in writing, of insurance coverage, other methods of payment and any liability for payment.
23. The patient has the right to be informed of changes in the initial payment information and the liability for payment as soon as possible after the agency becomes aware of such change, but no later than thirty working days from the date the agency becomes aware of the change
24. The patient has the right to information as to any relationship of the agency to any hospital, nursing facility, or educational institution.
25. The patient has the right to be informed as to the ownership of the agency and any vested interest in referrals.
26. The patient has the right to be informed of the complaint/grievance procedure.

27. The patient has the right to expect that the agency, within its capacity, will make reasonable response to the request of the patient for service.
28. The patient has the right to expect that the agency will investigate grievances made by a patient, patient's family or guardian regarding treatment or care provided or that fails to be provided and lack of respect for the patient's property by anyone providing services on behalf of the agency and that such grievances will be entered into a log which shall include date, nature of grievance and resolution.
29. The patient has the right to voice a grievance regarding service or staff without fear of retribution or discrimination from agency regarding treatment or care to be provided or regarding the lack of respect of or property by anyone providing agency services to:
 - A. The agency Administrator. All complaints made to this agency will be acknowledged and responded to promptly.
 - B. The Massachusetts Home Health Hotline 1-800-462-5540
 - C. The Consumer Protection Division of the Massachusetts Attorney General's Office. At 617-727-8400 between the hours of 9 and 5 weekdays.
30. The patient has the right to not be subjected to discrimination or reprisal for exercising his/her rights
31. The patient has the right to be informed about research in the agency that would directly affect the patient's care and refuse to participate.
32. The patient has the right to consideration of spiritual and cultural preferences in planning and implementing his/her care.
33. The patient has the right to examine and receive an explanation of his/her bill regardless of the source of payment.
34. The patient has the right to receive information about the services covered under the hospice benefit.
35. The patient has the right to receive information about the scope of services that the hospice will provide and specific limitations on those services.
36. The patient has the right to participate in the development and/or changes in the care plan and discharge plan, and to be informed in advance of all treatments or care the agency is to provide, the expected outcomes, barriers to treatment, changes in the care to be furnished and the name and function of any agency staff involved in the case.
37. The patient has the right to recommend changes in policies and services without discrimination or reprisal.
38. The patient has the right to be informed regarding the utilization of contracted help for the provision of his/her care and with regard to any financial responsibility he may incur as a result of that.
39. The patient has the right to be informed regarding admission and discharge criteria for the agency.
40. The patient has the right to be informed regarding third party coverage, any personal financial responsibility and the existence of any sliding fee schedule or uncompensated care provision.
41. The patient has a right to have assistance in understanding and exercising his/her rights.
42. Finally, the patient has a right to be informed as to the Hospice philosophy and concept.

In order to provide the most appropriate and effective care, it is the responsibility of the patient to cooperate with the agency in several important areas.

1. It is the responsibility of the patient to provide the agency with timely medical and insurance information.
2. It is the responsibility of the patient to participate in the development and implementation of the home health care plan.
3. It is the responsibility of the patient to give the agency complete information about the medical services you are receiving and physicians and facilities that are providing care.
4. It is the responsibility of the patient to inform the nurse or physician about previous medical advice and all medications or treatments being followed.
5. It is the responsibility of the patient to inform the nurse or physician if he/she does not understand instructions pertaining to medications or treatments.
6. It is the responsibility of the patient to inform the nurse or physician of changes in his/her health or reactions to medications or treatments.
7. It is the responsibility of the patient to follow the plan of care as designed by the patient and the care team.
8. It is the responsibility of the patient to remain under the care of a physician while receiving services from the agency.
9. It is the responsibility of the patient to assume costs for services not covered by a third party source.
10. It is the responsibility of the patient to inform the agency of any changes in the physician orders.

SUBJECT

CLIENT GRIEVANCE

POLICY

A grievance is a complaint or concern relating to patient care, conditions, or to the relationships between New England Hospice or caregiver, in which the patient believes that he/she has been wronged and wants the wrong corrected.

PROCEDURE

When the patient is admitted to New England Hospice, he/she will be given an admission packet that includes a copy of New England Hospice's Bill of Rights and Responsibilities. Receipt will be acknowledged and documented by the client's (or designee's) signature.

All complaints and concerns are to be dealt with by the Administrator (or designee).

When a complaint - whether written or verbal - is received, the recipient of the grievance will document receipt. It will also be documented at that time in the Client Grievance Log.

Once a resolution to the grievance is reached, the resolution will be documented in the same manner.

Each written grievance received by New England Hospice shall be responded to by New England Hospice in writing within 15 working days. A grievance received only verbally may be responded to verbally, but must be documented.

New England Hospice will notify the patient of his/her right to appeal its response.

A copy of the written response will be filed in New England Hospice grievance file and with the person designated as responsible for Quality Improvement.

If the patient files an appeal, it too shall be reviewed and responded to by the Administrator within 30 days of receipt.

The responses to the appeal will also be filed in the grievance log and with the person responsible for Quality Improvement.

Grievances shall be reported to the Board of Directors quarterly.

You can also contact the Joint Commission by following this link:
<https://www.jointcommission.org/en/contact-us/>

Or: Fax: 630-792-5636

Mail: Office of Quality and Patient Safety
The Joint Commission
One Renaissance Boulevard
Oakbrook Terrace, Illinois 60181

Phone: 630-792-5000

SECTION 504 GRIEVANCE PROCEDURE

New England Hospice has adopted an internal grievance procedure for prompt and equitable resolution of complaints alleging any action prohibited by the U. S. Department of Health and Human Services regulations (45 C.F.R. Part 84) implementing Section 504 of the Rehabilitation Act of 1973 as amended (29 U.S.C, 794).

Section 504 states, in part, that "no otherwise qualified handicapped individual shall, solely by reason of his/her handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." The law and regulations may be examined in the office of the Administrator:

**190 Old Derby Street, Suite 304
Hingham, MA 02043
781-749-2900
TDD:617-899-6831 (to leave message)
or 800-439-2370 for Mass relay service**

who has been designated to coordinate the efforts of the compliance of regulations.

1. A complaint should be in writing, contain the name and address of the person filing it and briefly describe the action alleged to be prohibited by the regulations.
2. A complaint should be filed in the office of the Section 504 coordinator within a reasonable time after the person filing the complaint becomes aware of the action alleged to be prohibited by the regulation.
3. The Administrator or his/her designee, shall conduct such investigation of a complaint as may be appropriate to determine its validity. These rules contemplate informal but thorough investigations, affording all interested persons and their representatives, if any, an opportunity to submit evidence relevant to a complaint. Under 45 C.F.R. S 4.7 (b), New England Hospice need not process complaints from applicants for employment.
4. The Administrator shall issue a written decision determining the validity of the complaint no later than thirty (30) days after its filing.
5. The Section 504 coordinator shall maintain the files and records of New England Hospice relating to complaints filed hereunder. The Section 504 coordinator may assist persons with the preparation and filing of complaints, participate in the investigation of complaints and advise the Administrator concerning their resolution.

NOTICE OF NONDISCRIMINATION

In accordance with the laws and regulation cited below *, New England Hospice does not discriminate on the basis of race, color, national origin, handicap, or age in admission or access to, or treatment or employment in, its programs or activities.

The person whose name appears below has been designated to coordinate our efforts to comply with the U. S. Department of Health and Human Services regulations implementing these Federal laws. You may contact this person for further information about these regulations and our grievance procedure for the resolution of discrimination complaints.

New England Hospice
190 Old Derby Street, Ste 304
Hingham, MA 02043
800-921-4538
TDD: 617 899-6831 (to leave a message)
Or 800-439-2370 for Mass Relay Service

*

- Title VI of the Civil Rights Act of 11964 (42 U.S.C. §2000d et seq.);
45 C.F.R. Part 80

- Section 504 of the Rehabilitation Act of 1 973, as amended (29 U.S.C. §794);
45 C.F.R. Part 84

- Age Discrimination Act of 1 97 5, as amended (42 U.S.C. § 61 01 et seq.);
45 C.F.R. Part 91

SERVICES AND FINANCIAL RESPONSIBILITIES

A. SERVICES

1. The hospice provides necessary services for the patient and his or her family and caregivers during and after the patient's life-limiting illness. These services include:
 - a. physician care, nursing, home health aides, homemakers, and continuous care nursing in times of crisis;
 - b. social services, spiritual care, and volunteer support;
 - c. physical therapy, occupational therapy, nutritional counseling, speech therapy, laboratory analysis;
 - d. drugs and biologicals, medical supplies, durable medical equipment
 - e. palliative chemotherapy, radiation, and certain surgical procedures when needed for pain and symptom management;
 - f. short inpatient stays, respite care;
 - g. bereavement care
2. A plan of care is developed and continually evaluated by the hospice team, the patient's primary physician, the patient and the patient's primary caregiver. All services listed above are provided in accordance with the plan of care. It is essential that any changes to the plan of care be done in consultation with the patient, family and hospice team members.
3. The hospice provides comprehensive coordination and analysis of needed drugs and medical supplies. This includes 24-hour emergency service for drugs and biologicals and home delivery as needed. It also includes drug monitoring, planning, education and anticipating undesirable side effects. The hospice will assist with and devise a plan with the family for disposal of medications that are no longer needed.
4. The hospice is primarily home care. However, if temporary inpatient care becomes necessary for symptom control or respite purposes, it will be available if authorized in the plan of care at the facility.

Patient care in this facility has been designed specifically for the need of the hospice patient and care is carried out jointly with the hospice team. Arrangements have been made to ensure continued care in these settings by the patient's own physician, whether or not he or she regularly practices there.

B. FINANCIAL RESPONSIBILITIES

1. For Medicare or Medicaid beneficiaries:

- a. For Medicare and Medicaid beneficiaries, all services for the care of the patient's life-limiting illness will be provided by The hospice, either directly or through contracted services. During the patient's 210 day benefit period, and beyond if still medically appropriate, the hospice, through Medicare or Medicaid, will cover the patient's full financial responsibility for these services with the following exceptions:
 1. If the patient decides to pursue a curative, non-palliative course of treatment;
 2. If the patient enters an inpatient facility without prior authorization from the hospice;
 3. If the patient enters an inpatient facility for a condition unrelated to his or her primary hospice diagnosis
 4. If the patient enters an inpatient facility that does not have a contract with the hospice to provide care to hospice patients

In each of the above cases, the patient will need to revoke his or her hospice election and return to traditional Medicare or Medicaid coverage, giving up the remaining days within that benefit period.

2. For patients with other insurance coverage:

- a. Many of the professional services offered by the hospice are covered by various types of insurance plans. The hospice Social Worker is available to discuss your insurance with you to ensure that you receive maximum coverage for needed services. By reviewing your policy and speaking to your company directly, hospice can better help you to know exactly what is covered and what, if anything, will remain your financial responsibility.
- b. After insurance payments are made, if there is an uncovered balance payable to hospice, our staff will discuss this with you and charges will be billed directly to you.
- c. The hospice will never refuse or discontinue services because of an inability to pay.

NOTICE OF HOSPICE PRIVACY PRACTICES

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION.

PLEASE REVIEW IT CAREFULLY.

USE AND DISCLOSURE OF HEALTH INFORMATION

The hospice may use your Private Health Information (PHI), for purposes of **providing you treatment, obtaining payment for your care and conducting health care operations.** The Hospice has established policies to guard against unnecessary disclosure of your health information.

YOUR HEALTH INFORMATION MAY BE USED FOR THE HOSPICE TO:
PROVIDE TREATMENT, OBTAIN PAYMENT and CONDUCT OPERATIONS.

To Provide Treatment. The Hospice may use your health information to coordinate care within the Hospice and with others involved in your care, such as your attending physician, members of the Hospice team and other health care professionals who have agreed to assist the Hospice in coordinating care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. The Hospice also may disclose your health care information to individuals outside of the Hospice involved in your care including family members, clergy who you have designated, pharmacists, suppliers of medical equipment or other health care professionals for the purpose of providing treatment to you. As well as releasing information for qualification of services/programs such as handicap plaques.

To Obtain Payment. The Hospice may include your health information in invoices to collect payment from third parties for the care you receive from the Hospice. The Hospice may need to obtain prior approval from your insurer and may need to explain to the insurer your need for hospice care and the services that will be provided to you. The Hospice may need to submit information to your insurer for payment.

To Conduct Health Care Operations. The Hospice may use and disclose health information for its own operations in order to facilitate the function of the Hospice and as necessary to provide quality care to all of the Hospice's patients. Health care operations includes such activities as:

- Quality assessment and improvement activities.
- Activities designed to improve health or reduce health care costs.
- Protocol development, case management and care coordination.

- Contacting health care providers and patients with information about treatment alternatives and other related functions that do not include treatment.
- Releasing appropriate information to airlines for family to qualify for

NOTICE OF HOSPICE PRIVACY PRACTICES

emergency flights.

- Professional review and performance evaluation.
- Training programs including those in which students, trainees or practitioners learn under supervision.
- On-call services via Answering Service (nights, weekends and holidays)
- Accreditation, certification, licensing or credentialing activities.
- Review and auditing including: compliance reviews, medical reviews, legal services, and financial audits.
- Business planning, development and management including cost management and planning related analyses and formulary development.
- Periodic phone calls or mailings related to bereavement support from The Hospice, containing counseling information, support groups and memorial activities that you or your family may wish to participate in.

THE FOLLOWING IS A SUMMARY OF OTHER PURPOSES and CIRCUMSTANCES UNDER WHICH YOUR HEALTH INFORMATION MAY BE USED AND DISCLOSED.

For Fundraising/Marketing Activities. The Hospice *may* use information about you including your name, address, phone number and the dates you received care in order to contact you or your family to acknowledge donations we receive in memory of you or to raise money for the Hospice.

When Legally Required. The Hospice will disclose your health information when it is required to do so by any Federal, State or local law.

When There Are Risks to Public Health. The Hospice may disclose your health information for public activities and purposes in order to:

- Prevent or control disease, injury or disability, report disease, injury, vital events such as birth or death and the conduct of public health surveillance, investigations and interventions.
- Report adverse events, product defects, to track products or enable product recalls, repairs and replacements and to conduct post-marketing surveillance and compliance with requirements of the Food and Drug Administration.
- Notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease.
- Notify an employer about an individual who is a member of the workforce as legally required.

NOTICE OF HOSPICE PRIVACY PRACTICES

To Report Abuse, Neglect Or Domestic Violence. The Hospice is required to notify Department of Public Health officials if the Hospice believes a patient is the victim of abuse, neglect or domestic violence. The Hospice will make this disclosure only when specifically required or authorized by law.

To Conduct Health Oversight Activities. The Hospice may disclose your health information to a health oversight hospice for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. The Hospice, however, may not disclose your health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits.

In Connection With Judicial And Administrative Proceedings. The Hospice may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal as expressly authorized by such order or in response to a subpoena, discovery request or other lawful process, but only when the Hospice makes reasonable efforts to either notify you about the request or to obtain an order protecting your health information.

For Law Enforcement Purposes. As permitted or required by State law, the Hospice may disclose your health information to a law enforcement official for certain law enforcement purposes as follows:

- As required by law for reporting of certain types of wounds or other physical injuries pursuant to the court order, warrant, subpoena or summons or similar process.
- For the purpose of identifying or locating a suspect, fugitive, material witness or missing person.
- Under certain limited circumstances, when you are the victim of a crime.
- To a law enforcement official if the Hospice has a suspicion that your death was the result of criminal conduct including criminal conduct at the Hospice.
- In an emergency in order to report a crime.

To Coroners And Medical Examiners. The Hospice may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

To Funeral Directors. The Hospice may disclose your health information to funeral directors consistent with applicable law and if necessary, to carry out their duties with respect to your funeral arrangements. If necessary to carry out their duties, the Hospice may disclose your health information prior to and in reasonable anticipation of your death.

For Worker's Compensation. The Hospice may release your health information for worker's compensation or similar programs.

NOTICE OF HOSPICE PRIVACY PRACTICES

AUTHORIZATION TO USE OR DISCLOSE HEALTH INFORMATION

Other than is stated above, the Hospice will not disclose your health information without your written authorization. If you, or your representative, authorize the Hospice to use or disclose your health information, you may revoke that authorization in writing at any time.

YOUR RIGHTS WITH RESPECT TO YOUR HEALTH INFORMATION

You have the following rights regarding your health information that the Hospice maintains. Please contact the appropriate individual identified below at the hospice office.

- **Right to request restrictions.** You may request restrictions on certain uses and disclosures of your health information. You have the right to request a limit on the Hospice 's disclosure of your health information to someone who is involved in your care or the payment of your care. However, the Hospice is not required to agree to your request. If you wish to make a request for restrictions, please contact ***Administrator***.
- **Right to receive confidential communications.** You have the right to request that the Hospice communicate with you in a certain way. For example, you may ask that the Hospice only conduct communications pertaining to your health information with you privately with no other family members present. If you wish to receive confidential communications, please contact ***Administrator***. The Hospice will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.
- **Right to inspect and copy your health information.** You have the right to inspect and copy your health information, including billing records. A request to inspect and copy records containing your health information may be made to ***Clinical Services Coordinator***. If you request a copy of your health information, the Hospice may charge a reasonable fee for copying and assembling costs associated with your request.
- **Right to amend health care information.** You or your representative have the right to request that the Hospice amend your records, if you believe that your health information is incorrect or incomplete. That request may be made as long as the information is maintained by the Hospice. A request for an amendment of records must be made in writing to ***Clinical Services Coordinator***. The Hospice may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your health information records were not created by the Hospice, if the records you are requesting are not part of the Hospice's records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy, or if, in the opinion of the Hospice, the records containing your health information are accurate and complete.
- **Right to an accounting.** You or your representative have the right to request an accounting of disclosures of your health information made by the Hospice for certain reasons, including reasons related to public purposes authorized by law and certain research. The request for an accounting must be made in writing to ***Administrator***. The request should specify the

NOTICE OF HOSPICE PRIVACY PRACTICES

time period for the accounting starting on or after April 14, 2003. Accounting requests may not be made for periods of time in excess of six (6) years. The Hospice would provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

DUTIES OF THE HOSPICE

The Hospice is required by law to maintain the privacy of your health information and to provide to you and your representative this Notice of its duties and privacy practices. The Hospice is required to abide by the terms of this Notice as may be amended from time to time. The Hospice reserves the right to change the terms of its Notice and to make the new Notice provisions effective for all health information that it maintains. If the Hospice changes its Notice, the Hospice will provide a copy of the revised Notice to you or your appointed representative. You or your personal representative have the right to express complaints to the Hospice or the Secretary of DHHS if you or your representative believe that your privacy rights have been violated. Any complaints to the Hospice should be made in writing to the Administrator. The Hospice encourages you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

CONTACT PERSON

The Hospice has designated the Administrator as its primary contact person for all issues regarding patient privacy and your rights under the Federal privacy standards.

EFFECTIVE DATE

This Notice is effective April 14, 2003.

CONTRACTED SERVICES

The hospice program makes every effort to provide care to patients through the utilization of its own staff members. There may be occasions, however, when the use of contracted services is appropriate. In all cases, required licensure, certification and other regulatory requirements would be determined by the hospice prior to contracting for service. All services provided through a contractual arrangement will be evaluated on a regular basis as part of the hospice’s on-going quality improvement and assessment program.

Contracted staff will generally be used when certain specialized therapies are prescribed which require trained staff not directly available. This would be the case for Physical Therapy, Occupational Therapy, and Speech Therapy. These specialties require licensing by the Commonwealth.

There may also be instances when increased patient census or illness will require using contracted staff for services generally provided directly such as nursing, social work and home health aides. These services also require licensure or certification.

The provision of durable medical equipment, inpatient care and pharmaceuticals will always be through a contractual arrangement. These vendors must be licensed and approved by Medicare and Medicaid.

All services provided as part of the hospice plan of care for Medicare and Medicaid recipients are paid for by the hospice and no financial responsibility rests with the patient or family. Managed care plan payment will be discussed and determined on a case by case basis. Any patient financial responsibility will be approved by the patient prior to the provision of that service. In the case of additional services requested by the patient or family, arrangements would be privately made between the vendor and the patient and the cost of those additional services would be borne by the patient.

All care provided through the hospice is under the supervision of hospice staff members and the hospice is solely responsible for the management of that care.

The following is a list of contractual arrangements which may be utilized:

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| <p>Skilled Nursing, Home Health Aides and Homemakers Interim Healthcare 615 Concord Street #3 Framingham, MA 01702 508-872-9888</p> <p>Favorite Nurses/Favorite Temps 333 Washington St., 8th floor Boston, MA 02108 617-367-2607</p> <p>Brandon Woods Home Care/Home Resources 567 Dartmouth Street South Dartmouth, MA 01748 508-999-0878</p> <p>Durable Medical Equipment Oxygen and Respiratory Therapy</p> <p>Harbour Medical Services. Inc. 70 Heritage Ave Unit 13 Portsmouth NH 03801 800-233-0734</p> <p>Agawam Medical Supply 56 Abrams Drive Agawam, MA 01001 413-789-1100</p> | <p>Enos Home Oxygen 285 Washington Street North Easton, MA 02356 508-230-2800</p> <p>Home Care Specialists Inc. 113 Neck Road Haverhill, MA 01835 800-698-8113</p> <p>Life Supply (Diversified Medical) 711 East Main Street, Ste A Chicopee, MA 01020 413-593-5555</p> <p>Boston Orthotics 1000 Crane Ave. South Unit 1100A Taunton, MA 02780 508-821-7655</p> <p>Medical Supplies</p> <p>Medline NEH Acct #: 1298576 560 West Street Mansfield, MA 02048 847-968-7766 Sales Rep (Allison Escandon) 800-633-5463 Customer Services</p> |
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| Inpatient/respite care / routine care | |
|---|--|
| <p>Town and Country 259 Baldwin Lowell, MA 01851 (978) 454-5438</p> <p>Birch Gardens 44 New Lombard Rd. Chicopee, MA 413-592-7738</p> <p>Blaire House in Tewksbury 10B Erlin Terrace Tewksbury, MA 01876 978-851-3121</p> <p>Blaire House in Milford 20 Claflin St. Milford, MA 01757 1-508-473-1272</p> <p>Brandon Woods of Dartmouth 567 Dartmouth Street Dartmouth, MA 508-997-7787</p> <p>Blaire House of Worcester 116 HOUGHTON ST WORCESTER, MA 01604 (508) 791-5543</p> <p>Westside House 35 Fruit Street Worcester, MA 01609-2198 508) 752-6763</p> <p>Buckley Healthcare Center 95 Laurel Street Greenfield, MA 01301 413-774-3143</p> <p>Life Care Center of Acton 1 Great Road Acton, MA 01720 (978) 263-9101</p> <p>Life care Center Auburn 14 Masonic Circle Auburn, MA 01501 (508) 832-4800</p> | <p>Life Care Center of Merrimack Valley 80 Boston Road North Billerica, MA 01862 (978) 667-2166</p> <p>Brandon Wood New Bedford 397 County Street New Bedford, MA 02740 (508) 997-9396</p> <p>Holyoke Healthcare Center 282 Cabot St Holyoke, MA 10140 413-538-7470</p> <p>D'Youville Senior Care 981 Varnum Ave Lowell, MA 01854 978-454-5681</p> <p>Merrimack Valley Hospital 140 Lincoln Ave Haverhill, MA 01830 (508)791-5543</p> <p>Poet's Seat Nursing Home 359 High St Greenfield, MA 01301 413-774-6318</p> <p>Royal Fairhaven 184 Main St Fairhaven, MA 02719 508-997-3193</p> <p>Royal Taber Street Nursing and Rehab 19 Taber Street New Bedford, MA 02740 508-997-0791</p> <p>Sippican Health Care Center Inc. 15 Mill Street Marion, MA 02738</p> |

Physical Therapy, Occupational Therapy Speech Therapy

Rehab Group
120 Houghton Street
Worcester, MA 01604
508-752-7318

Laboratory Services

US Labs
2 Jonathan Dr.
Brockton, MA 02301
508-583-2000

Life Labs (Now Mercy Medical Ctr)
299 Carew Street
Springfield, MA 01104
413-748-9000

Pharmaceuticals

Hospice Pharmacy Solutions
1221 Corporate Drive, East
Arlington, TX 76006
866-851-4866

Western Mass Compounding Ctr
138 Memorial Avenue
West Springfield, MA 01089
(413) 737-2600

Apothecare Compounding
3303 South Country Trail
East Greenwich, RI 02818
401-821-5000

Physician

Dr. Robert Sol Mausel
Hampden County Physician Assoc.
98 Shaker Road
East Longmeadow, MA 01028

Dr. Tavano
77 E Merrimack St # 19
Lowell, MA
(978) 459-2152

Dr. Efrain Torres
651 Orchard Street, Ste 202A
New Bedford, MA 02744
774-202-3090

Dr. Sawant
Private Office
770 Pond Street
Franklin, MA 02038
508-528-3814

Dr. Nancy Said
1 West Boylston Street
Suite 206
Worcester, MA 01605
508-854-2636

Mental Health Services

West Central Family and Counseling, Ltd
103 Myron Street, Ste A 01089
West Springfield, MA
413-592-1980

Ambulance Transportation

Trinity EMS Inc.
1221 Westford St.
Lowell, MA 01851
978-441-9191

AMR of Massachusetts
4 Tech Circle
Natick, MA 01760
508-650-5600

Mobile X-ray/EKG

Mass Tex Imaging
3 Electronics Ave #201
Danvers, MA 01923
800-508-6277

Mobilex USA
2 Jonathon Drive
Brockton, MA 02301
508-583-2000