What is Hospice?
In a word, Relief.

We are traditionally afraid to talk about death. Hospice is a concept, a place that makes it easier to begin the conversation about end-of-life issues. Death is a natural, inevitable part of life, and hospice is beneficial for everyone: the patient, the family, friends, caregivers, medical staff—all those who are affected by the “dying of the light,” as the poet Dylan Thomas wrote. Hospice serves the dying and their loved ones on many levels: medical, social, spiritual, emotional.

Many people on hospice choose to die at home among family, friends, pets, and familiar settings. But not everyone can stay at home, for various reasons, whether for a need for specialized care or a lack of support at home, to name two possibilities. Hospice brings dignity to the dying no matter where they reside.

Relief for terminally ill patients means making them comfortable and providing a range of services for them, their families and caregivers. Hospice means handling late-term medical issues and symptoms, relieving pain, as well as shepherding patients and their families through...
What is Hospice?
In a word, Relief.
Continued from page 1

the maze of paperwork and decisions that must be faced. Hospice helps everyone begin the conversations that are essential, the good-byes, but it also helps make the most of any remaining time, to live life as fully as possible until death.

Today hospices are found in every state and throughout the world. According to the National Hospice and Palliative Care Organization (NHPCO), about 1.5 million patients are cared for through hospice in the United States each year. Some of the earlier hospices were based in religion or community, but now they are often, but not always, a branch of a hospital system.

Lisa Melchionna is an RN and Interim Hospice Director at the Hospice of the South Shore, which is part of the South Shore Hospital organization. “We provide a whole continuum of care to the south shore region and are fortunate to be affiliated with some of Boston’s well-known teaching institutions. Although many of our patients come to us from South Shore Hospital, many others are referred from a variety of community resources.”

When you have the courage to make that initial call to a hospice, you are at once helping yourself, whether you are the patient or someone who loves or cares for that patient. You will be placing your trust in a well-grounded program that has long provided relief in many forms.

How Will Hospice Relieve My Burdens?
The philosophy of hospice is to care for dying patients, tending their physical and emotional needs and those of their families and other loved ones. A Medicare guide explains: “Here are some important facts about hospice:

• Hospice helps people who are terminally ill live comfortably.
• The focus is on comfort, not on curing an illness.
• A specially trained team of professionals and caregivers provide care for ‘the whole person,’ including physical care, counseling, drugs, equipment, and supplies for the terminal illness and related conditions.
• Care generally is provided in the home.
• Family caregivers can get support.”

Types of Hospice
The goal is to keep patients in their own homes in familiar surroundings, but that is not always feasible. Hospices vary by type of location and size. Most hospices offer a variety of settings for their patients, whose needs determine the appropriate choice. They may be:

• Dedicated beds within a traditional hospital setting
• The patient’s private home (the first choice of most, if possible)
• A stand-alone hospice facility, like the Pat Roche Home of Norwell VNA and Hospice
• A nursing home or assisted living facility
• Any place a patient calls home and feels comfortable

Who Benefits From Hospice?
Everyone. Hospice accepts patients with all conditions, though that group makes up about a third of the total. Diagnoses range from end stage renal disease to heart conditions and, rarely now, AIDS. The age of patients ranges widely as well. While 84% are over the age of 65 and 41% are over 85, there is a small percentage of children who are served by hospice. The youngest are babies in utero who are expected to live short lives because of serious defects diagnosed before birth; families who choose to continue the pregnancy receive services through special perinatal programs.

Hospices think of their patients as living life as fully as possible, not dying. With help maintaining control and independence, they set goals and aspirations. Hospice helps them have the time to live until they die, with the best care and comfort measures that can be put into place.

The hospice care team has a broad spectrum of practitioners, and patients and their families can expect:

• Medical services from physicians, nurses, nurse practitioners and other specialists.
• Therapists to improve function with speech, eating, mobility, and other daily tasks
• Home care assistance from home health aides and respite for caregivers
• Social services, from licensed social workers, bereavement

Continued on page 3
What is Hospice?
In a word, Relief.

Continued from page 2

specialists, and child life specialists
• Friendly visits from volunteers who will chat with the patient, read, or just be present for a bit.
• Spiritual care from clergy and lay ministers, from your belief system or from nondenominational providers.

Meeting the Needs of Terminally Ill Patients

Palliative care, or easing the symptoms of the ill, is provided throughout the course of the illness, while hospice care, which also alleviates physical symptoms but provides so much more, is for the weeks and months at the end of life. Since each case is different, services are adjusted to the needs of patients and their families through a team of caregivers coordinated by hospice.

“Hospice is helpful in preparing a family for the steps that come after a death occurs,” noted John Keohane. “They often have conversations with the family regarding funeral planning and it puts a family at ease and helps us as we begin to help them plan a celebration of life.”

Who Works at Hospice?
Whatever the setting for the patient’s care, there are a number of folks they can expect to work with over their final days and weeks. Many staff members are licensed social workers, nutritionists, home health aides, nurses, pastoral caregivers and medical professionals including doctors and nurses. They are not likely to meet Emergency Medical Technicians, Emergency Room personnel, and others often encountered in highly dramatic, frightening terminal crises.

The background of hospice staff and volunteers is as diverse as the human race. Joan Wright, Director of Marketing at Norwell VNA and Hospice, came to work in hospice through two personal experiences; both of her parents benefitted from the programs and she found her calling. “I wanted to work on behalf of promoting hospice, helping people understand the benefits, what a difference it makes for patients and their families.”

While a life expectancy of six months is the benchmark for hospice, patients may receive services as long as needed. The important thing is to begin with hospice as soon as possible to gain that essential relief.

Medical Intervention
While social and emotional aspects of dying are certainly important, patients and their families need to think about medical intervention. This can be a difficult conversation to begin, but hospice experts can offer guidance. Dr. Chery Arenella, writing on the American Hospice Foundation website (www.americanhospice.org) discusses advanced care planning and specific medical treatments that may be included in those directives like a Living Will or a Health Care Proxy. In a lengthy and thoughtful article, she notes that patients can specify which interventions they might wish to accept and which they would not. Among those are Cardiopulmonary Resuscitation (CPR), Ventilator Support, respiratory intervention with CPAP or BiPAP (used for sleep apnea), kidney dialysis, nutrition when the patient cannot eat and nourishment is received via vein or stomach tube, intravenous fluids (IV), surgery, blood transfusions, antibiotics, hospitalization, diagnostic tests and skin care. Some patients with pacemakers or implanted defibrillators decide when the time has come to turn off these devices.

In each of these cases, Dr. Arenella advises asking questions: What does the procedure involve? When is it likely to be helpful? In what circumstances is it not likely to be helpful? What are the side effects of the procedure? In other words, is it really worth it to subject the dying patient to treatments that are unlikely to result in long-term improvement?

Serving Patients with Dementia
Although patients with Alzheimer’s disease and other forms of dementia have different care needs, the families still must cope with multiple losses. The Alzheimer’s Association website (www.alz.org) provides a lot of information on what to expect as the disease progresses. Over time, the needs of the patient escalates, with loss of the ability to eat or swallow, to walk alone or even with help, to perform the simplest personal care functions, and the ability to

Continued on page 7
“Families are the best reporters of one’s decline,” said Joan Wright of Norwell VNA and Hospice. “They see a family member decline, being less mobile, sleeping more, eating less.”

Old Colony Hospice’s Mike Cruza agreed. “Ideally, families should use the six-month benefit, but there is no crystal ball that tells you when that point is reached. I hear a lot: ‘I wish I had known about this sooner.’ Nobody says, ‘I wish I hadn’t come so soon.’”

“Some people come for months, some only for a couple of days. People wait until the last minute,” Joan Wright said. “That’s unfortunate, because they lose out on the full hospice benefit. We often hear, ‘We would have come sooner if we knew how wonderful the experience would be. This was like coming home, only better.’”

At Hospice of the South Shore, Lisa Melchionna said, “We have had the opportunity to have patients on service for as long as two years. Having more time with the patient allows us to make much more of an impact on not only them, but also their families that we are caring for. For the patient, it is often a time of reflection and finding closure.”

Sometimes patients rally and no longer require hospice services, which can be suspended for a while until needed. One woman was caring for both her husband and her mother-in-law on hospice; her husband passed away but his mother’s health improved and now, a few years later, she is still at home and doing well at 96.

Who Can Benefit From Hospice?

Hospice serves patients of all ages, from all economic and social backgrounds. The one thing they have in common is that a life is coming to an end. It doesn’t matter if they are at home or in some other facility. Hospice staff will “take a load off” the caregivers. This is especially true for those in their own homes, where loved ones are doing medical care on top of normal household duties. Hospice staff can take over the medications, bathing, and other chores while the family can just enjoy what time they have left with their loved one—remembering, laughing, crying, having a last Sunday pizza party, watching favorite movies, reading together.

In other words, after a terminal diagnosis, there may be a lot of living left to do. Those who decide not to work with hospice services can really miss out.

When Should I Call hospice?

The time to call hospice is as soon as possible. Experts agree: the time to make that call is when it’s clear that death will occur as a result of the illness, even when there seems to be a significant time left, six months or less. That period of time can be a real blessing for families and patients who have turned to hospice for care and relief.

When a family member is dying, thoughts usually turn towards memorial services and funerals, but hospice is a step along the road. Hospice is usually contacted before funeral planning starts, but many times that call is put off until the very last days. As a result, caretakers miss out on the many services that hospice provides to ease their daily duties and allow them to spend quality time with their dying loved one.

Make that initial contact sooner rather than later to derive its full benefits.

How do I Choose a Hospice?

While all hospices provide the same basic services, there are differences among them.

Lisa Melchionna noted that the medical director and one of the founding physicians of Hospice of the South Shore is oncologist Dr. Jim Everett, who is very committed to educating and building staff to provide the best support to patients. While their office is in Rockland, they serve about 30 towns in the South Shore area, from Quincy and Milton to Plymouth.

At Old Colony Hospice, Mike Cruza suggested looking at patient loads. “We have a nice, manageable 12-13 clients per nurse case manager, which allows more time for each patient.”

Joan Wright pointed out that Norwell VNA and Hospice offers the full continuum of care so that patients who transition from one level of care to another may be able to continue working with the same caregivers which can be a great comfort to both the patient and their families. Further, their robust volunteer program enables patients to benefit from pet therapy visits, Storycorps, and their certified Veterans Recognition Program. Norwell VNA and Hospice is also a community partner with Honoring Choices, an initiative to ensure that patients’ wishes are followed for end of life.

As for choosing a hospice among those available, there may be several factors in play:

- Proximity to the family’s homes
- Word-of-mouth recommendations from friends
- Referrals from hospitals and other institutions
- Services required or desired (inpatient beds, medical issues)

Call around, visit different facilities and sites, and ask questions. Meet with hospice workers to choose the one where you feel most comfortable and cared for. The message to those with terminal illnesses and their loved ones or caretakers is clear: Contact hospice sooner rather than later to make full use of the services.
Hospice Serves the Whole Family

Hospice is for the family as well as the patient. Facing terminal illness in a loved one causes stress. There is also a potential for conflicting views on how the situation should be handled. Hospice staff are trained to help negotiate these troubled waters.

When the dying person has family living at a distance, it is important that they be included in decisions. While these relatives are unable to help with daily care, hospice workers use technology like Skype, telephone calls, and email to get and keep everyone on board.

Hospice works with all of the members of the family, of all ages, including children who are facing the loss of a parent or grandparent. Hospices have support groups of many kinds for those who need them and counseling for special populations. Using these services helps keep the dying person engaged in daily life as long as possible and results in a positive experience rather than a drain.

Hospice is Full of Surprises

Hospice workers are adept at discovering their patients’ wants, those desires that go beyond the basic needs, and try to fulfill them. Joan Wright of Norwell VNA and Hospice noted that they had celebrated baby showers, for example, “a little family affair in the gathering room including the patient resident at the Pat Roche Home. We also have had birthday and anniversary parties.”

At Old Colony Hospice, Mike Cruza remembered a wedding of sorts, when a couple was able to renew their vows with family five days before the husband died. Another time a patient’s granddaughter was getting married, so the ceremony was held at the nursing home with the chaplain. “These are little things that go a long way to making goals and wishes come true,” he said. “We like to do these wonderful things.”

Hospice of the South Shore has also hosted weddings. One of their patients had two daughters who were engaged to be married in a couple of years. The mother told the social worker how sad she was to miss these milestones. The staff kicked into high gear, and in record time the daughters had their dresses and other finery, and two weekends in a row there were weddings the patient could attend and enjoy. “The Mom showed everyone the photos and felt she had finished what she had to do,” said Hospice of the South Shore’s Lisa Melchionna.

Hospice has been able to fulfill other wishes, too, allowing a dying woman to go to Castle Island one last time, in an ambulance, and have one last lobster roll. Another patient wanted to visit the family’s second home one more time, and the staff made that happen, too.

Hospice Shoulders Some Burdens

Besides medical, emotional, and spiritual aspects of death and negotiating the paperwork jungle that passages inevitably trigger, hospice helps the family members by taking some of the burden off their shoulders. When Mom takes a turn for the worse, there is a plan already in place to deal with it without resorting to the drama of emergency response. Hospice workers can make referrals to whatever services might be needed from the wider community: home health aides, housekeeping, nutrition, and even respite care so caregivers can get a break from daily minutia.

A Doctor’s Advice About Getting Support

There are also rich resources to guide families through these difficult days. Writing on Hospice Net, Dr. Roger C. Bone offers insight into support opportunities for family members—how to find it, how to handle it. His advice in brief:

• One or two people will make great personal sacrifices to assist you. It may be an in-law or a friend rather than a spouse, but be grateful and accept the help.

• Some people will treat you differently when you are dying. They may seem “patronizing or overbearing” but they will get over it and come around.

• People will offer gifts of help. Cheerfully accept them.

• Ask for time to be alone if you need it. Don’t overbook yourself.

• Don’t feel you have to take all the advice people want to offer you. You are the patient’s or your own best resource. Do your research and ask for input from others, but ultimately the choice is yours.

• Slow down, take time to think, plan and prepare.

Mostly, with hospice, the message is an important one: You are not alone. Hospice will be there every step of the way.
What about the Children?

There is nothing in life more painful than the illness and death of a child. Nature is not supposed to work like that. But when a family is confronted with the unthinkable, hospice personnel are specially trained to help in any way they possibly can to ease the burden.

Some who love a dying child may not be willing to give up on the fight against the illness, while others disagree with continuing painful therapies. Hospice staff help the family find a way through the struggle between hope for a cure and the reality of the situation that a critically ill child endures. There is no “right” answer but hospice personnel can help families come to terms with the best way to handle the situation. Disagreements create more tension for families, but hospice staff can help bridge these differences and restore at least some unity, which is essential to the family’s emotional survival.

In this area, it is likely that the child has been a patient at the Children’s Hospital in Boston, and when the time comes for hospice, that institution has many resources. Other pediatric hospices are located in Massachusetts such as Care Dimensions in Danvers, Baystate VNA and Hospice in Springfield and Cranberry Hospice and Palliative Care in Plymouth. Of course, the services available will be determined by the child’s age. Parents may be reluctant to talk about death with their child, but children often understand more than we think and they welcome an opportunity to talk about what is happening. A youngster old enough to know she will not survive her illness will welcome a chance to say goodbye to her friends and family. One hospice worker noted that a family did not want their 11-year-old son to be told he was dying, but when the hospice worker went to meet him, he said he had looked up hospice online and knew what it was all about. He was grateful for the opportunity to clear the air.

The Grieving Child

It’s hard enough to comfort an adult who is grieving the loss of a loved one, but it is more difficult to help a child through his grief. To begin with, children of different ages often have false ideas of what death means. Preschoolers may not understand that death is permanent. Older children may think they are somehow responsible for the death, or they may be worried that they will be the next to die. Pamela Gabbay of The Mourningstar Center for Grieving Children and Teens has a list of “Ten Things Grieving Children Want You to Know” on the website for the National Alliance for Grieving Children (NAGC). Among them:

- Listen to the child
- Really hear them
- Follow their lead
- Validate their feelings
- Answer their questions
- Seek out additional resources as needed.

Memorial Projects Are Meaningful

Karen Gore, Bereavement Coordinator for the Norwell VNA and Hospice runs memory box projects at the residence hospice. “We had it right around Thanksgiving to partner with Child Grief Awareness Day [November 17 in 2016]. We invited children to the hospice house, where we had creative volunteers on tap. They decorated the boxes and put in mementos, trinkets, letters, whatever reminds them of the loved one. It deals with their grief in a creative way, gets them talking through the sadness; they were able to laugh about things. The adults who came with them also participated and loved it. We will have the program again.”

NAGC: A Rich Resource

The National Alliance for Grieving Children [https://childrengrieve.org/] has many helpful suggestions on their website, including “Ten Ways to Help Grieving Children” and lists of dozens of other sources of help listed by state. Many thoughtful links direct you to additional support programs and materials.

The Comfort Zone Camp, an affiliate of the NAGC, has overnight camps around the United States held throughout the year. “Comfort Zone offers free grief resources, resilience training and ongoing support to children who have suffered the loss of a parent, sibling or primary caregiver. Our programs focus on the strengths of each child, empowering them to grieve, heal and grow in healthy ways.” They serve children from the ages of 7 to 17. http://www.comfortzonecamp.org.

Adults are the key to helping grieving children by accepting and working through their own grief. Use all the resources hospice has to offer.
**Meeting the Needs of Terminally Ill Patients**

*Continued from page 3*

Communicate with words. Those in later stages of dementia perceive the world primarily through the senses, so touch, sight, taste, sound and smell are the avenues to reach them. The website recommends:

- Playing his or her favorite music
- Reading portions of books that have meaning for the person
- Looking at old photos together
- Preparing a favorite food
- Rubbing lotion with a favorite scent into the skin
- Brushing the person's hair
- Sitting outside together on a nice day

Old Colony Hospice & Palliative Care has a program of interventions for late stage dementia patients and their families. Called “Forget Me Not”, it looks to engage patients and families through the use of meaningful intervention, education and caring. An excellent brochure on their website discusses the stages of dementia, how patients are cared for, focusing on “habilitation rather than rehabilitation, ...which makes the most of what faculties remain and embraces them.” The brochure also suggests ways to care for this special population: compassionate touch/massage, music, memory boxes, using blankets for weight as well as warmth.

“These patients are not necessarily on hospice for dementia but may have another terminal diagnosis like Cardiac Disease or COPD too,” said Mike Cruza of Old Colony Hospice. “We use music therapy, do a full music assessment and put together a CD specific to what the patient likes. It helps change the brain waves a bit and puts them in a better place and time, rather than increasing medicine doses. We also use hand massage. At any given time, 40% of our patients have dementia as a primary or secondary diagnosis.”

**Home-like Settings**

With their multiple losses, dementia patients are more likely than most to require services that are difficult to provide at home. Those preparing for death also want human contact, although each patient’s wishes will vary. They want their loved ones nearby and able to visit at any time. Those who move to the Pat Roche Hospice House of NVNA & Hospice live in rooms that are regular bedrooms and do not feel like hospitals with medical equipment and beeping machines.

“We have the only non-profit residence on the South Shore,” said Joan Wright of Norwell VNA and Hospice. “It’s important to get a residence in the neighborhoods where the patients live. Our 12-bed residence was an old house, used as a rest home that morphed into assisted living. We bought it in 2012 and renovated it extensively to meet the Americans with Disabilities Act. We often have a waiting list.”

All hospices, wherever they serve their patients, strive to meet that home-like setting standard.

Wise words from someone who has been there

Rex Winsbury writes on http://www.hospicenet.org from an unusual perspective. Declared to be dying, he survived and shares what he learned. He needed:

- To get his finances in order
- To settle emotional accounts with friends and family
- An advocate to represent him, essential when a patient is on life support or receiving pain medications.
- To document his final wishes
- To make funeral arrangements
- Information. His words bear repeating: “Ignorance is the worst enemy. Some prefer ignorance, say it is bliss. It is not. Ignorance is the ultimate fright, the primal fear. Better to know what you are up against, know all there is to know about your illness, its treatments, the odds, the therapies, what others have done and said and suffered.”
- A safe place to talk
- Physical well-being, including the healing power of exercise that combines movement and meditation.
- To talk about death, to restore his hope within realism, to forewarn and teach him about the stress of his illness on others.
- To be told he was still beautiful and worthwhile

The most important factor is to listen to the dying, include them in all choices as much as possible, to provide the human touch both physically and emotionally.
Bereavement Services through Hospice

No matter how long you have to prepare for the death of a loved one, the loss will be difficult. Family members often need support to understand that their feelings are normal. You are allowed to take care of yourself now, to take time to feel sad and pick up your life again.

So it’s fortunate that hospice is available to provide this assistance. One of the most important aspects of this care is bereavement support. All three of the hospices highlighted in this publication have bereavement support teams with licensed social workers and others who provide individual and group programs to help families through their grief.

Memorial Programs
Each hospice has special programs and services to honor those we have lost. Lisa Melchionna of Hospice of the South Shore notes that they have sponsored summertime walks on Nantasket Beach for those who enjoyed visiting the seaside with their loved ones. This allows the bereaved to share favorite memories of happy times. They also hold a yearly Memorial Service that all families are invited to in remembrance of those who have passed away.

Old Colony Hospice has a quilt program where families can create a quilt square to be sewn with others into a Memorial Quilt to be displayed at their office and at public events. Families work together to fashion a square that is reminiscent of their loved one, perhaps a spray of flowers for a gardener, a piano for Dad who accompanied all the sing-alongs, a book for the writer or reader. The finished quilts are a living memorial for the families. “We have three quilts that circulate in the community,” said Mike Cruza.

Norwell VNA and Hospice is the only agency in Massachusetts offering the Story Corps Legacy Project, interviewing hospice patients to tell their life stories. Some of their stories have been aired on public radio. “In one case, a patient with Alzheimer’s was interviewed and he was able to tell his family things he was most proud of, in his own words and his own voice,” said Joan Wright of Norwell VNA and Hospice. “This is available for all patients who want it, and it allows people to say things that perhaps have not been said before. It’s part of their legacy.”

Support Groups
If you have lost a loved one, you can take part in support groups according to your specific needs. For example, if you have lost a spouse or partner, there is a group. Hospice doesn’t forget the children, either; for those who have lost a parent, grandparent, sibling or friend, there are specially trained staff, such as child life specialists, who guide the youngsters through the grieving process. Bereavement services are especially helpful for other situations as well, including loss due to suicide or violent death.

If you have lost a child, your sense of order in the world may be skewed; children are supposed to outlive their parents. There are specialized hospice support groups for you, too. Hospice groups for your specific situation will support you as you seek understanding of your loss.

No matter the situation of your loss or how old your loved one was, hospice will work to carry you through the difficult days as you seek your footing in a changed world. In the internet age, you can find many online groups where you can communicate with others who are walking the same road you are.

How Long do Bereavement Services Last?
Bereavement services continue for 13 months after the death—a number that seems odd but on closer inspection makes sense. This gets the bereaved past all the milestones: holidays, birthdays, anniversaries, religious celebrations, and vacation times.

Bereavement services might include:
• Regular contact for support and education.
• Friendly notes and cards with good wishes and messages of hope.
• Invitations to events of special interest.
• Counseling services.
• Support groups.
• Regularly scheduled memorial services and holiday remembrance programs.
• Holiday grief workshops.
• Referrals to other resources in the community as needed.
• Programs or camps for bereaved children.

These services are also available to families who have not been able to take advantage of hospice before their loved one’s passing, such as those who lose someone to an automobile accident, a heart attack, or other sudden death. With hospice support and the passage of time, you will feel better and live life again to its fullest.
How Will I Pay for Hospice?

Everyone’s economic situation is different, but the staff of your chosen hospice will help you wade through the finances. Hospice is a benefit of most insurance plans and may be covered by Medicare, Medicaid, and private companies. If you have Medicare Part A (Hospital Insurance) AND meet three conditions, you are eligible for hospice care:

• Your hospice doctor and your primary physician must certify that you are terminally ill, with a life expectancy of six months or less; AND
• You accept care for comfort (palliative care) rather than continuing to seek a cure for your illness; AND
• You sign a statement choosing hospice care instead of other Medicare-covered treatments for your terminal illness and related conditions.

When you meet these criteria, start by talking to your doctor to find a hospice program that is Medicare-approved to get Medicare payment. You can check with the Hospice and Palliative Care Federation of Massachusetts to identify approved programs; contact information is listed on the back of this flyer. Your doctor, social worker, friends or other health care professionals will have recommendations on finding a hospice that is a good fit for you and your family.

What Does Hospice Cover?

Hospice benefits include medical and social services, nursing aides, homemaker services, counseling, medications for pain and managing the disease, a range of therapy from physical to speech, short inpatient hospital stays for a spell of acute illness, and similar needs. Medicare will continue to cover health care costs that are not related to the terminal illness, after the patient covers the usual deductible and co-insurance costs; subscribers must continue to pay their Medicare premiums.

“In a residence hospice like the Pat Roche Home, Medicare and insurance pays for the patient’s care, but the residence itself is private pay. Room and board are separate,” said Joan Wright of Norwell VNA and Hospice.

While hospice may not cover everything, they do pay for some services you might not think of. In one situation, a woman caring for her husband at home ended up in the hospital herself and insurance paid for his care while she recovered. Caregivers get overwhelmed, so this respite break was a blessing.

What Other Sources of Financial Assistance Are Available?

Costs vary from patient to patient, but hospice staff will help the family with paperwork and find sources of funding for each person under their care. These trained professionals negotiate the often confusing regulations and rules to support their clients throughout the whole hospice experience.

Hospices often have their own special funds to help defray patient costs. All of these organizations do fundraising, which is not only a financial boon but which provides opportunities for family members to take part and “give back” as well as raise community awareness of these special services for the terminally ill. Golf tourneys, walks, gala dances, and sales of specially designed jewelry are just a sampling of hospice fundraisers.

With fundraising events, grants from government and nonprofit organizations, and the generosity of the community, hospices are able to provide care to all who need it. Every hospice will work with the family to find the best sources of funding for their situation.
Hospice Depends on Volunteers Like You!

Often, when a family member or a friend has experienced the death of a loved one in hospice, they have bonded with the staff and become volunteers. Linda Gordon has been volunteering with Hospice of the South Shore for about a year, although she has been doing the Walk for Hospice for 13 years in all.

“My mom was a hospice patient and so was my mother-in-law. My youngest daughter lost all her grandparents; I used to push her in the stroller during the walk. She decided she wanted to do the walk for Grandma, and by the time she was 10 she was fundraising and by 11 she was a walk team captain. Her Girl Scout troop volunteers at the kids’ craft table, so we have an annual sleepover the night before the walk! We had 8 girls, got up at 6:30, did the walk. It was very joyous, a wonderful family day.”

After the years taking part in the Walk, Linda decided she wanted to be trained to work with patients. “The application process took quite a few months, with training sessions, background checks, South Shore Hospital orientation, and health screenings. Most of us have had loved ones as hospice patients, but they make sure it’s not too close to the loss—at least a year or two. It’s pretty rigorous and a lot of red tape, but if you stick with it, you will make it.

“You only do what you are comfortable with. Volunteers provide respite to patients’ families so they can go out to lunch or get a break. One recent patient had a special place in my heart; I spent time with her in her last couple of months, every Thursday. It was just lovely. She was 98 and had had a great life, and I felt comfortable to help her.”

Linda said that hospice volunteers play cards with patients, read to them, make an occasional meal. Some have dementia and can no longer speak, but volunteers sit with them so their caregivers can get a little time off.

There are many opportunities at the Norwell VNA and Hospice Pat Roche Hospice Home in Hingham for volunteers to enrich the lives of the patients. They help with meal preparation, visit patients, welcome guests and visitors to the house, do gardening, assist with laundry, and share their musical talents, among other things. Other Norwell VNA and Hospice volunteers make pies for hospice families at Thanksgiving, deliver roses on Valentine’s Day. Their pet therapy program puts dogs and volunteers into the homes of hospice patients, which gives them great comfort.

Volunteers are Often Fundraisers

One of the ways that volunteers make a difference in hospice is through fundraising. All of the local groups have events to raise money. Walks, golf tournaments, holiday events, benefit galas—volunteers have plenty of opportunities to share their gifts and talents, support a good cause, and have some fun at the same time.

The Hospice of the South Shore has an annual Hospice Walk; this year was the 25th walk. “A couple of thousand people come,” said Hospice of the South Shore’s Lisa Melchionna. “Some folks come for several years, walking in memory of a family member. With balloon making and high school bands, it’s a beautiful warm event.”

“In Massachusetts hospice coverage is required of insurers, but some plans do limit it. That’s

End-of-Life Directives: What are they?

The term sounds scary: “end-of-life directives.” But these directives should not be scary at all; they are forms and orders that allow terminally ill patients to express their wishes regarding their care in their final days. Creating these forms is an important step in expressing the desires of the patient regarding measures that may be taken to prolong his or her life.

These directives not only specify what medical treatments the patient might want to have and which ones they do not wish to have. The documents also identify who will make decisions if the patient is not able to, who will be involved in their final care, and often clarify wishes for funerals, memorial services, and other rites that may occur after the death.

Hospice is here to help with these directives. The trained staff will guide you through the legal forms, help with decision-making, and generally reassure the patient and the family about what to expect in the last days and hours.

There are several different end-of-life directives that terminally ill patients and their families might encounter. A health care proxy and a living will are probably familiar. These are forms completed by adults over the age of 18 when they are capable of preparing them, but they only come into play when the patient has lost his ability to make medical decisions on his own.

Some of them are:

- A living will, which delineates the limits of medical intervention the patient would accept for prolonging life.
- Health Care Proxy, which allows the patient to designate who will make health care decisions for the patient who has become, even temporarily, unable to make them him- or herself.

Hospice: A Wealth of Information About a Rich Resource • A publication of Keohane Funeral Home
Local businesses pitch in as well to donate what is needed including flowers and meals that volunteers deliver to patients’ homes.

Veterans Recognition Programs

The Norwell VNA and Hospice started a Veterans Recognition program in 2009, just a year after the hospice opened. A volunteer and a clinician go to the home of veterans, some of whom had seen combat and some who had never left the country. They present a certificate thanking them for their service to the country. “This was extremely helpful for a lot of veterans who could not let go of the more painful memories of their service. They have to forgive themselves for what they had to do; those memories may be preventing a peaceful death,” said Joan Wright of Norwell VNA and Hospice.

“We were kind of on the cutting edge when the veterans’ recognition started,” Joan continued. Her passion for the program comes from a personal experience. “Watching my father die, he kept telling us he had some things he had to reconcile before he died, but we were not sure what it was. The undertaker told us he had 5 Bronze Stars from WWII and we were not aware of that. We lost the opportunity to share this with him.

Old Colony Hospice also has a Volunteers for Veterans Program, which seeks to recognize and honor the contributions made by veterans as they near the end of life.

Volunteers Learn about Themselves, too

Linda Gordon said working with hospice has changed her feelings and fears about her own death. “I used to be so afraid of it, almost a control freak, taking precautions, bike helmets, sunscreen...Now, when it happens, it’s going to happen. I’m not afraid. It’s a natural process that we go through. I know my family will be okay afterwards. I see these families, as long as there are good people in hospice helping them, it doesn’t matter if you can pay or can’t pay, you still get hospice. We’re not the angels of death. We’re the angels of living!”

• Five Wishes, which specifies not only medical and legal directives but also includes matters of pain management, family reconciliation, comfort issues, and spiritual needs.

• MOLST, or Medical Orders for Life Sustaining Treatment, is a form that health care professionals and patients use in deciding on various treatments that may arise during a final illness.

In Massachusetts, MOLST complements the traditional advance directives to ease the communication of medical orders that impact the end-of-life care choices and goes with the patient whether he is treated at home, in a hospital, or in some other setting. Health care proxies and living wills typically contain more general instructions, and cannot be followed by EMS providers in an emergency. MOLST, on the other hand, is like a doctor’s prescription that applies in Massachusetts and many other states.

Rather than taking effect after the patient is incapacitated, MOLST applies as soon as the patient consents to the orders in it and a physician signs it. It does not rely on a physician’s determination that the patient has lost mental capacity to make decisions.

The MOLST program is based on the belief that patients have the right to make their own health care decisions, including decisions about life-sustaining treatment, to convey these wishes to health care providers and to receive comfort care while wishes are being honored.

Patients and family members will want to think through these choices and create the forms that will put the force of law behind them. End-of-Life directives might sound scary at first, but hospice staff are trained to help initiate the discussions, create the forms, and ease the fear.

For additional information in a number of languages, including a video about MOLST, go to molst-ma.org.
For Further Information

- **HOSPICE OF THE SOUTH SHORE SOUTH SHORE HOSPITAL**, South Shore to 30 Reservoir Park Drive, Rockland, MA 02370 • (781) 624 7080. http://www.southshorehospital.org/hospice-of-the-south-shore

- **NORWELL VNA AND HOSPICE (NVNA AND HOSPICE)**, 120 Longwater Drive, Norwell, MA 02061 • (781) 659-2342 • www.nvna.org

- **PAT ROCHE HOSPICE HOME**, 86 Turkey Hill Lane, Hingham, MA 02043 • (781) 783-1627

- **OLD COLONY HOSPICE**, 321 Manley Street, West Bridgewater, MA 02379 • (800) 370-1322 or (781) 341-4145 • http://www.oldcolonyhospice.org

- **AMERICAN HOSPICE FOUNDATION**
  http://americanhospice.org • Although this group closed its doors last year, their website has a wide range of helpful information that remains relevant.

- **CHILDREN’S HOSPICE INTERNATIONAL**
  www.chionline.org • “Allowing Hope For Miracles.”

- **NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION** • http://www.nhpco.org
  Association of and for professionals in patient care, with interesting background information.

- **HOSPICE & PALLIATIVE CARE FEDERATION OF MASSACHUSETTS (HPCFM)** This state organization provides searchable files of end-of-life services and other resources, including those for special populations like veterans.
  www.hospicefed.org

- **NATIONAL DIRECTORY OF HOSPICES**
  www.hospicedirectory.org • State-by-State list compiled by the Hospice Foundation of America www.hospicefoudation.org, another wealth of information.

- **HOSPICE NET** is a rich resource for the dying and those who love and care for them.
  www.hospicenet.org