The Fairview Hospice Caregiver’s Handbook

This book is made possible by the generosity of the Cremation Society of Minnesota
Important phone numbers

Every call is answered in person. Please let us know if you are a hospice patient, family or caregiver.

Our hours are 8 a.m. to 5 p.m. (8 to 4:30 Hibbing, International Falls and Lakes) Monday through Friday. After business hours, please call only with medical concerns. You will reach our answering service and they will page a nurse. We do our best to return your call quickly. If a nurse has not called you within 15 to 20 minutes, please call again. If the phone is not working (Metro only), call 952-924-8185.

- Nurse/case manager: ________________________________

- Social worker: ________________________________

- Spiritual care provider: ________________________________

- Doctor: ________________________________

- Other Fairview Hospice staff: ________________________________
  __________________________________________________
  __________________________________________________
  __________________________________________________

Hospice billing questions: Metro: 612-728-2447. For all other sites, call the 24-hours numbers above.

Hospice must approve in advance all medical treatments and concerns. For example, tests, exams, medicines, equipment, trips to the emergency room or transportation. You must pay for any charges not approved.
Making a Donation

Many of our services are not covered by Medicare or private insurance. Your generous donations allow us to offer music and massage therapy, medication delivery, grief support and more.

Fairview Hospice is a non-profit organization. To donate to Fairview Hospice, call us at

- 612-728-2455 (Metro)
- 651-257-7836 (Lakes)
- 763-389-1923 (Princeton)
- 218-262-6982 (Hibbing)
- 218-283-3031 (International Falls)

Or write to us at Fairview Hospice,

- 2450 26th Avenue South, Minneapolis, MN 55406
- 11725 Stinson Avenue Chisago City, MN 55013
- 110 6th Avenue South, Princeton, MN 55371
- 1101 East 37th Street, STE 27, Hibbing, MN 55746
- 2716 Crescent Drive, STE 1, International Falls, MN 56649

If you prefer to donate online, go to www.fairview.org/foundation or www.range.fairview.org/HomeCareServices/Hospice.aspx.

Thank you for your generosity.
This handbook is made possible by:
*Cremation Society of Minnesota*
[www.cremationsocietyofmn.com](http://www.cremationsocietyofmn.com)

The Cremation Society of Minnesota is the largest provider of cremation services in the state.

**Minneapolis Chapel**
4343 Nicollet Avenue South
Minneapolis, MN 55409
Phone: 612-825-2435

**Brooklyn Park Chapel**
7835 Brooklyn Boulevard
Brooklyn Park, MN 55445
Phone: 763-560-3100

**Duluth Chapel**
4100 Grand Avenue
Duluth, MN 55807
Phone: 218-624-5200

**St. Paul Chapel**
1979 Old Hudson Road
St. Paul MN 55119
Phone: 651-789-0404

**Edina Chapel**
7110 France Avenue South
Edina, MN 55435
Phone: 952-924-4100
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The hospice journey

Thank you for choosing Fairview Home Care and Hospice for your hospice care. We are certified by Medicare and licensed by the State of Minnesota. You will see Fairview’s values of compassion, dignity, service and integrity in the care we give.

Our skilled staff offers care tailored for each person. We work closely as a hospice team and will include you and your loved one every step of the way. Patient and family goals are honored as we go through this period of time together.

This guide will help you understand how hospice can enrich the lives of our patients while offering guidance and support to family members and caregivers. Please keep this book handy for our staff to use on their visits.

While the Fairview standard of care is the same at all locations, our programs are not all exactly the same. Please talk to your hospice staff or case manager to learn the details about your hospice program.

You can also read this guide online at www.fairview.org/hospice. It is a good resource for family members who do not live with you. The website also has videos and other good resources about hospice care. You may also find www.fairview.org/Services/HomeCareHospice/GriefandSupportServices helpful. This website offers practical information about the grief process. It also has details about events sponsored by Fairview Hospice.

You are not alone.

We are here to support you. We are like the light that goes before you through the darkness to see things that are coming and to look around corners so we can know what is ahead. We will guide and help direct your care.
You are not alone

What is hospice care?

- Hospice is a philosophy of care. It is not a place. Hospice care can be given wherever you live.
- Hospice offers palliative (comfort) care. We care for the physical, emotional and spiritual needs of patients and their caregivers. We focus on living with dignity.
- Our goal is to address physical, emotional and spiritual pain and symptoms.
- In many cases, hospice care can extend the number of days for a patient. It can also greatly increase the quality of life.
- If you qualify for Medicare benefits (age 65 and over or disabled), you can get hospice care at no cost. But your doctor must first state that you have a terminal diagnosis. Medicare defines a terminal illness as one where the patient is not expected to live more than 6 months if the illness follows its predicted course. We carefully consider the diagnosis, needs and condition of each patient.
- If a patient improves or wants further treatment for their disease, the patient can no longer get the Medicare hospice benefit. In these cases, we will work closely with patients and caregivers to ease the transfer into other types of care.

Feel free to ask us questions about the personal and quality care we give. Our goal is to not only meet your expectations, but to exceed them. Your feedback lets us know how to best reach that goal. For more details about hospice, visit our website at www.fairview.org/hospice.
The patient and caregivers are at the center of all hospice decisions and support.

For more information about these services, please see the Index or ask your hospice team. Services will vary by location.
The plan of care

The plan of care is a very important part of hospice. The plan lists the medical and other care the patient needs, including spiritual and emotional needs. The plan also outlines who will do what. To make sure we can meet each patient’s needs, the patient and those who offer care and support work closely with us to make the plan. The hospice team reviews this plan every other week. We honor the goals of each patient in their own care. As needs change, the plan will change as well.

Care options

Patients can get hospice care wherever they live. If it is important for your loved one to stay at home, ask the hospice nurse or social worker about the caregiving options.

In some cases, care at home may not be what is best for the patient. In other cases, patients are already living in a long-term care residence when they are diagnosed with a terminal illness.

If you decide to move your loved one to long-term care, your hospice social worker will help you explore options. Though the staff will become the main caregivers, you can still offer love and support. The hospice team will still manage your loved one’s hospice care.

We will work closely with the care facility you choose. We will teach the staff about the hospice philosophy and process, and about caring for the terminally ill. The facility will offer social activities, give medicines and help with personal care. We’ll work closely with staff to make sure that your loved one’s needs are being met.

If your loved one is covered under the Medicare hospice benefit, this benefit will not cover custodial care (non-medical daily care like feeding, dressing, bathing, transferring to and from bed) or room and board in a facility. These services will have to be paid for by the patient or family. If you or your family have no insurance or can’t afford to pay for these services, we will help you apply for financial help.
Ethics

Fairview Hospice has an ethics committee with ethics advisors. This committee helps us respond to challenges, such as not giving treatment or choosing to stop treatment. You and your loved one have a right to take part in any discussions about ethical issues. If you have an ethical concern, please call the hospice office.

Spiritual issues

When dealing with a life-threatening illness, many people ask deep questions about their life’s meaning and purpose, faith and spirituality. With hospice, care for the spirit is just as important as care for the body. We know that different people have different ideas about spirituality. Some may not believe in a higher being. Others embrace a formal, organized religious faith. Still others have their own personal belief system. We know that spirituality is different for each person and we honor all belief systems.

Spirituality is what gives meaning, hope and purpose to a person’s life. Everyone has faith in something, even if it’s simply that the sun will rise in the morning. There is no set path or belief.

Spiritual care is a core service of the hospice program. Our spiritual care providers are always here for you. They can:

- **Listen.** They will hear you and your loved one’s words of grief, joy, anger and struggle. They will not judge, but help you and your loved one deal with your needs and personal issues.
- **Guide.** They will have the compassion, empathy and care to be with you and your loved one as you go through life’s journey. They can pray, read poetry or Scripture, offer guided meditation or just sit in silence.
- **Counsel.** Our spiritual care providers can help you and your loved one with questions of faith and life. They do not have all the answers, but can help your loved one find their life’s meaning and purpose.
- **Connect.** If you wish, they will talk with leaders from your loved one’s faith community. If your loved one does not have a faith community and would like one, our team can assist them. Your loved one doesn’t have to have a faith community or a certain belief system to get our support and care.
Complementary therapies

Hospice aims to treat the mind and spirit as well as the body. This is called complementary or holistic care. The word “complementary” means that these treatments are used with, or complement, other medical treatments. It is also sometimes called “integrative” or “holistic” therapy.

When complementary therapists talk about healing, they do not always mean curing. Curing is getting rid of disease. Healing involves creating new meaning in your life.

Complementary therapies such as music therapy and massage therapy can improve quality of life in ways you may not expect. They can bring relaxation and comfort, wholeness, meaning and healing. Talk with your hospice nurse about which of these therapies is offered in your program.

Music therapy

Music therapy can:

- Reduce anxiety and stress.
- Be relaxing.
- Help express emotions.
- Lead to reflection on the meaning of life.
- Improve speaking and thinking skills.
- Offer spiritual comfort.
- Reduce feelings of pain.
- Help process meaningful memories and review important life experiences.
- Create joyful and valuable memories.

We tailor each therapy session to your loved one’s needs. No two sessions are the same. We use your loved one’s favorite music. But each session is much more than just listening to recorded music. The benefits of a music therapy session last after the session ends.

- On the first visit, the music therapist will get to know your loved one. They will work with your loved one to set goals for therapy.
- During regular visits, the therapist will play live music with a keyboard or other musical instrument. The patient and those present can take an active role in the music therapy sessions if they wish.
• Sometimes a patient who has not responded to speaking does respond to music. They may smile, tap a toe or reach out with a hand.

• As your loved one’s needs change, your music therapist will change the music therapy session to meet those needs.

**Massage therapy**

During our life, touch is an important part of normal development and survival. It can help us feel safe and cared for. It is a universal language that communicates warmth, feeling and energy. Massage therapy can:

• Relieve stress.
• Increase blood flow.
• Be relaxing.
• Soothe sore muscles.
• Reduce pain.
• Help your loved one sleep better.
• Help to meet the need for physical touch.
• Ease depression and fatigue.
• Renew energy and wholeness of self.
• Help release or let go of emotions.

In many cases, the therapist will gladly teach simple massage to family members or caregivers. It gives others something helpful to do for their loved one. Touch is also a great way to communicate. Our massage therapists:

• Often work with patients in their beds.
• Are trained in many types of massage. Some examples are Swedish, Esalen, reflexology, pressure points, lymphatic relief and energy work.
• Will talk with your loved one about what clothing should be removed, if any. They always use a sheet or blanket to cover any areas of the body that are not being massaged.
• Use lotions that are light, non-greasy and unscented. Please let us know if your loved one would like to use his or her own cream or lotion.
• Will plan visits based on your loved one’s needs and goals.
**Aromatherapy**

Aromatherapy uses scented plant oils called essential oils. Aromatherapy can:

- Be relaxing.
- Lower anxiety, pain or upset stomach.
- Help your loved one sleep better.
- Lower the amount of medicine needed.

Lavender and peppermint are the most common oils used. Ask your nurse for more information.

**Acupressure**

Acupressure uses pressure points to treat symptoms. In Asian medicine, the pressure points are thought to carry energy called chi. Using acupressure can:

- Help your blood flow.
- Lower tension.
- Reduce nausea and vomiting.
- Ease heartburn and anxiety.

For nausea, you can put pressure on your wrist in the area shown in the drawing. Or you can wear anti-nausea wrist bands (also called sea bands). You can buy these at a local drug store and wear them as long as you wish. They do not have any side effects.

*The pressure point is three finger widths from the bottom of your wrist. It is a spot on your inner arm, between the two tendons.*
Hospice aides

Hospice Aides are an important part of the hospice team. They assist with bathing and personal care. If you have an aide come to your home, please have these items for them to use:

- Bath towel
- Washcloth
- Soap
- Shampoo
- Basin for water

We honor veterans

One out of every 4 dying Americans is a veteran.

If you are a hospice patient and a veteran, we honor your service and thank you for your sacrifice. We are here to listen to the stories you want or need to tell.

If you are the caregiver for a veteran, you may find a chapter of history becomes new again as your loved one faces the end of life.

Fairview Hospice takes part in the national We Honor Veterans program. The Veterans Administration and National Hospice and Palliative Care Organization have created this program. You can find out more at www.wehonorveterans.org.

Helpful reminders:

- Hospice is not a place. You can have hospice care wherever you live.
- Hospice offers hope and comfort care to the patient and their family.
- The family is the main caregiver. But we will help every step of the way.
- Hospice treats the mind, body and spirit.
- Complementary therapies can reduce stress and pain.
- You are not alone.
Volunteer Services

*Fairview Home Care and Hospice*

Volunteers can offer support to both you and your loved one. Below is a list of volunteer services in the metro area. If you are outside the metro area, please ask your hospice care team or call the Volunteer Department to learn what services your program offers. As our program grows, we may add new services.

All volunteers have been screened and trained. Visits last from 1 to 4 hours and may be 2 to 4 times per month, unless otherwise arranged.

**Patient support**

- Offer support for day-to-day needs of you and your loved one.
- Do not offer hands-on care such as bathing, feeding or giving medicines.

**Type of care**

- Caregiver relief for you to take a break.
- Sitting with your loved one: talking, reading, playing games, gentle touch and so forth.
- Light housekeeping, such as laundry, dishes or vacuuming.
- Prepare meals: cooking, heating food, making sandwiches and so forth.
- Run errands for you. Volunteers will not drive you or your loved one in their cars. You or your loved one must reimburse volunteers after they run an errand.
- Special projects, like writing holiday cards, sorting, organizing and so forth.

**Music or Do Re Mi**

- Music by talented musicians from our community.
- Enhance comfort and relaxation.
- Stimulate conversation and memories.
- This is NOT music therapy.

**Type of care**

- Play musical instruments or sing to you and your loved one.

**Energy work**

- Offered by trained energy therapists from our community.
- May help with pain management and relaxation.
- Your loved one stays fully clothed during energy work sessions.

**Type of care**

- Can include reiki, healing touch, three-heart balancing or other techniques.
- May involve touch or just working with the energy fields around the body.
Pet therapy
• Offered by trained and certified pet therapy animals and their handlers.
• May help improve mood and memory and lower heart rate and blood pressure.
• Pet therapists can’t visit homes with other dogs, cats or uncaged animals.
• Pet therapy animals can’t visit patients with active bacterial infections.

Type of care
• Visit with trained therapy animals and their handlers.

Vet to vet
• Offer support to patients who are military veterans.

Type of care
• Talk about military experiences.
• Talk about thoughts of death and dying.
• Pinning ceremonies to honor your loved one’s service to our country.

11th hour support
• Offer support in the final 24 to 48 hours of life.
• Have worked in hospice care for at least 6 months.
• Can be arranged by anyone on the hospice team at any time.

Type of care
• Sit with patients who are alone or agitated.
• Spend the night with your loved one so you can rest.
• Read, pray, hold hands or play music as needed.
• Offer support, help or guidance as needed.

Asking for a volunteer
You can ask for a volunteer at any time by calling:
• 612-728-2455 (Metro and Princeton)
• 651-257-8850 (Lakes)
• 218-262-6982 (Hibbing)
• 218-283-3031 (International Falls).
Ask for Volunteer Services. Your social worker will ask about any volunteer needs at the first visit.
The more details you can give us about your needs (such as time of day, needing help to the bathroom, and so on), the easier it will be for us to match you with the right volunteer.

If you are deaf or hard of hearing, please let us know. We provide many free services including sign language interpreters, oral interpreters, TTYs, telephone amplifiers, note takers and written materials.
Being a Caregiver

Caregiving may be the most rewarding thing you will ever do. But it does have some challenges. Caring for your dying loved one may compete with your usual responsibilities: children, work or other activities. Being a caregiver lets you show your loved one how much he or she means to you.

As a caregiver, you will have many roles: family spokesperson, patient advocate, information center and hospice team captain. You will look out for your loved one's best interests, making sure physical, emotional and spiritual needs are met.

There is much to learn. We will be here to teach you, and you will teach us as well. Please let us know what you expect and need as we join you in caregiving.

Reducing stress

Caring for a dying person can challenge you physically, emotionally and spiritually, no matter how much help you have. Both you and your loved one will no doubt feel stress. It is important that you learn how to reduce it.

To make it through these hard times, know your limits. Save your strength. Do your best. Try to keep your sense of humor. Laughing is a great stress-reducer. Also, try to stay in the present and think good thoughts. Positive self-talk, also called affirmation, can greatly reduce stress.

Tips to reduce stress:

- Talk to your loved one about his or her needs. What does he or she expect from you? Have backup plans in case you can't meet these needs. Include family members and friends if you can.
- Say “no” when you feel the need to do so.
- Ask for what you need.
- Don't try to guess what others want.
- Don't do work that someone else should be doing.
- Exercise.
- Journal.
- Do things that make you laugh.
- Ask us about aromatherapy and acupressure. They may help.
- Find a quiet place to relax for short periods of time.
• Ask for help from friends, family, volunteers and paid caregivers.
• Make full use of your hospice team.
• Set realistic expectations for yourself.
• Take time to be alone.
• Ask yourself, “What am I going to do today to take care of myself?”

**Tips to help you relax**

Try to find a quiet place to still your mind each day for at least 20 minutes. Try one or all of these methods:

- **Deep breathing.** Find a quiet place and sit somewhere comfortable. Close your eyes and try to make your mind blank. Slowly inhale through your nose to a count of 8. Then exhale through your mouth for a count of 8. Repeat these steps 4 or 5 times. Keep breathing, this time without counting. Try to get close to the count of 8. Do this for about 10 minutes. If thoughts pop up, simply let them go and focus once again on your breathing.

- **Mantra.** During your relaxation exercise, you might add a single word or phrase, known as a mantra. An example to try: As you inhale, say the word “love” to yourself. As you exhale, say the word “peace.” Or try using a phrase like “I am not alone” or “All shall be well.” Be creative. Find words and phrases that work best for you.

- **Visualization.** Find a quiet room and sit somewhere comfortable. Close your eyes and try to picture a favorite place. This might be a vacation spot such as a beach in Florida. Picture you and your loved one there. Smell the salty air and the suntan lotion. Hear the sea gulls’ cries and the waves crashing. Feel the warm sunlight flowing into your head and then down through your neck, shoulders, chest, arms, fingers, stomach, legs, feet and toes. Relax each part of your body as the warmth flows through it. Or, think of the love that you and your loved one share as a circle of light above your head. Again, feel the light enter your body and move from your head to your toes.

Our music therapists can lead visualization exercises. You can also buy relaxation CDs.
**Helpful reminders:**

- Being a caregiver can be very rewarding.
- You will face many challenges. Ask for tips about how to cope.
- Make use of the hospice aide and volunteer services.
- Take care of yourself. It is not selfish to take time-outs when you need them.
- Learn ways to relax and reduce stress.
- You are not alone. Ask for help when you need it. Hospice care is a partnership.
Coping with a terminal illness

When dealing with a terminal illness, it can help to change your view on life. In order to keep things in perspective, author John Schneider suggests three simple questions:

- What is Lost?
- What is Left?
- What is Possible?

We can help you sort through your feelings using this set of questions.

Ask yourself: What do I want to know? Ask your hospice team: What do I need to know? We are here to guide and teach. We don’t want you to feel overwhelmed. We always speak the truth, but in ways that are easy to understand and accept.

It may also seem that things are out of your control, or that “there is nothing more we can do.” But we believe that there is always much that can be done. Hospice care affirms life. It allows people to live until they die, sharing the end of their life with people important to them. It is very important for the patient and the caregiver to focus on what we can manage.

The reality of dying

The way that people live their lives can often predict the way they will die. A person who could never face pain may choose to not face death. A person who has faced hard times with anger may face death with anger too. Likewise, a person who tends to compromise in a conflict may continue to compromise all through their life.

Some people feel there is never enough time for all that we want to say or do. They feel that it is never really “okay” for someone to die. Others may feel at peace. It is important to know that many emotions can come up in the dying process. Each person dies in his or her own way.

Emotions and feelings

Patients and their caregivers may have many different feelings and emotions because things are changing. As a caregiver, you may think your feelings are crazy, selfish or unreasonable. But your feelings are valid expressions of your
inner emotions. Try to accept them, no matter how strange or unreasonable they may seem to you. Most of what we feel is more common than you would think.

Each person’s death is unique. As you read about the physical, emotional and spiritual realities of death and dying, take what helps and ignore what doesn’t. Talk to us about your emotions. We are here to help caretakers and family cope.

**Fear**

After the shock of being diagnosed with a terminal illness wears off, most people feel fear. Death is an unknown. It is beyond our control. Fear can cause stress. It can make people tense and short-tempered. Fear may come and go. This is all normal.

You can’t know the future, but you can get ready for it. Learn as much about death and dying as you can. Write down your fears. Talk about them with your loved one and with the hospice team. Be open to possible solutions. When you feel afraid, take deep breaths. Try to relax. Remind yourself that you’re not alone. You’re doing the best you can. Try to let the fear go.

**Guilt**

It is common to feel some guilt at this time. Guilt may come from past choices or hard decisions. Some patients may say, “Why didn’t I take better care of myself?” “Why didn’t I get medical help earlier?” They may feel guilty for how their illness affects their loved ones. “Why do I have to put my loved ones through this?” Families can feel guilt for how they respond to the illness and the dying process.

**Grief**

Grief happens throughout the dying process. It is a natural reaction to a loss. It can cause physical, spiritual and psychological pain. Give grief the attention that is due. Our bereavement (grief) staff is here to guide and assist you during this time.

**Anger**

Anger is an especially tough emotion for caregivers. But it is a normal, healthy reaction. It is usually a response to feelings of fear, helplessness and frustration. A dying person’s anger is one of the hardest emotions for caregivers to face. In fact, caregivers are often the targets of anger. Patients can get very demanding. They’ve lost so much control in their lives that they sometimes try to control the people around them.
Coping with your feelings

When dealing with feelings, remember:

- Express your feelings. Talk with a trusted friend or hospice staff member.
- Be a good listener. Telling your loved one to “cheer up” may not be helpful.
- Do what you can now instead of wishing you had done more in the past.
- Show compassion and understanding as your loved one talks about his or her feelings.
- Support and try to accept whatever your loved one feels.
- Give help after first asking if it is wanted.
- Ask your loved one if he or she is ready to talk about death and other subjects that are hard to talk about.
- Say things that will bring comfort, like “I am here for you” or “We will get through this together.”

The following can offer comfort and healing during hard times:

- Laughter
- Relaxation
- Aromatherapy
- Energy work
- Prayer and meditation.

Though these may not cause a medical miracle, they often cause miracles of attitude adjustment. They help people learn to cope with their illness. Talk with your hospice team if you need ideas about these areas.

Hospice celebrates living. It focuses on the positives in life. Though you will feel many things, with our support, you and your loved one can still feel joy, love and hope.

Hope

Even when death is certain, there is room for hope. You can hope for happy times together. You can hope to keep your loved one’s pain under control. You can hope that until death comes, you and your loved one will live your lives fully. If you hope for the things you can control, you can make them happen.

Keep hope alive. It can help protect you when today seems too hard to face.
Coping with a Terminal Illness

Coping with your feelings
When dealing with feelings, remember:
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• Do what you can now instead of wishing you had done more in the past.
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Hospice celebrates living. It focuses on the positives in life. Though you will feel many things, with our support, you and your loved one can still feel joy, love and hope.

Hope
Even when death is certain, there is room for hope. You can hope for happy times together. You can hope to keep your loved one’s pain under control. You can hope that until death comes, you and your loved one will live your lives fully. If you hope for the things you can control, you can make them happen. Keep hope alive. It can help protect you when today seems too hard to face.

Relationships
Many people see terminal illness as a wake-up call to start living life while there is still life to live. Knowing that death is near offers everyone a chance to show his or her true feelings. It’s a time for saying, “Thank you,” “I love you,” “I’m sorry, forgive me,” “I forgive you,” and “Goodbye.” Relationships often grow stronger as the patient and caregivers cope with living while dying. Once a person begins the transition from life to death, it is more important to love, forgive and make peace.

Tips to help children cope when a loved one is dying

• Take time to talk to each child alone.
• Ask what they already know about the illness.
• Be honest and realistic.
• Explain that the illness is not their fault. Let them know that a person or event never causes an illness.
• Teach them how to hope for things when a cure is not likely.
• Assure them that the illness is not “catching.”
• It’s okay to say, “I don’t know.”
• It’s okay to cry.
• Let them know you love them, and there will always be someone to take care of them.
• Be prepared for anger.
• Urge them to talk openly about their feelings. Or they may wish to write or draw pictures about how they feel.
• Ask them to tell you in their own words what they understand.
• Keep them updated.
• Make only promises you can keep.
• Ask them if they would like to visit their loved one. Tell them ahead of time what to expect before they see their loved one.

We have many other resources to help children cope with death. Let us know if you need help.
Sexuality

Don’t deny, ignore or discourage a dying person’s sexuality. It is natural. Sexuality is a personal matter. But talk to your loved one if it is an issue. We will respect this need.

Family and caregiver meetings

We can also help you organize family and caregiver meetings. These meetings are a great way to look at what needs to be done to give your loved one the best care. It is also a good way to hear how each person is feeling and coping. Ask your hospice team for more information.

Helpful reminders:

- Even when death is certain, there is still room for hope.
- You can still seek and enjoy the good in life.
- You will feel many emotions. Show them. Do not hold feelings in.
- This is a time to make relationships stronger.
- You are not alone. We can help you cope with dying, stressful feelings and finding meaning in life.
Creating a safe home

As a general rule, keep things as normal as you can, but follow these safety tips.

- If stairs are a problem, install handrails.
- Leave enough room for a walker at the top and bottom of the stairs.
- Make a clear path to the bathroom.
- Remove loose rugs or electrical cords that might cause a fall.
- If your loved one will be in a wheelchair, make sure there is space to move around.
- Keep medicines and medical supplies in a safe, secure area away from children and pets.
- Make sure all guns and ammunition are locked and stored safely.

After looking at the big picture, carefully check each room your loved one might use.

The bedroom

- Will your loved one use a hospital bed or a normal bed? We offer a hospital bed for those who need it. **Note:** hospital beds do not come with sheets. Also, a trapeze bar can help your loved one move in bed if they have upper arm strength.
- Have a large supply of sheets and blankets in case the bed needs to be changed a few times in one day. Hospital beds are twin size, but any size sheet will work.
- A foam mattress may make the bed more comfortable. A washable mattress pad can be very helpful.
- Offer 3 or 4 good pillows to keep your loved one comfortable. Pillows can be placed under the knees for better circulation.
- If your loved one will be eating meals or working on projects in bed, you may want to get a lap tray.
- If your loved one can’t walk to the bathroom, you may want a bedside commode, bedpan, urinal, catheter or disposable briefs.
- A sturdy nightstand or bedside caddy can hold glasses, tissues, books, remote controls and the like.
- Try to keep your loved one’s personal treasures in plain view. This can be reassuring and comforting.
• If hospital-style gowns are easier for both of you, you could cut the back of favorite nightgowns or nightshirts and sew ties on. The same can be done with favorite dresses and shirts.

• Make sure your loved one can alert you if needed. Try using a bell, whistle, intercom or baby monitor.

The bathroom

Bathrooms can be dangerous, especially for someone who is weak and unsteady. If your loved one can use the bathroom on their own, make the bathroom as safe, accessible and easy as possible.

• The door should open and close easily. You may want to remove the locks.

• If your loved one may have a hard time getting on and off the toilet, you can put a portable commode over it. Hospice can help you order this.

• To make bathing easier, use a bath chair in the bathtub or shower. If your loved one has trouble getting in and out of the bathtub, you may want a transfer bench.

• If your loved one will use the shower, shower curtains are safer than glass doors. A hand-held shower hose with a long, flexible tube makes showering easier.

• Both the bathtub and shower should have grab bars and safety rails. The floor of the tub or shower should have a non-slip bath mat or safety strips. A tub or shower caddy can hold washcloths, soap, shampoo and other items.

• If your loved one needs to sit while grooming, be sure the mirror is at the right height.

• Be sure the bathroom also has a device to alert you (bell, intercom) if your loved one needs help.

• A nightlight in the bathroom can increase safety.

The kitchen

Because the kitchen is often the center of activity, it should be accessible to your loved one if possible.

• Be sure a wheelchair can fit at the table.

• Use nonskid wax on the floor, and remove any scatter rugs.

• Be aware of odors created when preparing and cooking food. They may not smell good to your loved one. Check with him or her about what smells are okay.
The living room and family room

- If your loved one is mobile, offer a safe, easily accessible chair in the living room or family room.
- Keep a small pillow, a footstool and a blanket with the chair. You may also want to attach a swing-away, self-storing tray for your loved one's items.

Equipment and supplies

We can help you decide which equipment and supplies you will need for your loved one. Some are covered by insurance or the Medicare hospice benefit. Others are offered on loan through non-profits like the American Cancer Society or Easter Seals. Be sure to ask us before buying any equipment or supplies.

Preventing infections

- Washing hands is the best way to prevent infections (illness caused by germs). We suggest you wash your hands with liquid soap and warm water for 20 seconds as needed.
- Place items such as tissues, blue pads, disposable briefs, bandages and tubing in a plastic bag. Close tightly and throw it in the trash.
- Dirty laundry should be washed in hot, soapy water. Use bleach if needed.
- Equipment such as commodes, bedpans and bath seats should be washed with hot, soapy water and disinfected after each use.
- Clean spills of blood and other body fluids by putting on gloves and wiping the spill with paper towels. Then wipe the area with diluted bleach.

Helpful reminders:

- Keep your loved one's needs in mind when you prepare a home for hospice care. Make sure all areas where they will be are safe and easy.
- Your loved one may not want to ask for help. Let them know it is okay to need help.
- Ask others for help with chores and caregiving. You don't need to do it all alone.
Daily physical care

At first, your loved one may be able to do most things for him or herself. But your loved one will need more help as time goes on. Always explain what you are doing and why. Our hospice aide will help with personal care. These cares include (but are not limited to) bathing, dressing, mouth care, passive exercise, shampooing and changing linen. Please talk with your nurse about your loved one’s needs.

Bathing

Staying clean helps a person maintain dignity and a sense of control. When bathing your loved one, pay special attention to the genital and underarm areas, where odor-causing bacteria are likely to linger. To prevent dry skin, use warm water instead of hot, use mild soap and rinse the soap off well. Watch for changes in the skin, such as red spots or areas sensitive to the touch. Careful washing or bathing is even more important if your loved one loses control of bladder or bowels (incontinence).

After every bath, dry the skin well, paying special attention to any folds in the skin. Apply a lotion or cream with a water-soluble base, rubbing in gently. Avoid alcohol-based lotions or creams, as these will dry the skin.

Skin care

The skin is our largest organ. It controls our body temperature and lets us feel comforting touch. It gets thinner and less elastic as a person ages. Skin problems can be caused by changes in diet, incontinence or staying in one position for long periods of time.

Dry skin

Dry skin may be caused by dehydration (not getting enough water), heat, cold, radiation therapy or chemotherapy. Water-soluble skin creams can help.

Itching

Itching may be caused by dry skin, toxins in the blood, allergies or medicines. The normal reaction to an itch is to scratch it. This often makes the itch worse. Instead, use lotions and creams and avoid hot water. Don’t bathe your loved one too often. Avoid tight clothing. Ask the hospice nurse about medicines to help the itching.
Pressure ulcers

Pressure ulcers, also known as bedsores, are a concern. Pressure ulcers happen when an area of the skin loses its blood supply. This is often from staying still in one place for too long. They may also appear if the patient is left in urine or feces (pee and poop) too long. The areas most at risk are where the skin is close to the bone: the back of the head, shoulder blades, spine, elbows, tailbone, hipbone, heels and ankles.

To prevent pressure ulcers:

- Your loved one should move or change position every 2 to 3 hours. Exercise or simply turning in bed is very important. If your loved one must stay in bed, he or she might be able to sit up and dangle the legs over the side a few times a day. If in a wheelchair, your loved one might lift up the body every half hour or so. If your loved one can't move, your hospice nurse or hospice aide can show you how to turn the body. Even slight movement is helpful.
- Put a pillow between the legs and a towel between the arms and the body. You may also put a pillow under the legs so the heels don't touch the mattress.
- Make sure the sheets are dry and free of crumbs and wrinkles. A dense foam mattress or an air mattress can relieve pressure on the skin. Do not use a plastic or foam donut as this can prevent blood flow.
- Use a good moisturizing lotion.
- Watch for redness, especially in areas near bones. If the redness lasts, tell your hospice nurse.

If your loved one gets pressure ulcers, your nurse can tell you how to care for them. Because they are ulcers, they can be very slow to heal. Or they may not completely heal at all. Some sores need special supplies. Regular bathing will help reduce any odor from the ulcers.

Changes in skin color

Changes in the body may cause changes in skin color. Yellow skin may mean liver problems. If the skin is bluish, your loved one may be having trouble breathing. Talk to your nurse if you have any questions.

Odors

The skin may start to give off an odor. If this is a problem, you can:

- Put charcoal in a container and put it where pets or children can't reach it.
- Use wintergreen oil in a diffuser.
- Ask your nurse for other tips.
**Mouth care**

Your loved one may have a dry mouth, tongue sores or bleeding gums. These problems can be painful and can also cause bad breath. Follow these tips for good mouth care:

- Rinse the mouth often. But don’t use regular mouthwashes. They are made with alcohol, which can make the problems worse.
- Use mouth swabs every 4 hours. You can put petroleum jelly (Vaseline) on dry lips, unless your loved one is on oxygen (petroleum can cause oxygen to catch fire). Then, use K-Y jelly or another product without petroleum.
- Clean the mouth at least 2 times a day. Gently brush the teeth and gums with a soft, nylon-bristle toothbrush. If the toothbrush hurts, use a toothette (a small sponge on a stick). Rinse the toothbrush well after each use and store it in a cool, dry place.
- If your loved one wears dentures, remove and clean the dentures between meals or at least daily. Your loved one should not wear dentures if she or he has severe mouth sores.

**Foot care**

- Feet need activity for good blood flow. If your loved one is inactive, try to exercise the feet, moving them in a circular motion.
-Massage the feet. The power of touch is very important. Keep feet soft with a lanolin lotion.
- Due to our concern for your safety and well-being, Fairview Hospice staff do not give foot soaks. We do not recommend foot soaks or applying warm wet towels or heated products to the feet.

**Helpful reminders:**

- Your loved one may need help with daily care. Hospice aides can help and offer advice.
- It is very important for your loved one to move or be moved every 2 to 3 hours.
- You are not alone. We will teach you the skills you need to be sure of your caregiving.
Caring for symptoms

We want your loved one to be as comfortable as possible. Below are the most common symptoms and suggestions for how to help.

Mouth sores

Mouth sores can bleed. They may be very red or have small white patches in the middle. They can make it hard to eat.

Tips to treat mouth sores:
- Offer ice chips or frozen pieces of fruit to suck on.
- Ask your hospice nurse for medicine to numb the mouth and treat the sores.
- Put lip balm on the lips and corners of the mouth to prevent cracking.
- Make foods soft and moist. If needed, puree them.
- Offer cool foods or drinks.

Dry mouth

Mouth dryness is a common problem for many ill people.

Tips to treat dry mouth:
- Moisten foods with sauces, gravies, yogurt or salad dressing.
- Offer frequent sips of liquid, small chips of ice, Popsicles or frozen pieces of fruit or fruit juice to suck on.
- Offer sugar-free gum or candy. Lemon drops and other citrus-flavored candies work well.
- Keep water near your loved one.
- Don’t serve foods that need to be chewed well.
- Use a moist toothette as needed.

Nausea or vomiting

Sometimes, bad tastes or smells are so strong that patients get nauseated. Nausea and vomiting make eating and drinking nearly impossible. But there are many medicines that can help an upset stomach. Tell your hospice nurse if your loved one vomits or feels nauseated.
To help with nausea:
- Give nausea or pain medicines an hour before eating.
- Offer small meals.
- Offer mildly seasoned foods and avoid sweet, spicy, fatty or greasy foods.
- Offer plain foods that are broiled, boiled, steamed or baked.
- Offer dry foods, such as crackers.
- Serve food cold or at room temperature to reduce its smell and taste.
- Offer cool, clear beverages such as ginger ale, apple juice and broth.
- Offer a distraction while your loved one eats. Turn on music or watch a TV program together.
- Use relaxation exercises like deep breathing at the first sign of nausea (see page 22). Acupressure may also help (see page 16). Aromatherapy, especially peppermint oil, is also helpful.
- After your loved one has eaten, have him or her rest by sitting up or reclining with the head and shoulders elevated. If possible, your loved one should not lay flat for at least 2 hours after eating.
- Take note of when, how often and how much your loved one vomits.

Nausea with vomiting can be a serious problem. Your loved one may lose important medicines as well as vital fluids. Inform your nurse if this happens. If your loved one vomits, a mouthwash may be helpful.

Trouble breathing

At times, your loved one may have trouble breathing. A person who has trouble breathing feels like he or she is not getting enough air. The heart rate (pulse) may increase. Your loved one may wheeze. Breathing may become irregular or labored. It may even briefly stop sometimes. If this happens, stay calm. If you seem alarmed, this may frighten your loved one.

To make breathing easier:
- Use a humidifier or vaporizer to increase the humidity. This will help loosen phlegm. Ask your hospice nurse if you have questions about how to keep the machine clean.
- Open the windows or use a fan to increase airflow through the room.
Medicines:

- Morphine and similar medicines can make breathing much more comfortable for people who are short of breath.
- People who are short of breath can become anxious. Sometimes anti-anxiety medicines are helpful as well. Talk to your hospice nurse to see if this would be helpful for your loved one.

Using medical oxygen:

- Medical oxygen is not always helpful at the end of life. We have a way to measure if your loved one needs this. If so, a doctor will prescribe this.
  - For your loved one's comfort, you might pad the part of the tube that goes over the ears with cotton or gauze held in place by tape.
  - Because oxygen dries out the nasal passage, it may help to put K-Y jelly in the nostrils. Do not use any petroleum-based products.
  - Oxygen can very easily catch fire, so keep it away from open flames. Do not use oxygen near an electric or gas stove. Do not allow smoking when oxygen is being used.
  - Store oxygen tanks securely.
  - Clean oxygen condenser filters as you were shown.
  - Be prepared for power outages. Portable oxygen is used for this reason. Call your power company to place you on a priority list for power to be restored as soon as possible in an outage.
  - Please be aware that oxygen stays in the room and on clothing for a period of time after it is turned off.

Airway fluid

Fluid in the airway (secretions) may cause a rattling sound in the throat. This may be more stressful for you than for your loved one. It will sound like gurgling. It doesn't mean your loved one is drowning, uncomfortable or can't breathe. It's just the air moving through the fluid.

Talk to your hospice nurse about treating secretions with medicine. Reassure your loved one that everything is all right. Put him or her in a comfortable, raised position, or it may help to change position from one side to the other.

Coughing

Coughing is a common symptom. It has many different causes. Medicines can help. Ask your nurse about which medicine would be best for your loved one.
**Fever**

Many things can cause fever. Infection, tumors, dehydration and treatments are all causes, but many people have a fever as the body starts to shut down. Your loved one has a fever if:

- Oral (under tongue) temperature is over 100.5°F (38°C)
- Rectal (in the bottom) temperature is over 101.5°F (38.6°C)
- Axillary (under the arm) temperature is over 100.0°F (37.5°C)

It is not uncommon for temperatures to reach 103°F at times. Your loved one might look flushed, and the head or cheeks may feel warmer than usual. Or your loved one may complain of being hot. Take your loved one's temperature to see if there is a fever. Retake your loved one's temperature every 4 to 6 hours until your loved one is no longer flushed or complaining of feeling hot.

**To treat a fever:**
- Sponge the body with cool, not cold, water.
- Offer fluids often.
- If your loved one can't swallow or drink, use a sponge or toothette to wet the mouth.
- Cover and uncover the body as needed.
- Cuddling your loved one can reduce chills and offer good bonding time.
- Give medicines like Tylenol. But always check with the doctor or nurse first.

Call your hospice nurse if your loved one's temperature is greater than 103°F (39.44°C) for more than 24 hours or if you have any questions or concerns.

**Trouble swallowing**

Your loved one may gag, cough, spit or complain of pain when trying to swallow.

**Tips to help your loved one swallow:**
- Offer bland foods that are soft, smooth and high in calories and protein such as yogurt, milkshakes or puddings.
- Add sauces and gravy to dry food.
- Don't serve hard or sticky foods. Mash foods to baby-food consistency.
- Offer liquids that have some consistency, such as milkshakes or pureed fruit. These are easier to swallow than clear liquids.
• Have your loved one eat while sitting upright. If your loved one is bedridden, get as close to a sitting position as he or she can.

• Offer a straw for liquids.

Elimination problems

Your loved one may have elimination trouble, or problems with urine and feces. This can include incontinence (unable to control the bladder or bowels), constipation or diarrhea. These may be caused by medicines, illness or the body slowing down. Your hospice nurse will teach you know how to prevent problems and treat them if they occur.

Incontinence

If your loved one becomes incontinent, you can use special underclothes, pads and other disposable products. You might put a disposable pad under him or her. A urinal, bedpan or commode near the bed may also help. Urge your loved one to empty the bladder and bowels often. Limit fluids at night.

Urine

For urine incontinence, a nurse may place a catheter (tiny tube) in your loved one’s bladder. The nurse will teach you how it works and how to take care of it. Catheters drain urine into a bag so that the skin stays dry and disposable briefs are not needed. Be sure to empty the drainage bag a few times per day. Also check the tubing often for kinks and straighten if needed. The bag should hang below the body level to help with draining.

Bowels

For bowel incontinence, you’ll need to use either a bed pad or adult disposable briefs. Special creams, lotions and deodorant sprays can help clean the genital or anal area and help keep it dry. It is very important that your loved one follows his or her bowel program.
Diarrhea
Diarrhea is the passing of watery or loose stools 3 or more times a day. It may be accompanied by gas and cramping. If your loved one has diarrhea, tell your hospice nurse.

To prevent or treat diarrhea:
- Give smaller meals more often rather than 3 larger ones.
- Add nutmeg to food. Nutmeg can help slow the intestines.
- Try the BRATY diet of bananas, rice, apple juice, dry toast and yogurt.
- Avoid spicy, fried or fatty foods. Also avoid alcohol, carbonated (fizzy) beverages, artificial sweeteners, very hot or very cold foods, cabbage and beans. Offer fewer fruits and vegetables.
- Serve fluids at room temperature. Hot or cold fluids may increase bowel movements. Avoid caffeine.
- It is important your loved one stays hydrated. Ask your nurse for other suggestions.

Constipation
Constipation means not having bowel movements often enough. The stool (poop) is hard, dry and difficult to pass. If your loved one hasn't had a bowel movement in 3 days, he or she is constipated. Constipation can cause discomfort, even pain. At the first sign of constipation, call your hospice nurse.

To prevent or treat constipation:
- Increase high-fiber foods such as bran, wheat germ, fresh raw fruit (with skin and seeds) and fruit juice (especially prune juice).
- Your loved one's doctor or nurse may also suggest laxatives, enemas or stool softeners.
- Avoid foods that can cause constipation, such as cheese and eggs.
- Give plenty of fluids. Hot fluids increase bowel activity. A cup of tea or warm water with lemon taken first thing in the morning can be a gentle, natural laxative.
- Increase daily activity if you can.

Constipation is a frequent side effect of narcotic pain medicine. If your loved one is taking narcotics, your loved one may be put on medicine that makes bowel movements easier. It will be important to write down when your loved one has a bowel movement so the nurse can make the right changes to the medicines.
Seizures

Seizures are not common, but the fear of seizures is. A seizure is a sudden jerking (convulsing) of the muscles that you can't control. It usually lasts less than 5 minutes. But it may leave the person feeling confused and tired for a few hours. Jerky, uncoordinated movements may mean a seizure is coming.

If your loved one has a seizure:

- Lay him or her down. Turn the head to the side to keep the airway open.
- Your loved one may lose bladder or bowel control during the seizure.
- Do not put anything between his or her teeth, as this may hurt the teeth or jaw.
- If your loved one's bed has side rails, pad them.
- You can get special seizure medicines, but they may cause sleepiness. Many patients would rather stay awake despite the risk of a seizure. It's important to discuss these medicines with your loved one and the hospice nurse.

Safe transfers

Your loved one may not be able to get around easily on his or her own. If this is the case, the following tips can help. The use of a transfer belt may add safety and security. Ask your hospice team if you have questions or need help.

Chair to toilet or toilet to chair

1. Help the person scoot to the edge of the chair. Be sure the patient's feet are under his or her body. Lift as the person pushes up.

2. Keep the person's weaker knee between your legs. Turn the person around in front of the toilet or chair. Lower him or her gently.
**Sit the patient up in bed**

1. Place the wheelchair close to the bed and lock the wheels.
2. Help the patient turn over onto his or her side, facing you.
3. Put an arm under the patient’s neck with your hand supporting the shoulder. Put your other hand behind the knees.
4. Swing legs over the edge of the bed, helping the patient sit up.

![Diagram of moving patient up in bed]

**Stand the patient up**

1. Have the patient scoot to the edge of the bed.
2. Put your arms around the patient’s chest and clasp your hands behind his or her back.
3. Support the leg farthest from the wheelchair between your legs, lean back, shift your weight, and lift.

![Diagram of standing patient up]

**Sit the patient down**

1. Have the patient pivot toward the chair, as you continue to hold on. Always transfer toward the person’s stronger side.
2. As the patient bends toward you, bend your knees and lower the patient into the back of the chair.

![Diagram of sitting patient down]

**Move patient in bed**

1. Cross the patient’s arms and bend their knees up if you can.
2. Reach across their body, putting your hands under their hip and shoulder to roll them toward you. Be careful not to pull on their neck.

![Diagram of moving patient in bed]

**If you have a helper:**

1. Each person should put an arm under a shoulder and knee on the patient.
2. Work together by counting before movements. Example: 1, 2, 3, lift.
Falls

A natural part of the dying process is increased weakness. Memory changes and medicine may affect balance and safe decision making. These can all cause falls. For added security, you may want to use Lifeline. Call 952-885-6185 for more information, or if not in Metro area, ask your hospice staff.

To help prevent falls:

- Keep areas around bed and walkways free of clutter.
- Avoid bending and reaching.
- If your loved one uses a walker or cane, keep them near at all times. Talk to your hospice team about the right equipment to help your loved one get around safely.
- Clothing should fit well. Wear good footwear to avoid slipping.
- Good lighting is also important.

If your loved one falls:

- Ask if he or she is all right.
- Ask about pain. Don't move him or her if there is severe pain or there is fluid draining from the mouth, nose or ears.
- Check his or her body for any area that looks different and might be broken.
- If there is no pain and everything seems normal, help him or her back to a seated position or back into bed. If you need help lifting or moving, call the non-emergency number for your local fire department.
- If there is pain, call hospice to talk with a nurse. If there is severe bleeding, call 911, then call hospice.
- Tell your hospice nurse about any falls.
Memory and confusion

Your loved one may have trouble with memory, thinking, language and judgment. He or she may not know familiar people and places, remember past events or think logically. Your loved one may lose a sense of reality. They can be confused or feel like they are going crazy. This may be due to the illness, medicine, emotional upset or a buildup of waste products in the body.

To help your loved one:

- Point out familiar objects.
- Keep a large wall calendar and large clock with a lighted face nearby if you have one. Announce the day and time first thing each morning.
- Circle important dates on the calendar and often remind your loved one of upcoming events.
- You might also show photos of people who are coming to visit or of family members or friends he or she has not seen for a while.

Your loved one may see or hear things that aren’t there. This is called hallucinating. It is common, but can be very upsetting. You do not need to correct or disagree with your loved one. You may want to gently tell them what is really going on. If your loved one is scared, explain that what he or she is seeing or hearing is because of the illness or the medicines being taken. Let your nurse know if this is happening.

Agitation or anxiety

Your loved one may feel restless, angry, afraid and anxious. This is especially true in the later stages of dying. You may want to try the following:

- Breathing exercises. Your spiritual care provider can teach these to you.
- Music therapy can be a great way to reduce anxiety.
- Have someone sit with your loved one. Ask for help from a hospice volunteer, friend or family member.
- Medicine. Ask your nurse about options.

Sleep problems

Your loved one may be afraid to go to sleep for fear of not waking up. Some terminally ill people sleep more and more and eventually slip into a coma. Or, your loved one might sleep in the daytime and feel wide awake at night. It is okay for your loved one to sleep when he or she feels tired, even if it is during the day.
To prevent or treat sleep issues:

- Try to set regular sleep patterns.
- You might keep a large, lighted clock by the bed. Let your loved one know what time you or another caregiver will be checking in.
- A bedtime routine may also help. Begin with toileting and brushing teeth. Play soft, slow music in a quiet, dimly lit room. Make sure the room has good airflow and a comfortable temperature.
- Exercise or fresh air may help your loved one sleep better at night.
- If insomnia (unable to sleep) is severe, talk to your hospice nurse to see if medicine can help. If your loved one is cognitively impaired, medicine may have the opposite effect.
- Lavender essential oil can also be helpful.

Movement

Movement is very important when your loved one is less active or spending more time in bed. Moving the body has many benefits. It can:

- Release tension
- Increase appetite
- Prevent pressure sores
- Promote elimination of bodily wastes
- Make a person sleep better
- Improve physical and mental health.

If your loved one can’t exercise alone, a hospice aide can help.

Helpful reminders:

- Movement and exercise are important parts of managing symptoms.
- Using oxygen isn’t always helpful. Your nurse will help decide if this is right for your loved one.
- If you need to move or lift your loved one, use the tips in this book to help you do this safely. If you need help, call the non-emergency number for your fire department.
Pain

One of the main goals of hospice is to control pain at a level that is comfortable for each patient. Not everyone uses the word pain. Some may call the feeling discomfort. This section refers to either pain or discomfort.

Not all dying people have pain. And pain is more than just physical. People can have emotional pain, spiritual pain and social pain. We are experts at helping with pain and its symptoms. Reach out to us for help. When your loved one no longer worries about pain, a great burden is lifted. He or she can then focus on living each day to the fullest.

Understanding pain

Pain does have a purpose. Pain is our inner alarm. It is our body’s way of telling us that something is wrong. When cells in the body are injured, they release certain chemical substances. These substances excite the nerves. The nerves send a message through the spinal cord to the brain to tell it that we hurt. Doctors may not be able to find the exact cause of the pain, but never doubt that the pain is real.

Pain has a wide range, from slight to severe. It can be described many different ways. Everyone has their own way of feeling and thinking about pain.

Emotional, spiritual and social pain

A dying person may feel afraid, sad or depressed. They may worry about family and friends being left behind. There may even be concerns about money as a loved one worries about how to pay for care, or how the family will survive the loss of income.

Emotional pain, stress and tension may reduce the effects of pain medicine. They can also make the body more likely to feel pain. A less anxious person may need smaller doses of pain medicine. Ask your loved one to talk openly about his or her fears. See page 25 for tips.

Spiritual pain can be just as harmful as physical pain. If your loved one is having spiritual pain, you may wish to talk to a spiritual leader or counselor. Or, ask for the hospice spiritual care provider.
Pain assessment

How strong and how often your loved one feels pain will vary. Pain is whatever the person says it is. It depends on how much pain a person can tolerate. This is called a pain threshold.

Your loved one may show pain in different ways. He or she may moan, groan and twist the body. He or she may be restless and agitated. The heart and breathing rate may increase. If your loved one has any of these symptoms, tell your nurse. If your loved one has been in pain for a long time and has a high pain threshold, these symptoms may not appear. Ask your loved one the following questions.

- Where is the pain? Can you point to it? Is it deep or close to the surface?
- How bad is the pain on a scale of 0 to 10, with 10 being more than you can bear or the worst pain you have ever felt?
- Is it constant or does it come and go?
- Can you describe it? Does it throb? Ache? Burn? Is it sharp or shooting?
- What seems to help it? To make it worse?

Note any other symptoms such as nausea, crankiness and inability to sleep. These details will help us make a pain management plan if you don't already have one. If you do have a plan and your loved one is still in pain, the plan should be reviewed and changed. Talk to your hospice nurse.

False beliefs about pain

Sometimes ideas can get in the way of good pain management. You or your loved one may have false beliefs such as:

- Ignore pain and it will go away.
- Pain is all in the mind.
- Admitting there is pain means you are weak.
- Treating pain with medicine may mean the medicine will not work as well later when the pain is more severe.
**The pain management plan**

Effective pain control is at the heart of palliative care. It includes:

- The right medicines given at the right time.
- Giving medicine in the most effective way.
- Using the least amount needed to control pain and keep the patient as alert as possible.
- Giving the medicine on a schedule.
- Addressing spiritual and emotional pain.

We will make a pain management plan based on your loved one’s pain assessment. This plan will vary from person to person. If no pain is the goal, the patient may be less alert.

**Preventive scheduling**

Palliative care experts suggest treating pain with preventive scheduling. This means pain medicines are given at regular times to help reduce pain.

- Preventive scheduling keeps a certain level of pain medicine in the bloodstream. Just knowing that the medicine is there can greatly reduce your loved one’s anxiety about pain.
- The schedule will vary from person to person and may need some changes.
- Medicines may need to be given at night. Waking a loved one for medicine is far better than having him or her wake up in pain.
- If the pain returns or gets worse, call your hospice nurse. We may need to raise the dose or give medicine more often. This is normal. The important thing is to stay ahead of the pain.
- If the schedule is working, your loved one may be tempted to stop taking the pain medicine. But this is a big mistake. The pain will probably come back very soon.
- Whenever you give medicine, write down the name, when it was given and the dose. Be sure to note any extra doses given and tell your hospice nurse of any changes.
Pain medicines

Ask your hospice doctor or nurse about all medicines given and their side effects. All medicines have benefits and side effects. You need to know why they are being given and what they do.

- Write down the names of all the medicines, getting the correct spellings.
- Find out if certain brand names are being prescribed or if the pharmacist can choose a generic drug.
- If you have any questions about the possible side effects, ask.
- Keep at least a 1-week supply of all medicines on hand. We will ask to see your medicine bottle so we can help make sure you don’t run out. Some medicines need a signed prescription each time they are refilled. Allow more time for these.
- Keep all medicines out of the reach of children.
- Your hospice program will offer you a comfort kit of special medicines for certain symptoms. Keep them safe but handy. Let your hospice nurse know where you keep them so they can be found and used quickly, if needed. Do not use them unless your hospice nurse has explained them to you.

Types of pain medicines

- **Non-narcotic** pain medicines are used for mild pain. They do not need a prescription. For that reason, they are often called over-the-counter or OTC drugs.
  - The most common OTC drugs for pain are ibuprofen and acetaminophen.
  - Ibuprofen should be taken with food or with antacids to prevent an upset stomach.
  - Acetaminophen should be taken on an empty stomach. It can cause liver damage in high doses.
  - If your loved one has swallowing problems, both ibuprofen and acetaminophen come in liquid and suppository form.
  - In general, people over age 65 should not take ibuprofen.

- **Narcotic** pain medicines are used for both medium and severe pain. Most hospice patients need narcotic pain medicines at some point. A prescription is needed for these medicines.
The most common narcotic is morphine. Morphine comes in slow-release tablets for longer pain relief. It also comes in liquid form for those who have trouble swallowing.

Other narcotic pain medicines include codeine, hydromorphone (Dilaudid), levorphanol, methadone (Dolophine), oxycodone (Percodan or Percocet), hydrocodone (Vicodin) and Fentanyl.

Narcotics cause constipation. Patients will need to take bowel medicines with them.

- Other medicines may be used along with narcotics to help them work better. These are called co-analgesics. They may include nonsteroidal anti-inflammatory drugs (NSAIDs), antidepressants, anticonvulsants, muscle relaxants, corticosteroids and sedatives.

**Giving pain medicines**

Pain medicines can be given in many ways. The simplest and least invasive way is by mouth (oral). Oral medicines come in pills, tablets, capsules or liquids. Pain medicine can be given dissolved in liquid or applesauce. This may make them easier to take.

If your loved one has trouble swallowing or vomits often, you may need to explore other options. Some medicines can be given under the tongue (sublingual). The body absorbs these very quickly. Other medicines are given through a skin patch (transdermal). Transdermal medicines are absorbed slowly through the skin. Rectal suppositories may also be used. Hospice nurses can teach caregivers how to give rectal medicines.

**Side effects**

- **Constipation** is one of the most common side effects of morphine and other narcotic pain medicines. See page 41 for tips to treat this.

- **Nausea** is common, though it will often go away after a few days. See pages 36–37 for tips to treat this.

- **Sleepiness** is another common side effect. This may be temporary.

- **Mental confusion** may happen when a new narcotic is started or increased. This may be temporary. It may also happen as your loved one's illness gets worse.

- **Nightmares or hallucinations.** If your loved one has these, we may need to change the medicines.
When patients refuse to take their medicine

If your loved one won’t take pain medicine, the pain will return. It is important to find out why your loved one doesn’t want the medicine. He or she may have one of these common fears:

- **Fear of building up a tolerance.** Some patients worry that taking too much medicine will mean it won’t work as well when pain gets worse. If your loved one is worried about this, let them know that the medicine will be changed as needed to control the pain.

- **Fear of an overdose.** In hospice, we are very good at avoiding overdose by starting patients on low doses and increasing the dose slowly.
  - Signs of overdose include sleepiness, slurred speech, hallucinations, confusion and slowed breathing (10 breaths or fewer per minute). If you notice these symptoms, call your hospice nurse.

- **Fear of addiction.** Most people who use narcotics for pain do not get addicted. Hospice patients use narcotics for pain relief, not for emotional or psychological reasons. People may get addicted to pain medicines if they use them for reasons other than pain, like to get high. Patients with long-term severe pain may need their medicine, but this is not drug abuse. It is similar to how a person with diabetes needs insulin.

**Helpful reminders:**

- Keeping pain under control and at a level of comfort for your loved one is a main goal of hospice.
- Pain can be felt in more than just the body. It can be emotional, spiritual, social or financial.
- A good pain management plan prevents or lowers pain before your loved one feels it.
- Medicine isn’t the only way to treat pain. Music, massage, prayer, meditation, aromatherapy or acupressure may help relieve pain.
- You are not alone. We are experts at managing pain and will do our best to keep your loved one comfortable.
Eating and Drinking

We know that we must eat to live. But as the end of life nears, it is normal to no longer want food and fluids.

It can be stressful when a loved one does not eat. Try to accept it as a normal part of the dying process. Forcing your loved one to eat will only cause more frustration. It can also cause stress or choking.

It is normal to fear what will happen if your loved one doesn’t eat. Though you may think your loved one is suffering, dying patients often do not feel hunger or discomfort. If your loved one is hungry, he or she may feel full with small amounts of food.

The body lets us know when it no longer wants or can handle food or drink. Losing this desire is a sign that the body is getting ready to die. As weakness grows, it will be harder for your loved one to swallow. If you notice food building up in your loved one’s cheeks, do not keep feeding.

Mealtime suggestions

Though eating and drinking may not be as important physically, meals and snacks can still bring your loved one pleasure. Try some of the following tips:

- Forget “good” nutrition. Let your loved one decide what, when and how much to eat. Don’t fight with or nag your loved one.
- Offer choices, but do not force.
- Plan small meals more often with favorite foods.
- Serve meals when your loved one is rested and appears comfortable.
- Try to reduce cooking odors by serving food cold or at room temperature. The smell of food can cause nausea or make a person feel full.
- Change the seasonings in food to fit your loved one’s tastes.
- Make the most of breakfast time. Appetite tends to decrease as the day goes on.
- Encourage your loved one to feed him or herself for as long as possible.
- Allow your loved one to rest after meals. Keep the head of the bed elevated to aid digestion.
Fluid needs

If your loved one refuses liquids, don’t force it. At this point, dehydration (lack of fluid) does not cause discomfort. It is best to serve fluids between meals. Liquids at mealtime can make your loved one feel too full to eat. Also, give your loved one quality liquids. For example, high-calorie, high-protein drinks offer both fluids and nutrition. You can add more calories and protein to milk by adding nonfat dry milk to whole milk. For better flavor, refrigerate the mixture at least 4 hours before drinking. Foods such as Jell-O, pudding, ice cream, yogurt, milkshakes and eggnog are also a good source of fluids. If your loved one has trouble with dairy products, try crushing popsicles or frozen fruit juice from an ice cube tray instead.

Common causes of eating problems

Mouth sores, trouble swallowing, nausea or other problems may lower your loved one’s desire for food. If you have questions or concerns, talk with your hospice nurse. See pages 36-37 and 39 for more information.

Taste changes

To your loved one, the taste of food may change from day to day. He or she may complain that foods taste “off,” metallic or too sweet. On some days, food may have lost its taste entirely. Ask your loved one what tastes best and what doesn’t taste good. Respect this and be flexible. Remember that the goal is to make eating pleasant.

Artificial hydration and nutrition

Artificial hydration uses a tube to carry nutrients and fluid into the body. The tube may be put in a blood vessel (vein), through the abdominal (belly) skin into the stomach.

Feeding tubes have many risks, such as pneumonia, ulcers or infections. The tube may also be accidentally pulled out by the patient or caregiver.

Some people think not using or stopping artificial hydration and nutrition starves the patient or causes suffering before death. This is not true. In the process of dying, it is normal for patients to lose fluids from their body. The symptoms of this loss of fluid are a dry mouth and thirst. These symptoms can
be eased by good mouth care, sips of water or ice chips. Artificial hydration often does not help these symptoms. Most doctors believe that this normal dehydration in the end stage of a terminal illness makes dying more peaceful.

Reasons for not using artificial hydration in a dying patient:
- Less fluid in the lungs means breathing will be easier.
- Less discomfort due to too many fluids as the body is shutting down.

Comfort care and pain control are the main goals of any hospice team, no matter the treatment choice. If you are thinking about artificial feeding, it is important to talk about these issues long before a crisis. Artificial feeding does not often lengthen the life of hospice patients. In fact, it often adds greater burdens. Ask your hospice team if you have any questions.

**When eating and drinking stop**

At some point, your loved one will lose interest in favorite foods. As your loved one’s illness gets worse, he or she will eat and drink less. Meats are often the first to go, followed by vegetables and other hard-to-digest foods. Finally, eating and drinking stop.

This stage often upsets caregivers and friends more than the loved one. Dehydration is not painful. As the body slows down, it is less able to use nutrients and fluids. In fact, these may increase symptoms and add to discomfort. Dying patients often are much more comfortable without food and drink.

**Helpful reminders:**
- Your loved one will slowly eat and drink less. This is normal.
- Don’t force your loved one to eat or drink.
- Try different ways to make meals enjoyable.
- You are not alone. We will help make sure your loved one is still comfortable, even when eating and drinking slow or stop.
Money and legal preparations

Money and legal issues at the end of life can all add to stress. But often the biggest concern is the cost of caring for a terminally ill loved one.

Paying for hospice care

Some programs may help pay for hospice care. These include private health insurance, Medicare, and medical assistance. Hospice care at home often costs less than care in a hospital. No one is denied hospice care, even if they can't pay. Your hospice social worker can help you find resources to pay for care.

Medicare

The Medicare hospice benefit covers hospice services. You may choose the hospice benefit if you answer yes to all of the following:

- You are eligible for Medicare Part A.
- Your doctor and the hospice medical director certify in writing that you have a terminal illness with a life expectancy of 6 months or less if the disease runs its normal course.
- You sign an agreement with a Medicare-certified hospice (instead of accepting standard Medicare benefits for a terminal illness) and choose hospice services.

Under the hospice benefit, Medicare pays for only those services authorized by the hospice program. It pays around-the-clock care only when needed to control symptoms on a short-term basis.

Services Medicare covers:

- Routine nursing visits.
- Around-the-clock nursing care in the home for symptom management only. This benefit is covered only when approved by hospice.
- Medical equipment and supplies.
- Medicines for symptoms and pain relief.
- Short-term in-patient care, including respite care for the caregiver.
- Hospice aide services.
- Physical, occupational and speech therapy when approved by hospice.
- Medical social work visits.
• Nutritional counseling.
• Spiritual care visits.
• Volunteer services.
• Grief services.

**Services Medicare does NOT cover:**

• Aggressive treatment of a terminal illness, other than symptom and pain control.
• Treatment of health problems not related to the terminal diagnosis. These will still be covered under Medicare Part A or Part B.
• Room and board at a long-term care or hospice facility.
• Custodial care, or staff to care for your loved one for long periods of time. (For example, while you are at work.)
• 24-hour care.
• Care offered by another hospice program.
• Care from another provider that duplicates care we give.
• Services or treatments that have not been approved by the hospice team and are not within the hospice plan of care.

Hospice may offer other services that may not be covered under the Medicare benefit. For example, music therapy and massage therapy are paid for with donations and memorials.

If you are covered by both Medicare and private health insurance and you need a service that is not paid for by Medicare, it might be paid for by your private health insurance, and vice versa. Ask your hospice social worker to help you sort through your options.

**How long will Medicare pay for hospice?**

The Medicare hospice benefit pays for hospice care as long as the patient meets the requirements. Your hospice nurse will review these with you.

You may cancel hospice care at any time, return to standard Medicare coverage, then later choose the hospice benefit. You may also change hospice programs (if you move, for example).
Federal laws make Medicare guidelines. Because laws change, it is important to talk about current guidelines with your hospice team. For a free copy of the Medicare Handbook, call 1-800-633-4227.

**Medical Assistance**

The states and the federal government pay for Medical Assistance. It offers financial assistance for those who can't pay for their own medical fees. Hospice care may or may not be covered, depending on your plan.

**Health insurance**

If you have health insurance, a hospice social worker can call your insurance company to ask about the coverage.

**Other options**

Your hospice social worker will help you find out if you can get hospice benefits through Medicare or Medical Assistance. You might also qualify for government programs such as social security benefits, veterans' benefits or legal aid services. Call the Social Security Administration office, the State of Minnesota Health Department or the Minnesota Network of Hospice and Palliative Care for information.

If the patient's family can't pay, we still offer services using money raised in the community or from memorials or donations.

**Lifetime planning**

“Lifetime planning” means setting up wills, joint bank accounts, powers of attorney, health care directives and so forth. Your hospice social worker can offer general information about each of these. But laws change often and differ from state to state, so it is best to talk to a lawyer or financial planner for all legal and money matters. If you can't pay for legal help, your hospice social worker can help you find out if you qualify for legal aid services.

You and your loved one will need a notebook to write down legal and money decisions made during this time. You can also use it to write down where you are keeping important papers and valuables. It also helps to have a folder for wills, health care directives and other important documents. You can find a document checklist on page 65.
Money matters
Money issues may cause anxiety. Making a money plan as soon as possible can ease this anxiety.

Bank accounts
Write down your loved one’s bank accounts and account numbers.

Durable powers of attorney
This legal document allows a spouse, an adult child or another trusted person to manage your loved one’s money when he or she is no longer able.

Wills and living trusts
With a will or living trust, your loved one can say what will happen to his or her money, property and other assets after death. Write down where the original will, living trust or estate plan is kept.

Other money matters
Your loved one should write down information about his or her stocks and bonds, social security or veterans’ benefits, pensions and insurance policies (noting location, kind of policy, amount, settlement options and status of any loans against the policies). If your loved one has a safe-deposit box, it is important to write down where the box and key are, as well as what is in the box.

Other steps you and your loved one can take to protect his or her assets and avoid legal battles:

• Make sure all joint assets correctly reflect who owns what. Write down all the right names.
• To change the name on a deed, contact the registrar of deeds in the county where the property is located.
• Remove your loved one’s name from jointly held stocks or bonds. Add the names of other appropriate people, such as adult children.
• Remove your loved one’s name from joint bank accounts. Tell the bank what is happening.
• If survivors are covered under your loved one’s health insurance, check to see how long they will be covered after the death. If needed, get health insurance for the survivors.
• Transfer auto and home titles.
• Ask your loved one where any other assets might be.

**Expenses**
You should keep a careful record of expenses. Some expenses may be paid for through Medicare or your insurance. Others may be tax deductible.

For each expense, note the date, item, purpose, cost and if it was suggested by a doctor. Keep your receipts for all caregiving expenses in a separate folder.

**Health care decisions**
Able adults have the right to make their own health care decisions, including whether to accept, reject or stop certain kinds of medical care. Not only is it important for your loved one to have a completed advance health care directive, but it offers the chance to talk about choices and wishes with family and close friends. See pages 84–85 for more information.

**POLST forms**
POLST stands for “Provider Orders for Life Sustaining Treatment.” It is a signed medical form that states a person's end-of-life health care wishes during an emergency.

POLST forms are used as a way to clarify people's wishes when they are faced with a serious or terminal condition. In contrast, health care directives can be filled out at any point in time, often when people are healthy. POLST forms let patients and their caregivers talk about potential life-sustaining treatments. It also gives patients another chance to make their wishes known.

Also, because the POLST is a medical order, emergency personnel can use only the POLST, not a health care directive, if called to a home for a medical emergency. Once the POLST is completed and signed by a doctor or nurse practitioner, it will be returned to you. Put it in a very visible place in your home, such as the refrigerator. It is important for all caregivers to know where the POLST is and what it means.

If your loved one has not yet completed a POLST at a clinic or in the hospital, your hospice team will help complete one. Completing a POLST form does not cancel any wishes stated in a health care directive. But if a patient’s wishes have changed, the POLST will be honored as the most recent directive. The POLST also includes more treatment detail than many health care directives.
Financial and legal matters after your loved one dies

The first few days after your loved one’s death are full of activity. You may be exhausted from the final days of caregiving and from saying goodbye. Even so, there are practical matters you must take care of. Take some time each day to do what needs to be done.

If you need help, be sure to ask. Hopefully, most of the practical matters have already been dealt with. Do not sign any papers before reading them carefully. It never hurts to have someone you trust, such as a lawyer, look over the papers too.

Applying for benefits

If your loved one was employed when he or she became ill, call the employer to see if any insurance benefits, death benefits, profit sharing or pension payments might be owed to you or the estate. You must also notify the Social Security Administration, insurance companies, unions, credit unions and so forth.

Former employers

Unless your loved one was retired, check with former employers to see whether survivors can get payments from a pension plan or life insurance policy.

If your loved one was retired and getting a pension, ask whether payments will be made to survivors at a reduced rate, or if they will end. If the illness was work-related, you may be able to get to workers’ compensation benefits.

Social security

If your loved one had been getting Social Security benefits, do not cash any checks that come after his or her death. These checks will need to be returned. If your loved one was not on Social Security, he or she may be eligible for two types of benefits. Check with your local Social Security office or call 1-800-772-1213.

Veterans’ benefits for the funeral and burial

If your loved one was a veteran, ask the funeral director to help you apply for veterans’ benefits. Or call the Department of Veterans’ Affairs (VA) at 1-800-827-1000.
**Insurance**

Check all life and casualty insurance policies for benefits. Your loved one might also have mortgage insurance, loan insurance and credit card insurance. If your loved one had insurance through a credit union, trade union or fraternal organization, one of these organizations may give survivors' benefits or pay for part of the burial expenses.

**Credit cards and other payments**

To protect your credit rating, make credit card payments on time. Cancel any credit cards that are only in your loved one's name. For shared accounts, tell each company of your loved one's death and ask them to remove his or her name from the account. Some credit card companies will cancel debt upon the death of a cardholder, so be sure to ask. Also ask if your loved one had credit card insurance. Review all other debts and installment payments to find out if any will cancel the debt.

**Updating records**

After your loved one's death, you will need to update records on anything in your loved one's name. Examples:

- Life, medical, automobile and homeowners insurance.
- Vehicles.
- Bank accounts, safe deposit boxes and shared stocks or bonds.
- If you have your own will and it states that property should pass to your loved one upon your death, you will need to update your will.

**Executing the will**

If your loved one had a will, it may be in a safe deposit box, in a safe or with your family lawyer. The will details how your loved one wants his or her property and possessions to be distributed.

Insurance proceeds, Series E bonds, death benefits and jointly owned property and bank accounts will bypass the will and go to the designated beneficiary or joint owner. The rest of the estate may need to go through probate.
Paying taxes

Your loved one’s federal and state income taxes are due for the year of his or her death. A federal estate tax may also need to be paid. For more information, go to the Internal Revenue Service website at www.irs.gov or talk to a tax lawyer. You may also wish to ask a lawyer about inheritance tax.

Other money matters

If your loved one had debts, these debts will likely be paid from the estate account. But if you have shared debts, such as mortgage payments and utility bills, you should keep paying them.

If you have trouble paying bills after the death of your loved one, you can apply for emergency funds from your local social services department. This is not a good time to make important money decisions, such as whether to sell your house. Give yourself time to sort things out.

Helpful reminders:

- Hospice does not offer 24-hour in-home care. This service can be added through private pay.
- Talk about money and legal issues while your loved one is still able. This will ease anxiety and help you stay organized.
- Your loved one’s wishes, priorities and preferences for their health care are very important. Everyone who gives care to your loved one should know about these wishes.
- Money and legal matters are confusing. You are not alone. Your social worker will help.
- After the death, don’t forget to take care of practical matters, like changing bank, insurance and tax records.
Money and Legal Preparations

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Document Checklist

___ Address book
___ Advance health care directive
___ Automobile titles or leases
___ Bank statements (checking, savings, line of credit)
___ Birth certificate
___ Bonds
___ Burial plot or cemetery information
___ Credit/debit cards
___ Deeds to property
___ Document authorizing donation of body
___ Driver’s license
___ Funeral/cremation arrangements, prepayments
___ Health insurance policies
___ Income tax returns
___ Inventory of possessions
___ Life insurance policies
___ Living trust
___ Living will
___ Loans
___ Marriage certificate
___ Medicare ID card
___ Membership lists
___ Military discharge papers
___ Mortgage papers (including any mortgage insurance)
___ Organ donor card
___ Pension or retirement plans
___ Powers of attorney (general, durable health care)
___ Property and casualty insurance
___ Safety deposit box (list of contents and location of keys)
___ Savings bonds
___ Social Security card
___ Stock certificates
___ Valuables (complete inventory and locations of items)
___ Veterans’ Administration papers
___ Will
Planning for your loved one’s funeral or memorial service can be hard. Some families find it helpful to have things in order before the death to lower stress. Below are some commonly asked questions. Our staff can also guide you through this process.

**What is the difference between a funeral and a memorial service?**

A funeral service is generally held with the body present. The cremains (ashes) may or may not be present at a memorial service.

**Should we have a visitation to view the body in the funeral home?**

Most grief counselors agree that seeing the body lets you process the loss of your loved one. But, there are times when family or friends would like to remember the person how they were before they died. In this case, a picture by the casket may be best. You may want to ask your funeral director for advice. Sometimes the person who has died will look more like they did before they were ill. In this case, the final viewing can bring comfort.

You may also choose to have a visitation with the body before cremation.

**Can the family have a private viewing if they would like?**

Yes. Sometimes this is the right thing to do.

**Should young children attend the visitation?**

You may want to refer to the Fairview Hospice pamphlet, “Helping Kids Cope When a Loved One is Sick and Preparing to Die.” Your social worker can give you a copy. Whether or not a child should attend often depends on their maturity level. It is best if someone can be with the child to help them understand what they are feeling.

**Can we bury someone in the clothes they liked wearing?**

Yes. The funeral home will honor personal requests.

**How do I buy a cemetery plot or a space in a mausoleum?**

Your funeral director will help you with this process.

**Where can we scatter the ashes?**

You need permission to scatter ashes on private property. You do not need permission for public places like lakes and parks. Scattering services should be a respectful way to disperse a person’s cremains. Some faiths may also have rules about this.
My loved one does not belong to a church. Where can the service be held? Who will do the service?

You may have the funeral or memorial service at the funeral home. Our hospice spiritual care providers can conduct services. Your funeral home will likely have a list of local clergy who can help as well.

After my loved one dies, how long can the body stay in the home or care facility before the funeral home comes?

Some families ask that the body stay at home for a number of hours to give the family the time they need. Minnesota law allows the body to stay in the home for up to 72 hours to honor cultural and religious practices.

Funeral home staff are very sensitive to the needs of the family. They will come when you feel ready.

Can I make arrangements with a funeral home before the death of my loved one? Should I check out more than one funeral home, or are they all about the same?

You can make most arrangements before the funeral if you would like. A funeral director will go over your options and show you a price list. Some people visit a few funeral homes before choosing one. Other families prefer one funeral home to another based on location or a past experience.

What should I include in my loved one’s obituary?

The funeral director can help you with this. You may want to think ahead of time about what you would like written. A few things you might include: names of relatives, past jobs, hobbies, accomplishments, clubs and organizations, date and time of the service and where memorials are to be sent.

Does Fairview Hospice accept memorials?

Yes. Our music and massage therapy programs and children and teen grief counseling are funded entirely through donated dollars. We have envelopes addressed to Fairview Hospice that can be used at the funeral home. The Fairview Foundation will acknowledge all who send in a donation. The family will get a list of donors as well. All gifts are tax deductible.

It is helpful to give an address for Fairview Hospice when writing the obituary. Our addresses are below.

Fairview Home Care and Hospice
2450 26th Avenue South
Minneapolis, MN 55406

Fairview Home Care and Hospice
110 6th Avenue South
Princeton, MN 55371

Fairview Lakes HomeCaring & Hospice
11725 Stinson Avenue
Chisago City, MN 55013

Fairview Hospice – Hibbing
1101 East 37th Street, STE 27
Hibbing, MN 55746 or

Fairview Hospice – International Falls
2716 Crescent Drive, STE 1
International Falls, MN 56649

If you have questions about memorials or donations to Fairview Hospice, please call our 24-hour number (see the first page of this handbook).
Planning the funeral or memorial

The questions below will be helpful in planning a funeral or memorial service:

- Who will be notified of the death (relatives, friends, business associates)?

- Who can make the calls?

- Which funeral home will you be using?

- Will you have a funeral or a memorial service for your loved one?

- What type of service does your loved one want?

- Would you like to have a printed program for those going to the service that would include the music, the readings, the presider and so forth?

- Who will preside over the service?

- What music is to be played or sung?

- What readings will you use for the service?

- Who will do the readings?

- Who will speak?
• If there are children, how can they be involved? Might they draw pictures to be placed in the casket?

• What objects might you want to bring to the visitation or funeral to represent your loved one’s interests or hobbies?

• Will there be a graveside service? Public or private?

• Will there be a reception following the service? If so, where?

• Will refreshments be served?

• Will photographs of the loved one be displayed?

• What will be done with the flowers after the service?

**Helpful reminders:**

• Your loved one may find it meaningful to plan his or her funeral ahead of time.
• Make sure you know your loved one’s wishes before they die.
• You are not alone. We can help you plan a service that honors your loved one’s life.
When death is near

Completing the circle of life can be very hard. Your caregiving, support and love will be most important as your loved one begins a journey that only he or she can truly understand. Hospice also offers a unique chance to surround your loved one with proof of his or her value to others and to focus on what the present day has to offer.

Involving children

Children can be deeply affected by the illness and death of a loved one. Depending on their ages, children may or may not be able to show their feelings. These tips may help children cope:

• Be open about what's happening. Children can tell if you are keeping something from them. Your secrecy may confuse them or add to any feelings of guilt or responsibility that they may have.

• Ask the child to tell you what is happening. This will let you know if the child really understands.

• Listen and answer questions honestly and briefly. It's okay to say that you don't know all the answers.

• Help children say goodbye to their loved one. Saying goodbye doesn't need to be a long, drawn-out process. Ask children to simply tell their loved one something they will always remember about them and how much they love them. Goodbyes can be said directly to the person, in a letter or through a picture or other art.

• Avoid clichés such as “Grandma went to sleep” or “God needs Daddy more than we do.” Use the terms death and dying. “Sarah, I have something very sad to tell you. Grandma died this morning. Her heart stopped beating and her lungs stopped breathing early this morning. We're going to miss her very much but we're grateful that she is no longer in pain.”

• Remind children of happy memories. Tell them it’s okay to remember their loved one and to say his or her name. Keep photos of happy times.

• Call Fairview Bereavement Services, Fairview Youth Grief Services (www.fairview.org/youthgrief) or your religious community about support groups and other resources to help children and parents through the grieving process.
If your loved one wants to die sooner

As the end draws near, your loved one may want to die quickly. Reasons for this may be:

- **Uncontrolled pain.** If this is the case, tell your hospice nurse right away. We can change the pain management plan so your loved one is more comfortable.

- **Your loved one feels like a burden.** It is important to let your loved one know that you want to have as many days together as possible. Ask for support from the hospice social worker and spiritual care provider.

- **Loss of dignity and control.** For example, loss of bladder or bowel control can be embarrassing for anyone. If your loved one does not have a urinary catheter, this might be a good time to explore this option.

Let your loved one make as many decisions as possible so he or she feels more in control of other areas in his or her life. Ask us about other ways to comfort and reassure your loved one.

No matter what the underlying cause, if your loved one wants to die sooner, you need not be shocked, and you need not agree. Ask your hospice team for help.

Staying close until the end

It is often hard to be with a person who will die soon. You may want to plan for more support during these final days. The hospice nurse and other team members can visit more often in the days just before death. You can also ask for an 11th hour volunteer to give extra support at this time.

As a caregiver, you often have to juggle many duties at any given time. So you may find it hard to just sit and talk with your loved one. But at this point, just being there is the most important thing you can do. These other tips may be helpful as well:

- Let your loved one know that you understand his or her concerns.
- Be positive.
- Repeat what you have heard in a tone of voice that shows acceptance. “I understand that you are angry. Do you want to talk about it?”
- Be okay with long periods of silence. It may be tiring for your loved one to talk or even to listen.
• If your loved one asks questions you can’t answer, admit that you don’t know. Then, ask your hospice team for the information.
• Try to keep a sense of humor.
• Keep your loved one clean, dry and warm.
• Touch, hug and kiss your loved one. Be gentle and slow.
• Let your loved one be the boss. Ask what he or she would like to do or to have done. This helps your loved one feel in control as much as possible.
• When visitors or family members come, do not whisper. Do not talk behind your loved one’s back.
• Try to arrange for someone to be with your loved one. But keep in mind that sometimes a dying person may need to be alone.
• Do not stop the pain medicines.
• Do not force foods or fluids.

**Death anxiety**

When death is near, you and your loved one may be afraid. This is normal. Most people are not afraid of being dead, they are afraid of the moment of death. Read about the signs of death on pages 75–76 so you know what to look for.

**Letting go**

During the last few days, your attitude needs to be one of letting go, of releasing your loved one, of letting your loved one know that you’ll be okay.

• Let your loved one know that he or she will be deeply missed but not forgotten.
• Give your permission to let go if you feel your loved one needs this.
• Help your loved one make peace with any unfinished business.
• Ask for help from a hospice spiritual care provider.

**Saying goodbye**

Each person will have his or her own way of saying goodbye.

• It’s okay to lie in bed with your loved one, holding hands and saying everything you need to say.
• Tears are normal. Let them flow.
• Read “Signs That Death Is Near” on the next 2 pages. This will give you an idea of what to expect. It is not meant to alarm you or your loved one, but to prepare you for what may happen.
• Dying may take hours or days. The signs may appear and disappear.

Other final preparations

• List all unfinished projects and put them into priority order.
• Consider organ or tissue donation as well as donating the body to medical science.
• Prepare for death by honoring religious rites such as the Anointing of the Sick (formerly known as last rites). Ask your hospice spiritual care provider or the leader of your faith community for help with this.
• If your loved one is a single parent with dependent children, they must name a guardian or guardians.

Helpful reminders:

• When death is near, your love and support are the most important to your loved one.
• Take time to just be with your loved one. Be a good listener. Be kind, honest, flexible and patient.
• Say goodbye however you need to. Don’t worry about what you say or do.
• Being with your loved one during hospice was a wonderful gift.
• You are not alone. We can offer extra support during this hard time.
# Signs that Death Is Near

*What to Do Before and Right after Death*

<table>
<thead>
<tr>
<th>Symptoms to expect</th>
<th>How to cope or respond</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 to 3 months before death</strong></td>
<td></td>
</tr>
<tr>
<td>Withdrawing from the world and people</td>
<td>Don't take this as a lack of love. Keep talking to and spending time with your loved one.</td>
</tr>
<tr>
<td>Eating less or losing interest in food</td>
<td>Give food and fluids as your loved one is able to take. Don't insist. Keep your loved one's lips moist with ice chips, ointment and mouth sponges. Use a straw. Food and drink is a part of our daily life, but forcing your loved one to eat or drink may cause them distress.</td>
</tr>
<tr>
<td>Sleeping more often and for longer periods.</td>
<td>Urge those close to the patient to plan their visits for when your loved one seems most alert. Keep talking to and touching your loved one, even when they do not respond. Hearing is the last sense to leave.</td>
</tr>
</tbody>
</table>

| **1 to 2 weeks before death**                  |                                                                                                                                                           |
| Mental changes:                                | Remind all visitors to say who they are. State the day and time. Don't contradict your loved one. Let them talk about whom they see or hear, as this could be meaningful to them. Be calm and reassuring. Remind your loved one of things gently. Be aware. Too many visitors or too much talk can be overwhelming. |
| • Fear                                         |                                                                                                                                                           |
| • Distress                                     |                                                                                                                                                           |
| • Talking to people who aren't there           |                                                                                                                                                           |
| • Confusion                                    |                                                                                                                                                           |
| • Picking at clothes                           |                                                                                                                                                           |
| Physical changes:                              | Keep a blanket on your loved one so they don't feel too cold. Place a moist cloth on the forehead. Give a cool sponge bath if needed. Keep bedding dry. Give Tylenol suppositories (medicine given in the rectum), if needed. Raise the head of the bed to help with breathing. Do not increase or “push” fluids. Small sips will help avoid choking. |
| • Blood pressure, pulse                        |                                                                                                                                                           |
| • Temperature                                  |                                                                                                                                                           |
| • Sleeping but able to wake                    |                                                                                                                                                           |
| • Tiredness and heaviness                     |                                                                                                                                                           |
| • Pale, bluish skin                            |                                                                                                                                                           |
| • Breathing may be shallow or rapid            |                                                                                                                                                           |
| • Eating and drinking less                     |                                                                                                                                                           |
| • Congestion                                   |                                                                                                                                                           |
## Symptoms to expect

<table>
<thead>
<tr>
<th>Days or hours before death</th>
<th>How to cope or respond</th>
</tr>
</thead>
<tbody>
<tr>
<td>The signs that death is near are more intense</td>
<td>See the first page.</td>
</tr>
<tr>
<td>Surge of energy</td>
<td>This may be sudden. Patients often muster all their energy for their need to complete their goals.</td>
</tr>
<tr>
<td>Eyes glassy, tearing, half open</td>
<td>This is normal.</td>
</tr>
<tr>
<td>Restlessness</td>
<td>Try to distract your loved one with things they enjoy. Talk to the hospice nurse about medicines that can help.</td>
</tr>
<tr>
<td>Pulse weak and hard to find. Color changes or splotches on feet, hands, and legs. Blue coloring may move up the arms and legs.</td>
<td>This is normal.</td>
</tr>
<tr>
<td>Urinating less. Urine is darker. May wet or stool the bed.</td>
<td>Ask your nurse about a catheter or disposable pads and diapers.</td>
</tr>
<tr>
<td>Fluid buildup may increase and collect in the back of the throat. It will sound like gurgling. It doesn't mean they are drowning, uncomfortable or can’t breathe. It’s just the air moving through the fluid.</td>
<td>Raise the head of the bed. Move your loved one’s position often. Medicine can dry up much of the fluid. Ask the nurse if you have questions.</td>
</tr>
</tbody>
</table>

## Signs of death

You will know your loved one has died when:

- Breathing stops.
- There is no pulse.
- There is no response to your voice or touch.
- The skin feels cold and has no color.

Your loved one’s eyes and mouth may be open. You may wish to close your loved one’s eyes and prop their head up with a pillow. There may be a release of stool or urine.

Write down the time of death. You will be asked for this when you report the death.

## After the death

There is nothing you need to do right away. Pause a moment. A few deep breaths can help you relax. Even though death may be expected, it can still be a shock.

When you are ready, call Fairview Hospice. You don’t need to call 911, the police or the funeral home.

Minnesota law does not require a nurse or medical person to pronounce the death.

- We will ask if you would like a staff member to visit. This is optional.
- We will also ask some questions for the medical examiner. We need to know:
  - Time of death.
  - Where your loved one was at the time of death.
  - The most recent medicine they took before death.
  - The funeral home you’d like to use.
- We will remind you to throw away all medicines. See “How to Dispose of Your Medicines Safely” in your hospice folder.
- Then, we will call the medical examiner who will contact the funeral home. The funeral home will call you to ask when they should come. Take the time you need.
- If you rented medical supplies, the company will call you and set up a time to pick up the supplies.
The end of a journey

Death is the end of the journey you have made with your loved one. You will have many feelings and emotions in the days ahead. It is now time to take care of yourself. As you do, know that you gave the gift of service and being there to your loved one. You did what you could to give comfort and support.

After the loss

The death of a loved one is life changing. Though everyone dies and it may be a relief, the grief you feel may still be intense. In fact, you may have started grieving while your loved one was still alive.

At first there are many details to take care of, both personal and financial. Family and friends visit often and include you in their get-togethers. But in time they return to their normal routine and you are left to deal with your grief. You are not alone. Our bereavement program will help you through your grief and give you a list of support options. To use these services, call the hospice office or visit www.fairview.org/grief.

Grief

Grief is a normal reaction to loss. You grieve not only for your loved one, but also for yourself and your changed world. You may grieve over lost friendship, lost chances and lost dreams.

You may find yourself alternating between feelings of grief for your loss and relief that your loved one’s struggle is over. Though grieving may seem irrational at times, you are not going crazy.

The “firsts” may be emotionally difficult—the first birthday, Thanksgiving, wedding anniversary and death anniversary. For a while, your grief may be all you think about. You may imagine your loved one’s reaction to every event. You may want to share every piece of news, good or bad.

You may be afraid of the future, of life without your loved one. But you won’t be without your loved one. You will always have your memories and feel that special love you shared. Only the body is gone.

You may fear that you will also die, perhaps leaving your children alone. You may fear that others you love will die. All of this is normal. Death makes us notice how fragile life is.
The grieving process

Grieving is a unique, personal process that has its own timeline for each of us. There is no norm. Some people grieve for a shorter time, others for longer and some forever. It will be easier to cope as time goes on. Your grief is as unique as your thumbprint.

The information in this section is only a guide. You may feel one or more of these common grief reactions. Or you may feel none at all. But we hope it will help you understand the many ways people feel grief.

Trust your mind, body and spirit to heal your feelings of loss in the way and timing that is best for you. If you feel unsure about how you are doing, call our grief counselors. We offer private and caring support at no charge to friends and family of hospice patients.

Shock and denial

You may feel dazed, numb, bewildered, angry and hostile. You may feel disbelief even though you knew death was coming. You might go on autopilot, taking care of things and keeping very busy. Your heart may race, your stomach may ache and you might become dizzy and light-headed. This feeling will change as you learn to cope with new feelings.

Searching for connections to your loved one

You may sense your loved one’s presence and expect to hear a call for your help. You might talk to your loved one. You might even think that you hear or see your loved one. This is normal.

Despair and disorientation

As reality sets in, you may feel helpless, uncertain and fearful. You may feel angry and look for someone to blame for your loss. You don’t want to change. You don’t want to be without your loved one. You might feel guilty. You may blame yourself for not having done everything possible for your loved one. You may question your faith. You might be confused, depressed and withdrawn. You might feel a loss of identity or self-worth. You may find yourself wandering aimlessly around the house or starting projects and forgetting to finish them. You may need to tell the story of your loved one and his or her death over and over again. Your mood may change very often and you may cry uncontrollably at unexpected times.
Hope, healing and resilience
You may be surprised by your resilience and ability to heal from what you once believed would be unbearable. Many people find strength within themselves they never knew they had. Rejoice in this discovery! Your loss does not destine you to a life of sadness and despair. Loss can be a time to learn about yourself, find new insights and continue life with an attitude of gratitude, grace and hope.

The physical toll
Grief can take a toll on you physically. You may lose or gain interest in food. You may lose or gain weight. You may have intense dreams or disturbing sleep patterns. You may be very restless, unable to concentrate or relax. Grief can also hurt. You might feel a knot in your stomach, tightness in your throat or heaviness in your chest. You may need more rest than usual. Listen to your body and do what feels right at this time.

The emotional toll
Grief can be a powerful and often painful emotion. You may feel lonely all the time, even when other people are around. Try to accept the emptiness, knowing that you can grow a new life there when the time is right. Do not try to fill the emptiness with meaningless activity. Use it to work through your loss. Ask your hospice grief counselor for support and guidance with this.

Some people feel little or no distress or grief after a loved one dies. In fact, it is common for grief to be “borne lightly.” This can be a sign of resilience and of a deep, enduring love. Belief in a higher power may also lessen grief for some, especially when they see death as part of life's grand plan. If you do not feel distress or grief, others may think you are cold or unloving. More likely, they will think you are hiding your true feelings or toughing it out. Try not to let what others think bother you. However you need to cope with loss is the right way for you.

Showing grief
Cry, yell, scream, stomp around, sob softly, sit in silence, laugh, play, exercise. Cry as much as you want to. It's a good release for those pent-up feelings. The closest thing we have to a “magic pill” for resolving unwanted feelings is exercise. Get moving any way you can. Do whatever feels right. Don't try to be strong if you don't feel like it. Handle your grief in your own way. Some are very open about their grief. Others may try to hide it. You may try to avoid
your grief by keeping busy. You may hold your grief back, fearing that once you start grieving you won’t be able to stop. Friends may give you advice. They may tell you to keep a stiff upper lip, get on with your life and so forth. They mean well, but only you know how best to grieve your loss.

But know that grief may be too intense or too prolonged. If you feel like you are stuck in grief, get counseling, join a support group or talk to your hospice team. Try to look forward instead of always looking backward at the way things used to be. If you need help, ask. That’s what your family, friends and the hospice bereavement team are there for.

Hospice grief support

Hospice cares for the family and caregivers long after a loved one’s death. Fairview Hospice offers support for 13 months after the death.

When your loved one dies, the hospice care team may grieve too. Soon, the hospice bereavement team will replace the hospice care team. These are skilled grief caregivers who can offer support and advice.

The hospice bereavement team will be in touch with you by phone and by letters and invitations to events sponsored by the Fairview Hospice program. For more grief resources, visit our website at www.fairview.org/grief or e-mail us at griefresources@fairview.org.

In addition to information, support and understanding, we may refer you to professionals who can help you work through your grief. If you need to talk to someone right away, call your hospice bereavement counselor.

Getting past the pain

It is very important that you take care of yourself during the grieving process. Try to eat right, even if you aren't hungry. Try to get enough sleep, even if you are restless and dread the loneliness of your bed each night. Practice meditation and other relaxation techniques. Try to stay physically active and challenge your mind. Take care of your health by seeing your doctor when you need to.

Family and friends may offer lots of advice. They may tell you to take a vacation, get rid of your loved one’s personal items, join a bridge club. Don’t do something just because they suggest it. Do only what feels right and when it feels right.
Children and grief

Children and teens don’t grieve the same ways as adults do. They often show their grief in short bursts and then quickly return to play and normal activities. This can confuse parents, who often talk about their loss to heal. Parents often believe that their children aren’t grieving because they aren’t talking about their loss. But any child who loved someone who died will grieve the loss. The question is not if the child is grieving but how the child is grieving.

Parents can begin talking about grief and loss by sharing what they miss about their loved one. Children need and want to show their loss and share their memories. Sometimes their silence means that they are afraid to talk about it. Perhaps they’re afraid they’ll upset their family. If you talk openly with your children about the loss, you are letting your child know it is okay to share their memories, sadness and confusion.

Tell teachers, doctors, coaches, music teachers and other adults in your child’s life about the death. This will save the child from having to explain and answer questions. It can also help prevent problems. It is especially important to tell doctors, school nurses and other health caregivers, as grief often has physical symptoms like stomachaches, headaches and fatigue.

Common reactions in children

Each child grieves in a unique way based on age, personality, nature of death, relationship with the loved one and development. The most common reactions are listed below. Most of the time, these reactions are normal and lessen over time.

- Physical symptoms, such as headaches or stomachaches.
- Eating too much or not eating enough.
- Changes in sleep (too much or not enough) and feeling tired all the time.
- Regressive behavior (thumb sucking, wetting, whining).
- Clinginess.
- Withdrawing from friends, family or activities.
- Behavior issues such as tantrums, moodiness or crankiness.
- Worry about whom else might die, including themselves.

If you are worried about your child’s reaction, think about how long it lasts and how strong it is rather than the behavior itself. It is perfectly normal for a grieving child to have emotional outbursts from time to time. It is not normal
to have daily outbursts for weeks at a time. It is also not normal for children to harm themselves or say they want to die. Call our grief counselors, your child's doctor or a mental health doctor if you see these signs.

Remember that you are not alone. We are here to support you. Fairview's grief counselors offer support through parent coaching and education as well as individual counseling with children and teens. Youth Grief Services also offer grief support groups and Camp Erin, an annual children's bereavement camp each summer, that are free of charge to all families. Visit Youth Grief Services at www.fairview.org/youthgrief for more information.

<table>
<thead>
<tr>
<th>Tips to help children cope</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Keep home, school and other routines as normal as possible. Pay special attention to bedtimes and healthy meals and snacks.</td>
</tr>
<tr>
<td>2. Be open with your feelings of grief and loss. Children look to the adults in their lives for how to behave.</td>
</tr>
<tr>
<td>3. Offer honest, simple and brief explanations.</td>
</tr>
<tr>
<td>4. Listen to, accept and encourage healthy expression of children's feelings.</td>
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<tr>
<td>5. Let your child know that his or her needs will be met.</td>
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<tr>
<td>6. Maintain age-appropriate activities and interests. Children often process their thoughts and feelings through play.</td>
</tr>
<tr>
<td>7. Urge your child to work through feelings by drawing, painting, clay, music and storytelling.</td>
</tr>
<tr>
<td>8. Rituals are a tool for recovery and a chance to pay respect to a loved one. Urge your child to take part in funerals, birthdays and anniversaries.</td>
</tr>
<tr>
<td>9. Remember that children will rework their grief at each developmental stage and slowly integrate the loss into their lives.</td>
</tr>
</tbody>
</table>

Moving forward

It will never be okay that your loved one has died. In time, you will start to move on, just as you did when you first learned of the terminal illness. Working through your grief does not mean forgetting your loved one. It simply means that you can live your life fully in spite of your loss. You may even grow as you begin to feel a new normal for your life.
**Gone From My Sight**

I am standing upon the seashore. A ship, at my side, spreads her white sails to the moving breeze and starts for the blue ocean. She is an object of beauty and strength. I stand and watch her until, at length, she hangs like a speck of white cloud just where the sea and sky come to mingle with each other.

Then, someone at my side says, “There, she is gone.”

Gone where?

Gone from my sight. That is all. She is just as large in mast, hull and spar as she was when she left my side. And, she is just as able to bear her load of living freight to her destined port.

Her diminished size is in me—not in her. And, just at the moment when someone says, “There, she is gone,” there are other eyes watching her coming, and other voices ready to take up the glad shout, “Here she comes!”

And that is dying.

—unknown

**Helpful reminders:**

- The death of a loved one is life changing. You will feel many emotions in the days ahead.
- Grief has many forms. There is no norm. Whatever form it takes for you is right for you.
- It is important to take care of yourself. You did what you could for your loved one. Now it is time for you to heal.
- You are not alone. Our grief counselors can give you extra support as you learn to let go and move on.
Appendix

Honoring Choices – Your Rights
Making Your Own Healthcare Treatment Decisions

Minnesota Law:
Minnesota law allows you to inform others of your health care wishes. You have the right to state your wishes or appoint an agent in writing so that others will know what you want if you can’t tell them because of illness or injury. The information that follows tells about health care directives and how to prepare them. It does not give every detail of the law.

What is a health care directive?
A health care directive is a written document that informs others of your wishes about your health care. It allows you to name a person (“agent”) to decide for you if you are unable to decide. It also allows you to name an agent if you want someone else to decide for you while you still have capacity. You must be at least 18 years old to make a health care directive.

Why have a health care directive?
A health care directive is important if your attending physician determines you can’t communicate your health care choices (because of physical or mental incapacity). It is also important if you wish to have someone else make your health care decisions. In some circumstances, your directive may state that you want someone other than an attending physician to decide when you cannot make your own decisions.

Must I have a health care directive? What happens if I don’t have one?
You don’t have to have a health care directive. But, writing one helps to make sure your wishes are followed. You will still receive medical treatment if you don’t have a written directive. Health care providers will listen to what people close to you say about your treatment preferences, but the best way to be sure your wishes are followed is to have a health care directive.

I wrote my directive in another state. Is it still good?
Health care directives prepared in other states are legal if they meet the requirements of the other state’s laws or the Minnesota requirements. But requests for assisted suicide will not be followed.

How do I make a health care directive?
There are forms for health care directives. You don’t have to use a form, but your health care directive must meet the following requirements to be legal:

- Be in writing, dated, and state your name.
- Be signed by you or someone you authorize to sign for you when you can understand and communicate your health care wishes.
- Have your signature verified by a notary public or two witnesses (notaries and witnesses cannot also be named as agent).
- Include the appointment of an agent to make health care decisions for you and/or instructions about the health care choices you wish to make.

Before you prepare or revise your directive, you should discuss your health care wishes with your doctor or other health care provider. Information about how to obtain forms for preparation of your health care directive can be found in the Resource Section of this document.

What if I’ve already prepared a health care document? Is it still good?
Before August 1, 1998, Minnesota law provided for several other types of directives, including living wills, durable health care powers of attorney and mental health declarations. The law changed so people can use one form for all their health care instructions. Forms created before August 1, 1998 are still legal if they followed the law in effect when written. They are also legal if they meet the requirements of the new law (described above). You may want to review any existing documents to make sure they say what you want and meet all requirements.

What can I put in a health care directive?
You have many choices of what to put in your health care directive. For example, you may include:
• The person you trust as your agent to make health care
decisions for you. You can name alternative agents, in case
the first agent is unavailable, or joint agents.
• Your goals, values, preferences, and cultural beliefs about
health care.
• The types of medical treatment you would want (or not
want).
• How you want your agent or agents to decide.
• Where you want to receive care.
• Instructions about artificial nutrition and hydration.
• Mental health treatments that use electroshock therapy or
neuroleptic medications.
• Instructions if you are pregnant.
• Donation of organs, tissues and eyes.
• Funeral arrangements.
• Who you would like as your guardian or conservator if
there is a court action.

You may be as specific or as general as you wish. You can
choose which issues or treatments to deal with in your health
care directive.

Are there any limits to what I can put in my
health care directive?

There are some limits about what you can put in your health
care directive. For instance:
• Your agent must be at least 18 years of age.
• Your agent cannot be your health care provider, unless
the health care provider is a family member or you give
reasons for the naming of the agent in your directive.
• You cannot request health care treatment that is outside of
reasonable medical practice.
• You cannot request assisted suicide.

How long does a health care directive last? Can I
change it?

Your health care directive lasts until you change or cancel
it. As long as the changes meet the health care directive
requirements listed above, you may cancel your directive by
any of the following:
• A written statement saying you want to cancel it
• Destroying it
• Telling at least two other people you want to cancel it
• Writing a new health care directive.

What if my health care provider refuses to follow
my health care directive?

Your health care provider generally will follow your health
care directive, or any instructions from your agent, as long as
the health care follows reasonable medical practice. But, you
or your agent cannot request treatment that will not help you
or which the provider cannot provide.

If the provider cannot follow the agent’s directions about
life-sustaining treatment, the provider must inform the agent.
The provider must also document the notice in your medical
record. The provider must allow the agency to arrange to
transfer you to another provider who will follow the agent’s
directions.

What should I do with my health care directive
after I have signed it?

You should inform others of your health care directive and
give people copies of it. You may wish to inform family
members, your health care agent or agents, and your health
care providers that you have a health care directive. You
should give them a copy. It’s a good idea to review and update
your directive as your needs change. Keep it in a safe place
where it is easily found.

What if I believe a health care provider has not
followed health care directive requirements?

Complaints of this type can be filed with the Office of Health
Facility Complaints at 651-201-4200 (metro area) or toll free
at 1-800-369-7994.

What if I believe a health plan has not followed
health care directive requirements?

Complaints of this type can be filed with the Minnesota
Health Information Clearinghouse at 651-201-5178 or toll
free at 1-800-657-3793.

For more information:
• Minnesota Board on Aging’s Senior LinkAge Line:
  1-800-333-2433
• Fairview has trained staff to help you complete a health
care directive at no cost. We also offer free classes on
advance care planning and health care directives. For a
free form, information, or to sign up for a class: ask a
staff member, visit www.fairview.org/choices, or call 612-
672-7272 or 800-824-1952.
• Forms also available at http://www.mnaging.org
  651-201-5000 or 888-345-0823.

Fairview is committed to making your health care wishes
known and available in your medical record. You may give a
copy of your directive to any Fairview care team member to
have it added to your medical record.
Responsibilities and rights

You and your loved one have the following responsibilities:

1. To give correct and complete health information about past illnesses, hospitalizations, medicines, allergies and other relevant items.
2. To have and keep a safe environment. This would include locking up guns and ammunition.
3. To tell Fairview Hospice when you will not be able to keep a scheduled visit.
4. To take part in the making and updating your care plan, to follow your care plan or to help revise the plan and/or to accept the responsibility if you refuse any treatment stated in the care plan.
5. To ask for more information about anything you do not understand.
6. To stay under a doctor’s care while getting agency services.
7. To give Fairview Hospice all needed insurance and financial information, to sign the required consents and releases for insurance billing and to pay promptly for services given.
8. To treat agency personnel with respect and consideration.
9. To follow agency policies that may limit the duties the staff may perform.
10. To help make a pain-relief goal and a plan for reaching that goal.
11. For patients with Fairview-owned equipment, to pay for replacement costs, repairs or cleaning charges of equipment (IV pumps, enteral pumps, videophones) and accessories (pouches, battery packs) that are damaged, destroyed, lost, stolen or excessively dirty due to misuse, abuse or neglect.
12. To not smoke in front of Fairview Hospice staff or volunteers due to the health and fire risks of smoking. Staff and volunteers may not help a patient smoke.
13. To confine pets that may create a distraction during a visit.
14. To tell Fairview Hospice staff if there are concerns about your care.
Minnesota Hospice Bill of Rights
PER MINNESOTA STATUTES, SECTION 144A.751

The language in **BOLD** print represents additional consumer rights under federal law for patients of Medicare-certified Hospices.

Subdivision 1. Statement of rights. An individual who receives hospice care has the right to:

**Be informed of his or her rights, and the hospice must protect and promote the exercise of these rights.**

(1) **Exercise his or her rights as a patient of the hospice.** Receive written information about rights in advance of receiving hospice care or during the initial evaluation visit before the initiation of hospice care, including what to do if rights are violated.

Notice of rights and responsibilities: (1) During the initial assessment visit in advance of furnishing care the hospice must provide the patient or representative with verbal (meaning spoken) and written notice of the patient’s rights and responsibilities in a language and manner that the patient understands; (2) The hospice must comply with the requirements of subpart I of part Code of Federal Regulations (CFR) 489 of this chapter regarding advance directives. The hospice must inform and distribute written information to the patient concerning its policies on advance directives, including a description of applicable State law; (3) The hospice must obtain the patient’s or representative’s signature confirming that he or she has received a copy of the notice of rights and responsibilities.

(2) Receive care and services according to a suitable hospice plan of care and subject to accepted hospice care standards and to take an active part in creating and changing the plan and evaluating care and services. **Be involved in developing his or her hospice plan of care.**

(3) Be told in advance of receiving care about the services that will be provided, the disciplines that will furnish care, the frequency of visits proposed to be furnished, other choices that are available, and the consequence of these choices, including the consequences of refusing these services.

(4) Be told in advance, whenever possible, of any change in the hospice plan of care and to take an active part in any change.
(5) Refuse care, services or treatment.

(6) Know, in advance, any limits to the services available from a provider, and the provider's grounds for a termination of services. Receive information about the scope of services that the hospice will provide and specific limitations on those services.

(7) Know in advance of receiving care whether the hospice services may be covered by health insurance, medical assistance, Medicare, or other health programs in which the individual is enrolled. Receive information about the services covered under the hospice benefit.

(8) Receive, upon request, a good faith estimate of the reimbursement the provider expects to receive from the health plan company in which the individual is enrolled. A good faith estimate must also be made available at the request of an individual who is not enrolled in a health plan company. This payment information does not constitute a legally binding estimate of the cost of services.

(9) Know that there may be other services available in the community, including other end of life services and other hospice providers, and know where to go for information about these services.

(10) Choose freely among available providers and change providers after services have begun, within the limits of health insurance, medical assistance, Medicare, or other health programs. Choose his or her attending physician.

(11) Have personal, financial, and medical information kept private and be advised of the provider's policies and procedures regarding disclosure of such information.

(12) Be allowed access to records and written information from records according to sections 144.291 to 144.298. Have a confidential clinical record. Access to or release of patient information and clinical records is permitted in accordance with 45 CFR parts 160 and 164.

(13) Be served by people who are properly trained and competent to perform their duties.

(14) Be treated with courtesy and respect and to have the patient's property treated with respect. To have his or her property and person treated with respect.

(15) Voice grievances regarding treatment or care that is, or fails to be, furnished or regarding the lack of courtesy or respect to the patient or the patient's property by anyone who is furnishing services on behalf of the hospice.

The patient has the right to not be subjected to discrimination or reprisal for exercising his or her rights.
(16) Be free from physical and verbal abuse. **Be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property.**

(17) Reasonable, advance notice of changes in services or charges, including at least ten days' advance notice of the termination of a service by a provider, except in cases where:

(i) the recipient of services engages in conduct that alters the conditions of employment between the hospice provider and the individual providing hospice services, or creates an abusive or unsafe work environment for the individual providing hospice services;

(ii) an emergency for the informal caregiver or a significant change in the recipient's condition has resulted in service needs that exceed the current service provider agreement and that cannot be safely met by the hospice provider; or

(iii) the recipient is no longer certified as terminally ill.

(18) A coordinated transfer when there will be a change in the provider of services.

(19) Know how to contact an individual associated with the provider who is responsible for handling problems and to have the provider investigate and attempt to resolve the grievance or complain.

(20) Know the name and address of the state or county agency to contact for additional information or assistance.

(21) Assert these rights personally, or have them asserted by the hospice patient's family when the patient has been judged incompetent, without retaliation. **If a patient has been adjudged incompetent under state law by a court of 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,**

(22) Have pain and symptoms managed to the patient's desired level of comfort. **Receive effective pain management and symptom control from the hospice for conditions related to the terminal illness;**

The hospice must:

(i) Ensure that all alleged violations involving mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property by anyone furnishing services on behalf of the hospice, are reported immediately by hospice employees and contracted staff to the hospice administrator

(ii) Immediately investigate all alleged violations involving anyone furnishing services on behalf of the hospice and immediately take action to prevent further potential violations while the alleged violation is being verified. Investigations and/or documentation of all alleged violations must be conducted in accordance with established procedures;
(iii) Take appropriate corrective action in accordance with state law if the alleged violation is verified by the hospice administration or an outside body having jurisdiction, such as the State survey agency or local law enforcement agency; and
(iv) Ensure that verified violations are reported to State and local bodies having jurisdiction (including to the State survey and certification agency) within 5 working days of becoming aware of the violation.

If the hospice provider operates a residential hospice facility, the written notice to each residential hospice patient must include the number and qualifications of the personnel, including both staff persons and volunteers, employed by the provider to meet the requirements of MN Rule 4664.0390 on each shift at the residential hospice facility.

IF YOU HAVE A COMPLAINT ABOUT THE AGENCY OR PERSON PROVIDING YOU HOSPICE SERVICES, YOU MAY CALL, WRITE, OR VISIT THE OFFICE OF HEALTH FACILITY COMPLAINTS, MINNESOTA DEPARTMENT OF HEALTH. YOU MAY ALSO CONTACT THE OMBUDSMAN FOR LONG-TERM CARE.

Office of Health Facility Complaints
(651) 201-4201
1-800- 369-7994
Fax: (651) 281-9796
Mailing Address:
Minnesota Department of Health
Office of Health Facility Complaints
P.O. Box 64970
St. Paul, Minnesota 55164-0970
TDD/TTY: 651-215-8980
Office Address:
Minnesota Department of Health
Office of Health Facility Complaints
85 East Seventh Place
St. Paul, Minnesota 55164-0970

Ombudsman for Long-Term Care
(651) 431-2555
1-800-657-3591
Fax: (651) 431-7452
Mailing Address:
Ombudsman for Long-Term Care
PO Box 64971
St. Paul, MN 55164-0971

Fairview Compliance Hotline
800-530-4694 or 612-672-2300
Please report anything your hospice worker does that concerns you, such as actions that seem wrong or suspicious. Your report will be kept private (confidential).
Licensee Name: Fairview Home Care and Hospice

Telephone Number: 612-721-2491

Address: 2450 26th Avenue South, Minneapolis, MN 55406

Name/Title of Person to Whom Problems or Complaints May be directed: President

OR

Licensee Name: Fairview Lakes HomeCaring & Hospice

Telephone Number: 651-257-8850

Address: 11725 Stinson Avenue, Chisago City, MN 55013

Name/Title of Person to Whom Problems or Complaints May be directed: President

OR

Licensee Name: North Star Hospice

Telephone Number: 218-262-6982

Address: East 37th Street, STE 27, Hibbing, MN 55013

Name/Title of Person to Whom Problems or Complaints May be directed: Manager

For informational purposes only and is not required in the Hospice Bill of Rights text: MN Statutes, section 144A.751

Subd. 2. Interpretation and enforcement of rights. The rights under this section are established for the benefit of individuals who receive hospice care. A hospice provider may not require a person to surrender these rights as a condition of receiving hospice care. A guardian or conservator or, when there is no guardian or conservator, a designated person, may seek to enforce these rights. This statement of rights does not replace or diminish other rights and liberties that may exist relative to persons receiving hospice care, persons providing hospice care, or hospice providers licensed under section 144A.753.

Subd. 3. Disclosure. A copy of these rights must be provided to an individual at the time hospice care is initiated. The copy shall contain the address and telephone number of the Office of Health Facility Complaints and the Office of the Ombudsman for Long-Term Care and a brief statement describing how to file a complaint with these offices. Information about how to contact the Office of the Ombudsman for Long-Term Care shall be included in notices of change in provider fees and in notices where hospice providers initiate transfer or discontinuation of services.
Notes

Use this space to write questions and concerns as they come to mind so you have them ready the next time you see a hospice team member.
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