Allina Health Hospice
Confident Caregiver and Patient Guide

Allina Health
HOSPICE & PALLIATIVE CARE
The publisher believes that information in this manual was accurate at the time the manual was published. However, because of the rapidly changing state of scientific and medical knowledge, some of the facts and recommendations in the manual may be out-of-date by the time you read it. Your health care provider is the best source for current information and medical advice in your particular situation.

All rights reserved. No part of this book may be reproduced in any form or by any means, electronic or mechanical, including photocopying, without permission in writing from the publisher.

Disclaimer
This publication is for general information only and is not intended to provide specific advice or recommendations for any individual. The information it contains cannot be used to diagnose medical conditions or prescribe treatment. The information provided is designed to support, not replace, the relationship that exists between a patient and his/her existing physician. For specific information about your health condition, please contact your health care provider.
How To Reach Allina Health Hospice

If a problem occurs that needs advice or assistance right away, a hospice nurse is always available. The hospice nurse has access to all patients’ complete charts. He or she will gather information about your situation and try to help you over the phone. If the problem cannot be resolved over the phone, an on-call nurse can make a visit. The hospice nurse will leave a message with your case manager so he or she knows why you called and how it was resolved.

We, at Allina Health Hospice, want to make sure you are confident in the care you provide. There is always a hospice nurse on duty. Please do not hesitate to call with any questions or concerns about the care of a patient.
Please keep this by your phone at all times.

_______________________'s (patient name) hospice team

Nurse(s): ________________________________________________________________

Hospice home health aide(s): ________________________________________________

Social worker(s): ___________________________________________________________

Chaplain(s): ________________________________________________________________

Volunteer(s): ______________________________________________________________

Others visiting: _____________________________________________________________

Primary care provider: ______________________________________________________

Phone number: _____ - _____ - _______

The name of my preferred hospital is: __________________________________________

To contact hospice anytime, please call:

Twin Cities Metro and surrounding areas: 651-635-9173 or 1-800-261-0879
Hutchinson/Glencoe: 320-234-5031
    New Ulm: 507-217-5555
    Owatonna: 507-446-0936

To contact hospice anytime, please call:

Twin Cities Metro and surrounding areas: 651-635-9173 or 1-800-261-0879
Hutchinson/Glencoe: 320-234-5031
    New Ulm: 507-217-5555
    Owatonna: 507-446-0936
Dear Caregiver,

At Allina Health Hospice we realize that providing care to someone who is seriously ill can be overwhelming and exhausting at times. Please know that you are not alone. The hospice team considers teaching and supporting primary caregivers an essential part of their mission. Our focus is on the total physical, emotional, social and spiritual comfort of you, your family and your friends.

Hospice is a special kind of care for people with terminal illnesses and for their families and caregivers. What you hold in your hands is a resource guide designed with the caregiver in mind to help you and your family during this transition to comfort care. It is not a substitute for an informed discussion about the hospice patient’s medical status with his or her primary care provider, case manager or other professional.

I believe that the information found within these pages will help provide you with the confidence to understand common symptoms, how to manage them and to encourage you to ask questions of your hospice team when you need help. While each person is unique and not every individual will experience the same symptoms or emotions, the information found in this guide is common and a normal part of the dying process. I encourage you to read ahead so that you can begin to have more detailed conversations about pain and symptom management with your hospice team.

Allina Health Hospice is available to you by phone 24 hours a day, 7 days per week and during regularly-scheduled visits with your hospice team.

If issues or concerns arise, please contact your hospice team right away so that together, issues and concerns can be resolved quickly. If, however, your concerns are not resolved to your satisfaction, please feel free to call my office directly at 612-262-7021. I will respond to your concerns as quickly as possible.

Thank you for inviting us into your life at this important time.

Sincerely,

Gloria Cade, director
Allina Health Hospice
# Table of Contents

Chapter 1: Welcome to Hospice ............................................................... 9  
  Hospice Team .............................................................................. 12  
  Family Conference ................................................................. 16  
  Worksheet: Plan of Care ......................................................... 17  

Chapter 2: Safety ............................................................................ 19  
  Smoking .................................................................................. 21  
  Oxygen Safety ......................................................................... 21  
  Medical and Self-help Equipment ............................................. 22  
  Home Safety ........................................................................... 23  
  Preventing Falls ...................................................................... 24  
  Emergency Planning ............................................................. 27  
  Infection Control ..................................................................... 28  
  Supplies .................................................................................. 29  

Chapter 3: Medicines .................................................................... 31  
  Medicine Safety ........................................................................ 33  
  Medicine Waste ....................................................................... 35  
  Medicine Delivery .................................................................... 40  
  Pain Medicines ......................................................................... 41  
  Radiation and Chemotherapy .................................................. 44  
  Keeping Track of Your Medicines ............................................ 44  
  Worksheets: My Medicines .................................................... 45  

Chapter 4: Caregivers ................................................................. 51  
  What You Can Do and What Hospice Can Do ...................... 54  
  Tips for Dealing with Caregiver Stress ................................... 55  
  Depression ............................................................................... 57  
  How to Ask for Help ................................................................ 58  
  Early Grief ................................................................................ 59  
  How Children Understand Death .......................................... 62  
  Additional Resources ............................................................ 66  
  Allina Health Written Resources ......................................... 67
Chapter 5: Symptoms ................................................................. 69
  Anxiety, Agitation and Restlessness ........................................ 71
  Confusion ............................................................................. 75
  Constipation .......................................................................... 78
  Dehydration and Thirst .......................................................... 81
  Eating Habit and Diet Changes ................................................ 84
  Fatigue, Drowsiness and Sleep Problems ................................. 86
  Loss of Appetite and Weight Loss ........................................... 89
  Nausea (Upset Stomach) and Vomiting .................................... 92
  Pressure Ulcers (Bedsores) ..................................................... 95
  Shortness of Breath .............................................................. 98
  Special Diet Circumstances .................................................... 101
  Transportation by Ambulance ............................................... 102
  Allina Health Pain Assessment Scale ..................................... 103

Chapter 6: Last Days of Life ..................................................... 105
  Signs and Symptoms ............................................................ 107
  Providing Comfort ............................................................... 110

Chapter 7: At Time of Death .................................................... 111
  What You Need to Do ........................................................... 113
  What Happens Next ............................................................. 114
  Worksheet: At Time of Death Information ............................... 115

Chapter 8: Documents ............................................................. 117
  Health Care Directives ......................................................... 119
  Provider Orders for Life-Sustaining Treatment (POLST) ............ 123
  Combined Minnesota and Federal Hospice Bill of Rights ......... 125
  Section 504 Grievance Procedure ......................................... 131
  Your Privacy ........................................................................... 133
  Notice of Privacy Practices .................................................... 135
Chapter 1: Welcome to Hospice

In This Chapter:
- Hospice Team
- Family Conference
- Worksheet: Plan of Care
Chapter 1: Welcome to Hospice

Hospice is a special way of caring for people with a terminal illness, their families and their caregivers. It treats the physical, emotional and spiritual needs of the patient, and focuses on comfort and having the highest quality of life possible (known as comfort care).

Hospice keeps the patient comfortable and not suffering while “nature takes its course.” Only medicines and actions to make the patient more comfortable are used or added. Dying is not hurried or delayed.

Tests and treatments to lengthen life are not usually part of hospice. If the patient chooses to try treatments for reasons other than symptom control, he or she may stop hospice at any time.

The goal of this book is to give a complete guide to hospice. The first step in hospice is meeting your hospice team.

Did You Know?

Hospice is available to any patient with a terminal illness when his or her primary care provider believes the patient has 6 months or less to live.
Hospice Team

Every hospice patient and family is assigned to a hospice team. The names of your team members are written on page 3 of this guide. Certain team members are assigned to provide care for each patient. This helps to build relationships between the patient, family and hospice team. The patient may see other team members if his or her assigned team member needs to take time off for an illness or a vacation.

The hospice team provides comfort care in the patient’s home when possible. The team includes:
- a registered nurse (RN) case manager
- a social worker
- a hospice home health aide
- a chaplain
- the patient’s primary care provider
- a pharmacist
- volunteers (and a volunteer coordinator).

Therapists, dietitians and grief counselors may also be a part of this team when they are needed.

Hospice nurses

The hospice nurses check the patient’s health status, help with medical needs, treat and monitor the patient’s physical symptoms, and help the patient’s family to properly care for the patient. Nurses are available by telephone 24 hours a day, 7 days per week and make home visits as needed.

The four types of nurses include:
- **a case manager:**
  This nurse is the primary director of care for the hospice patient. This person is a registered nurse (RN), and may also be a certified hospice and palliative care specialist.
- **a triage nurse:**
  Assists the case manager and answers the hospice phone lines 24 hours a day, 7 days per week.
- **a visit nurse:**
  Assists the case manager by visiting when the case manager is not able to do his or her visits.
continuous care nurses:
These nurses are only assigned during a medical crisis. (Medicare has special requirements that need to be met to be considered a crisis.) Your case manager will tell you if continuous care is needed.

Social worker

Social work services are available to patients and their families. Services may include:
- patient counseling
- family or caregiver counseling
- financial and legal information (such as power of attorney, Family and Medical Leave Act, money management or Social Security application)
- resources (such as discharge planning, community resources, children’s support resources or patient and family advocacy).

Hospice home health aide

Hospice home health aides are trained and certified to help with personal cares for the patient in his or her home. They are available to help the patient with personal hygiene matters such as:
- bathing
- shaving
- dressing changes
- linen changes
- household services to keep a safe and clean living space for the patient.

Hospice home health aide services are supervised by the nurse case manager.

Chaplain

Spiritual care is a broad service available to the patient throughout his or her stay. It is tailored to the patient’s personal and spiritual points of view, regardless of his or her faith, religion or cultural background.
The chaplain can provide spiritual and emotional support by listening to the patient’s life stories and experiences, and talking about any spiritual concerns the patient may have. The chaplain also provides guidance and explores the role of spirituality in illness, suffering and healing. Together, the chaplain and the patient’s spiritual leader make sure the patient is getting the highest quality of spiritual care.

**Primary care provider**

The patient’s primary care provider approves admission to hospice. He or she continues to manage the patient’s medical needs and concerns while in hospice.

In addition to the patient’s primary care provider, his or her team will also include a:

- **hospice doctor:**
  A doctor who meets weekly with the hospice team to give medical input and advice. Hospice will work with the patient’s family and make sure his or her primary care provider knows how things are going at home.

- **medical director:**
  A doctor who is available to the patient’s primary care provider and the hospice team for medical information and advice.

**Pharmacist**

The pharmacist reviews the patient’s medicine list to make sure the medicines are right and safe to take together. He or she meets weekly with the hospice team to provide information about medicine therapy. Together, the hospice team and pharmacist will create a medicine plan that is right for the patient.

**Volunteers**

Volunteers help the patient in many ways. They are available to:

- drive patients to and from medical appointments
- give the caregiver a break from caregiving responsibilities
- provide companionship and emotional support
- do light housework
- prepare meals.

---

**Tip**

Turn to pages 45 to 49 at the end of chapter 3 to fill out the *My Medicines* charts. These will help you to keep track of the medicines you are currently taking.
**Did You Know?**

Some volunteers have special skills in massage therapy, healing touch therapy, music therapy and hair care.

A volunteer coordinator on the hospice team will call the patient or the patient’s family to talk about how a volunteer might help. The volunteer coordinators put a lot of effort toward matching the needs of the patient with the skills and interests of the volunteer.

All Allina Health volunteers go through a careful screening and interview process that includes a criminal background check. The volunteers are trained and supervised by the hospice team.

**Grief counselors**

Support services and resources are available for 13 months after the patient’s death.

Family members will receive information about grief counselors at Allina Health Hospice by mail after the death of their loved one. Some of the resources available include:

- booklets and bibliographies
- referral lists for local support groups
- phone counselors
- volunteer grief support visitors
- grief counselors.

Allina Health Hospice also sponsors a web and phone grief support service. Visit allinahealth.org/griefresources or call 651-628-1752. This is not a crisis line. It is a resource about support groups, counselors and books for the community.

**Therapist(s)**

Other therapies such as physical therapy, music therapy and massage therapy are available on a limited basis. These therapies are used to treat the patient’s symptoms and make the patient more comfortable. Your case manager will be able to determine availability of these therapies based on the patient’s plan of care.
Family Conference

A family conference is a chance for the patient and family to meet with the hospice team to talk about the patient’s comfort and care. This is a good time to bring up any concerns or questions, or specific needs of the patient. Together, the team, patient and family will create a plan of care.

You can request a family conference at any time during hospice care. Family conferences may include:

- addressing physical, emotional and spiritual concerns
- developing a plan of care based on patient and family goals
- offering support and education to the patient and family
- reviewing physical status, symptoms and symptom management of the patient
- discussing how volunteers and the entire hospice team can support the patient and family.
Plan of Care

Use this chart to write down regularly-scheduled visits with your hospice team. If you any questions about your visits, please call 651-635-9173 or 1-800-261-0879.

<table>
<thead>
<tr>
<th>Hospice team member</th>
<th>Number of visits per week</th>
<th>Day and time of visits</th>
<th>Reason for visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case manager (nurse)</td>
<td></td>
<td>Day: _________________</td>
<td></td>
</tr>
<tr>
<td>Name: ________________</td>
<td></td>
<td>Time: <em><strong>:</strong></em> a.m. / p.m.</td>
<td></td>
</tr>
<tr>
<td>Social worker</td>
<td></td>
<td>Day: _________________</td>
<td></td>
</tr>
<tr>
<td>Name: ________________</td>
<td></td>
<td>Time: <em><strong>:</strong></em> a.m. / p.m.</td>
<td></td>
</tr>
<tr>
<td>Hospice home health aide</td>
<td></td>
<td>Day: _________________</td>
<td></td>
</tr>
<tr>
<td>Name: ________________</td>
<td></td>
<td>Time: <em><strong>:</strong></em> a.m. / p.m.</td>
<td></td>
</tr>
<tr>
<td>Chaplain</td>
<td></td>
<td>Day: _________________</td>
<td></td>
</tr>
<tr>
<td>Name: ________________</td>
<td></td>
<td>Time: <em><strong>:</strong></em> a.m. / p.m.</td>
<td></td>
</tr>
<tr>
<td>Primary care provider</td>
<td></td>
<td>Day: _________________</td>
<td></td>
</tr>
<tr>
<td>Name: ________________</td>
<td></td>
<td>Time: <em><strong>:</strong></em> a.m. / p.m.</td>
<td></td>
</tr>
<tr>
<td>Volunteer coordinator</td>
<td></td>
<td>Day: _________________</td>
<td></td>
</tr>
<tr>
<td>Name: ________________</td>
<td></td>
<td>Time: <em><strong>:</strong></em> a.m. / p.m.</td>
<td></td>
</tr>
<tr>
<td>Volunteer(s)</td>
<td></td>
<td>Day: _________________</td>
<td></td>
</tr>
<tr>
<td>Name: ________________</td>
<td></td>
<td>Time: <em><strong>:</strong></em> a.m. / p.m.</td>
<td></td>
</tr>
<tr>
<td>Name: ________________</td>
<td></td>
<td>Day: _________________</td>
<td></td>
</tr>
<tr>
<td>Time: <em><strong>:</strong></em> a.m. / p.m.</td>
<td></td>
<td>Day: _________________</td>
<td></td>
</tr>
<tr>
<td>Other team member(s)</td>
<td></td>
<td>Day: _________________</td>
<td></td>
</tr>
<tr>
<td>Name: ________________</td>
<td></td>
<td>Time: <em><strong>:</strong></em> a.m. / p.m.</td>
<td></td>
</tr>
<tr>
<td>Name: ________________</td>
<td></td>
<td>Day: _________________</td>
<td></td>
</tr>
<tr>
<td>Time: <em><strong>:</strong></em> a.m. / p.m.</td>
<td></td>
<td>Day: _________________</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Time: <em><strong>:</strong></em> a.m. / p.m.</td>
<td></td>
</tr>
</tbody>
</table>
Chapter 2: Safety

In This Chapter:

- Smoking
- Oxygen Safety
- Medical and Self-help Equipment
- Home Safety
- Preventing Falls
- Emergency Planning
- Infection Control
- Supplies
Chapter 2: Safety

Smoking

For the safety and health of your team, please do not smoke while team members are in your home.

Oxygen Safety

Medical oxygen is safe if used correctly. Oxygen is not flammable. It will not start on fire by itself. However, when it mixes with flammable materials, it will help them burn hotter and faster.

Follow these guidelines for oxygen safety.

- Never smoke while using oxygen.
- If you smoke, turn your oxygen off for at least 15 minutes before smoking. It takes that long for the oxygen to leave your clothing, hair and skin.
- Do not use oxygen around open flames, matches, stoves, grills or space heaters.
- Stay at least 8 feet away from someone who is smoking.
- Put “No Smoking - Oxygen in Use” signs in your home. Put one at each entrance and one in the room near the oxygen equipment. Make sure people can see the signs.
- Do not use or store oxygen in an area that does not have air flowing through it, such as a closet.
- Keep the oxygen unit away from oil, grease or aerosol sprays.
- Do not use petroleum-based products (such as Vaseline® or A&D Ointment®) on any areas of skin. These products may cause burns when they are mixed with oxygen.
- Be careful around electrical devices or toys that make sparks.
- Do not leave the cannula in bed or under furniture cushions. Oxygen will leak into these items if the unit is left on. A spark or flame could cause a fire.
- Turn off oxygen equipment when not in use.

Important

If you choose to smoke with your oxygen on, your hospice team will not stay in your home for their own safety.
Medical and Self-help Equipment

The right self-help equipment can help you maintain or improve your independence. Examples of self-help equipment include:

- canes
- walkers
- toilet seat risers
- cushions.

The nurse case manager will arrange any equipment you must have for medical reasons. This may include a:

- hospital bed
- wheelchair
- bedside commode.

Most insurance companies will cover this basic equipment. Any equipment ordered by your hospice team will be paid for by hospice.

You can buy any other self-help and comfort items from a discount, hardware or special medical supply store. Examples include:

- egg crate mattresses
- baby monitors for hearing between rooms
- Chux (waterproof pads for bed or chair)
- Depend® products
- cotton sleepwear.

Many times the best devices are those invented by family or the nurse to meet your needs. The nurse case manager can help arrange a meeting between your family and the physical therapist if more help in getting these items is needed.
Home Safety

Your safety and independence at home may become a concern as the illness progresses. It is important to identify common household hazards, plan ahead for emergencies and make changes to your home to fit your needs. Review the following safety information and make as many changes as possible.

Fire safety

Follow these guidelines for fire safety.

- Be sure all smoke detectors are in working order. Install smoke detectors if there are none.

- Arrange for regular maintenance of your heat source. Install a carbon monoxide detector for extra protection.

- Keep portable heaters at least 3 feet away from people and objects. Never dry clothes on heaters.

- If you do smoke, be sure to use large, deep ashtrays and never leave smoking materials unattended. Never smoke in bed or if drowsy. Never smoke while using oxygen. If you must smoke, turn the oxygen equipment completely off and wait 15 minutes before smoking.

- Store flammable materials away from heat sources.

Electrical safety

Follow these guidelines for electrical safety.

- Throw away or repair frayed or damaged electrical cords.

- Never overload electrical outlets.

- Keep electrical appliances away from the sink, tub and shower area.
Preventing Falls

Of all falls, 85 percent occur in the home. Hospice nurses and therapists can help to make your home safe. Here are some tips to guard against falling at home.

In your dress:
- wear non-skid shoes rather than socks when walking indoors or out
- never stand barefoot on wet floors
- whenever possible, wear lace-up shoes to better support your feet and ankles
- avoid loose-fitting, backless slippers or ones without covered toes
- wear an emergency alert system around your neck to make sure that you would be found if you fell and could not get to a phone
- be sure your clothes fit you well. People have been known to fall because of ill-fitting footwear or baggy trousers.

In the kitchen:
- never stand on a chair or step stool to reach a shelf
- place items used most often on lower shelves
- wipe up spills and clean up broken glass right away
- use non-skid floor wax
- store lightweight items on top shelves and heavier items on bottom shelves. You can use an extended reacher to get overhead items.

In the bathroom:
- install safety rails on the tub and toilet
- put a mat with rubber backing near the tub and toilet
- use a raised toilet seat to make coming to a standing position easier or talk with a hospice nurse about getting a bedside commode
- consider bath benches and shower curtains instead of shower doors
- use non-slip treads in the tub or shower
- always make sure the floor is dry
- ask your hospice team for advice on how to safely take a bath.
On the stairway:
- keep stairways well-lit
- install handrails
- put a strip of white tape across the edge of the last step to make it easier to see
- keep stairways clear and carpeting well-secured
- side-step up or down the stairs while keeping both hands on the rail
- put the bathtub-type, non-slip tread on the hand rail to give yourself a warning that you’re at the last step
- apply a non-slip surface to stairs without carpeting.

In the bedroom:
- put a light switch at the door to prevent accidents in a dark room
- avoid hazardous placement of furniture
- make sure lamp or light switches are within reach of the bed
- keep a phone within reach of your bed or close to the floor in case of an emergency
- keep bedding out of the way when the bed is turned down. This will prevent you from tripping on the bed clothes.

In the closet:
- do not stack items high on shelves. Make sure all items are stored securely
- store heavy boxes on the floor where they may be moved and reached safely. Do not stack heavy boxes.

Outdoors:
- wear non-slip shoes if you must stand on a wet concrete surface.
Throughout the house:

- keep all electrical cords out of high-traffic areas to avoid tripping
- repair unsteady furniture
- check carpet for loose threads or worn areas
- use night lights
- in doorways, thresholds should be removed or covered with carpet
- remove clutter in walkways
- keep your cane, walker or wheelchair in an easy-to-access place
- watch out for small pets, which can get under your feet and cause you to trip
- raise seat height with a firm cushion to help you rise to a standing position
- make sure the path between furniture is wide enough for wheelchairs, canes and walkers
- remove throw rugs
- have emergency phone numbers written on all phones
- use cordless phones and carry them with you at all times
- avoid rushing to the phone and door. Tell family and friends that the phone may ring 10 or more times
- avoid pulling yourself out of a chair using your walking aid, instead push up from the chair
- use sturdy chairs with armrests, not chairs with wheels
- eliminate surfaces that glare in the light such as a high-gloss linoleum floor in front of a picture window. Hang a sheet curtain to diffuse the light. This is safer and easier on the eyes.

Drugs, alcohol and balance:

- certain drugs (including tranquilizers, heart medicines, blood pressure medicines and mood-altering drugs) and alcohol are major causes when it comes to having a higher risk of falling because drowsiness, dizziness and slowed reflexes are common side effects
- be aware of potentially dangerous drug interactions when taking more than one medicine (including over-the-counter medicines or alcohol).
Emergency Planning

It is important to plan for emergencies before they happen. This will keep you and your family safe from harm. Review the following information and to make sure you are prepared for an emergency.

- **Prepare a fire escape plan.**
  Be familiar with fire escape routes.

- **Keep a list of emergency numbers by each phone.**
  Consider using preset buttons for emergency numbers on phones with automatic dialing.

- **Carry an emergency alert system.**
  This is usually worn around your neck or wrist (like a necklace or bracelet). It has a button you can push to call for help during an emergency. Talk with your hospice social worker for more information.

- **Keep exit doors clear.**

- **Ask for help.**
  Arrange for a neighbor to help you get out of the house if you are unable to move quickly.

- **Talk with your local fire department.**
  Consider telling the fire department if you think you may not be able to get out of your house without help. Also tell the fire department if you use an oxygen concentrator.

- **Keep the phone close.**
  Arrange the bedside with a phone and flashlight within reach. Carry a portable phone with you, if you have one.

- **Watch the weather.**
  Pay attention to weather conditions and plan for help from family and friends before storms occur.
Infection Control

Hospice patients are at a higher risk for infections because their bodies’ natural defenses against illness are weak. All members working with you follow standard infection control policies to protect you, your family and themselves against passing germs.

Hand washing

Wash your hands regularly with soap and water to help stop the spread of germs. Make sure you wash them after you:
- use the bathroom
- blow your nose
- cough or sneeze
- eat.

It is also important to remember to wash your hands before and after you do any health-related care. To wash your hands:
- use soap and warm, running water
- wet your hands
- put some soap on your hands
- rub your hands together for at least 15 seconds
- scrub between your fingers and under your fingernails
- rinse with running water
- dry your hands with a paper towel
- use a paper towel to turn off the faucet.

If you cannot get to a sink, clean your hands with a waterless alcohol hand rub. To use alcohol rub, dispense a walnut-sized amount into your hand and rub until dry before touching anything.

Laundry

Change bed linens when soiled or on a regular schedule. When doing your laundry:
- use a standard laundry detergent and hot water (you may also use bleach for white linens)
- dry linens in a hot dryer
- wash your hands when you are finished.
Personal hygiene

Caregivers and patients should bathe or shower regularly. Talk with your nurse about a hospice home health aide visit for help with bathing.

Supplies

Supplies should be stored in an out-of-the-way place, yet easy for the patient to reach. Avoid putting supplies in an area that can become wet, such as on the bathroom sink. Wet packages are no longer clean or sterile and should be thrown away.
In This Chapter:
- Medicine Safety
- Medicine Waste
- Medicine Delivery
- Pain Medicines
- Radiation and Chemotherapy
- Keeping Track of Your Medicines
- Worksheets: My Medicines
Chapter 3:
Medicines

Tip
The *My Medicines* charts will help you take all of your medicines correctly. Turn to pages 45 to 49 at the end of this chapter to fill out your charts. Your case manager will help you.

Medicine Safety

Medicines are powerful chemicals used to treat illness, relieve pain and heal injuries. Medicines have risks as well as benefits. It is important to know which medicines you are taking and how to use them.

- Some foods and drinks may react badly with medicines. Talk with your hospice nurse about foods to avoid while taking certain medicines.
- Keep medicines in their original containers (unless your hospice nurse wants to set up your pills in a pill box each day to help you).
- Don’t mix alcohol and medicine. The effects of mixing alcohol and medicine vary with the medicine and the person taking it.
- Ask your pharmacist or hospice nurse about possible side effects before you start taking the medicine. If you have any severe or unusual reactions, tell a member of your hospice team right away.
- Follow any special instructions you receive for where or how to keep your medicine. Read the labels of all prescription and over-the-counter medicines you take.
- Keep all medicines (including herbals and vitamins) out of reach of children and pets.
- Do not share your medicines with anyone else or take medicines prescribed for anyone else.
Medicine use safety tips

Follow these tips for medicine safety.

- **Look at the medicine.**
  If it doesn’t look like what you usually take, ask why. It might be a generic or it might be the wrong medicine.

- **Read the label.**
  Read the label every time and follow the directions carefully.

- **Take as directed.**
  Do not chew, crush or break any capsules or tablets unless your hospice nurse or pharmacist says it’s safe.

- **Take with water.**
  Always take your medicine with 6 to 8 ounces of water, unless your hospice nurse or pharmacist tells you differently.

- **Measure correctly.**
  Use an approved medicine measuring device to measure liquid medicines.

- **Store safely.**
  Store medicine out of reach of children and away from household chemicals.

- **Never take someone else’s medicine.**

- **Get rid of medicines properly.**
  Never save leftover medicines. For more information, see the following section on how to get rid of your medicines safely.

Make sure you ask and understand the following about your medicines.

- **What is the name of the medicine?** (Know both the generic and brand names of your medicine. For instance, warfarin and Coumadin®, or ibuprofen and Advil®.)
- **Why am I taking it?**
- **When do I take it?**
- **How much do I take?**
- **How long do I take it?**
- **Should I take it with food?**
- **What are the possible side effects?**
Medicine Waste

Properly getting rid of your unwanted medicines and used sharps (needles and lancets) is important to keep your family and community safe. This prevents adults, children and pets from finding and being harmed by them.

How to get rid of your medicines safely

Take-back programs

Many cities and counties offer medicine take-back programs for you to drop off your unwanted medicines to be properly thrown away. Your city or county government’s household trash and recycling service will have information about the programs in your area.

For more information about take-back programs or to find your county’s information, visit the following websites:

- **Minnesota:**
  - rethinkrecycling.com
  - Type "medicine disposal" in the search box (at top right).
  - Click on *Medicine & Prescription Drugs*.
  - Scroll down to find your county’s information.

- **Wisconsin:**
  - dnr.wi.gov
  - Type "household medicine waste" in the search box (at top).
  - Click on *Household health care waste - Wisconsin DNR*.
  - Click on *Pharmaceuticals* (first bullet point).
  - Scroll down to number 3 and click on listing of *upcoming pharmaceutical collection events [exit DNR]*.
  - Scroll down to find a collection site in your county.

If your county is not listed, you can get information about your city or county government’s household trash and recycling service by calling them at the number listed on their website or in your local phone book.

**Always take your unwanted medicine to a take-back program in your area.** You may throw your unwanted medicine in the trash only if your community doesn’t offer a take-back program and there aren’t any directions on your medicine container.
How to prepare your medicine for throwing it away

The following information will help you to prepare your medicine container for throwing it in the trash.

- Read the safety information on your medicine container. Follow any special directions.
- If there aren’t any special directions, take the following steps to prepare your medicine container:
  - Scratch off your name, your doctor’s name and the prescription number on the medicine label. (See photo at left.) Or you can scribble the information out with a black marker or pen. Doing this will protect your identity but leaves important safety information in case someone finds your unwanted medicine.
  - Keep the medicine in its original container.

The following information will help you to prepare your medicine for throwing it in the trash:

- **solid medicines (such as pills or tablets):**
  Add a small amount of water to dissolve most of the medicine. (See photo at left.)

- **liquid medicines:**
  Make an unappealing mixture by adding charcoal, sawdust, kitty litter, salt, flour, turmeric or other nontoxic powdered spices.

- **blister packs:**
  Wrap in several layers of tape. Use tape you cannot see through (such as duct tape).
The following information will help you to disguise your medicine container for throwing it in the trash.

- Tape the cap of your medicine container shut with a strong tape (such as duct tape or packaging tape).
- Put the taped medicine container in a bag or other container that you cannot see through (such as a paper lunch bag or an empty yogurt, sour cream or coffee container). **Do not put your medicine container in food products as this may encourage animals or children to eat or drink your medicine.**
- Throw the container in the trash (not in the recycling bin).

Source: Minnesota Pollution Control Agency
How to get rid of sharps (needles and lancets) safely

How to store your sharps at home

You will need to have a special container in which to store your used sharps at home. You can choose one of the following options:

- buy a sharps disposal container from your pharmacy. (See photo at left.)
- make your own container from an empty laundry detergent bottle with a screw-on lid. (See photo at bottom left.) To make your own sharps disposal container:
  - use a pen or marker to write “Do not recycle: household sharps” on a piece of masking tape and stick it on the front of the container
  - place your used sharps point-first into the container
  - screw the cap on tightly and do not take the cap off unless you are placing sharps into it
  - return the sharps to your county drop-off site or send them to a mail-back program. (Allina Health hospitals in Wisconsin do accept sharps. Check with your hospital before dropping your sharps off.)

When storing needles and sharps at home, it is important to remember the following.

- Do not store sharps in glass bottles, aluminum cans or coffee cans.
- Always keep your sharps storage container in a place where children and pets cannot reach it.
- Follow any directions from your county drop-off site or mail-back programs. Some may require that you to buy a special sharps disposal container.
How to destroy your sharps at home

To destroy your sharps at home, you can buy a device that:

- melts sharps:
  This device uses heat to melt the needles into small BB-size balls, which then can be thrown in the trash (not the recycling).

- cuts and stores sharps:
  The clipped needles need to be dropped off at your county drop-off site or sent to a mail-back program.

How to get rid of your sharps

Never place sharps containers in the recycling or loose sharps in the trash. Choose one of the following options to get rid of your sharps.

- Buy a device that:
  - melts sharps:
    The melted needles can be thrown in the trash (not the recycling).
  - cuts and stores sharps:
    You will need to return the clipped needles to your county drop-off site or a mail-back program.

- Store your sharps in a special container and return the container to:
  - your county drop-off site
  - a mail-back program. You will have to pay for this.

Important

Allina Health hospitals and clinics in Minnesota do not accept sharps. Please do not bring them to your hospital or clinic.
Drop-off sites

For more information about drop-off sites or to find your county’s information, visit the following websites:

- **Minnesota:**
  rethinkrecycling.com
  - Type "needle disposal" in the search box (at top right).
  - Click on *Needles & Syringes*.
  - Click on *household hazardous waste* (in green text).
  - Click on the *Drop-Off Sites* tab.
  - Scroll down to find your county’s contact information.

- **Wisconsin:**
  dnr.wi.gov
  - Type "health care waste" in the search box (at top).
  - Click on *Find* (light-purple box at top).
  - Find your county’s information.

If your county is not listed, you can get information about your city or county government’s household trash and recycling service by calling them at the number listed on their website or in your local phone book.

**Medicine Delivery**

Medicines provided by hospice must be from an approved Allina Health Hospice pharmacy and will be delivered to your home. Your medicines may be delivered in the evening. Call the triage nurse if you haven't received the medicine by 10 p.m.

You should always have a 1-week supply of your medicine on hand. Tell the hospice nurse case manager if your supply is getting low.
Pain Medicines

Preventing pain from starting or getting worse is the best way to control it (some people call this “staying on top of the pain”). You are encouraged to tell your caregiver or hospice nurse that you are having pain. For pain that cannot be controlled on its own there are pain medicines.

Although medicine may not take away all pain, the hospice team’s goal is to keep the patient as comfortable as possible.

Pain medicines can help when pain cannot be controlled on its own. To prevent pain from starting or becoming worse, pain relievers may be given on a regular schedule around the clock.

The most widely used prescription pain relievers have been opiates, such as morphine. Opiates are medicines that are very effective at relieving pain, but they can cause side effects.

Although not everyone has side effects from opiates, some of the more common ones include:

- drowsiness
- nausea (upset stomach)
- constipation
- vomiting
- weakness
- dizziness
- headache.

Side effects from opiate pain relievers can usually be treated and handled successfully so that pain relief is not compromised. Always talk with your pharmacist or hospice nurse about which options are best for you.
The following medicines may be able to help ease your pain:

- morphine (MsContin®, OMS®, Roxanol®)
- oxycodone (in Percodan®, Percocet®, OxyContin®)
- methadone (Dolophine®)
- hydrocodone (Vicodin®)
- hydromorphone (Dilaudid®)
- codeine
- fentanyl (Duragesic®)
- levorphanol (Levo-Dromoran®)
- oxymorphone (Numorphan®).

These pain relievers are only available with your primary care provider’s written prescription. They are given by different means such as by mouth, through the skin, rectally or by injection. Not all opiates are available in each of these forms. If the one being given is not effective, talk to your hospice nurse case manager to see if the dose should be changed or the medicine needs to be changed to another opiate.

Talk with your primary care provider, hospice nurse or pharmacist if you have any other questions about opiates or other pain relievers.
Common myths about opiate pain medicines

**MYTH:** You will experience respiratory distress (slowing of the breathing rate).

**FACT:** Respiratory distress does not occur when morphine or other opiates are started at a low dose and carefully increased as needed to reduce the pain.

**MYTH:** You will become addicted.

**FACT:** When the medicine is given regularly, a certain degree of physical dependence may occur. This is not the same as addiction. Addiction affects how your brain works and includes both physical and emotional dependence. This very rarely occurs in hospice patients.

**MYTH:** You will become tolerant of the medicine so it no longer works.

**FACT:** You can develop a tolerance, meaning you need to have a higher dose of the medicine to feel its effects. In most cases, patients with moderate to severe pain need to have a higher opiate dose because of increased pain and not tolerance to the medicine.

**MYTH:** You will get “high” or euphoric.

**FACT:** When given correctly, strong narcotics generally do not cause a “high” or the feeling of euphoria (pleasure). However, relief from pain may improve your mood.

**MYTH:** You will die a “living death.”

**FACT:** The proper use of opiates often improves your quality of life and helps to maintain your level of independence and dignity. Patients who are truly sentenced to a kind of “living death” are those who do not have enough pain medicine and must live with high levels of pain.

Contact your hospice nurse or pharmacist if you have any questions about opiates or other pain relievers.
Radiation and Chemotherapy

Radiation and chemotherapy are not usually used in hospice. In some cases, radiation and chemotherapy may help to relieve symptoms. Talk with your primary care provider and hospice team about the pros, cons and goals of these treatments. Together, you can decide if these treatments are right for you.

Pros of radiation and chemotherapy include:
- increased quality of life
- better pain control
- longer life.

Cons of radiation and chemotherapy include:
- transportation difficulties and discomfort getting in for therapy
- difficulty tolerating procedures due to weakness
- possible side effects of treatments such as nausea (upset stomach), vomiting, diarrhea or pain.

Keeping Track of Your Medicines

Use the charts on the following pages to keep track of all of the medicines you are taking. This will help you take them correctly. Your case manager will help you fill these out.
My Medicines

Use the following chart to keep track of the medicines you take with a medicine dropper or syringe. Write down the medicine name, use, start date and dose. Your case manager can help you with this.

**Medicine dropper**

<table>
<thead>
<tr>
<th>Medicine name:</th>
<th>Use for:</th>
<th>Start date:</th>
<th>Dose:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| | | | |

| 2.0 mL = ___mg |
| 1.5 mL = ___mg |
| 1.0 mL = ___mg |
| 0.5 mL = ___mg |

| | | | |

| | | | |

**Medicine syringe**

<table>
<thead>
<tr>
<th>Medicine name:</th>
<th>Use for:</th>
<th>Start date:</th>
<th>Dose:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| | | | |

| 1.0 mL = ___mg |
| 0.9 mL = ___mg |
| 0.8 mL = ___mg |
| 0.7 mL = ___mg |
| 0.6 mL = ___mg |
| 0.5 mL = ___mg |
| 0.4 mL = ___mg |
| 0.3 mL = ___mg |
| 0.2 mL = ___mg |
| 0.1 mL = ___mg |

| | | | |

| | | | |

© Allina Health System
My Medicines

How To Use This Chart

This chart will help you take all of your medicines correctly. Keep it with you at all times (including bringing it to your health care visits and pharmacy). Your case manager will help you fill out your chart. This includes:

- writing down the names of your prescriptions, over-the-counter medicines and supplements
- filling out the information for each of your medicines (including start date, why you are taking it and how to take each medicine)

<table>
<thead>
<tr>
<th>My medicine information</th>
<th>When do I take it?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Start date</strong></td>
<td><strong>Medicine name</strong></td>
</tr>
<tr>
<td>Feb. 25, 2013</td>
<td>Metformin</td>
</tr>
</tbody>
</table>

Patient name: ________________________________

Allergies: ________________________________

- placing an X in the column with the time of day you should take each medicine.

Look at the sample chart below. Use the blank chart on the other side to fill out your own.
# My Medicines

<table>
<thead>
<tr>
<th>My medicine information</th>
<th>When do I take it?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Start date</strong>&lt;br&gt;<strong>Medicine name</strong>&lt;br&gt;<strong>Why do I take it?</strong>&lt;br&gt;<strong>How much do I take?</strong>&lt;br&gt;<strong>How do I take it?</strong>&lt;br&gt;<strong>Morning</strong>&lt;br&gt;<strong>Noon</strong>&lt;br&gt;<strong>Evening</strong>&lt;br&gt;<strong>Betime</strong>&lt;br&gt;<strong>Other</strong></td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes: ____________________________________________________________________________________________________________________________
## My Medicines

<table>
<thead>
<tr>
<th>My medicine information</th>
<th>When do I take it?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Start date</td>
<td>Medicine name</td>
</tr>
<tr>
<td></td>
<td>Why do I take it?</td>
</tr>
<tr>
<td></td>
<td>How much do I take?</td>
</tr>
<tr>
<td></td>
<td>How do I take it?</td>
</tr>
<tr>
<td>Morning</td>
<td>Noon</td>
</tr>
<tr>
<td></td>
<td>Evening</td>
</tr>
<tr>
<td></td>
<td>Betime</td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>

**Notes:**

________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________
________________________________________________________________________________________________________________________

Allina Health®
HOSPICE & PALLIATIVE CARE
# My Medicines

<table>
<thead>
<tr>
<th>My medicine information</th>
<th>When do I take it?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Start date</td>
<td>Medicine name</td>
</tr>
<tr>
<td>------------</td>
<td>---------------</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes: ____________________________________________________________________________________________________________________________________________________________...
__________________________________________________________________________________________________________________________________________________________
__________________________________________________________________________________________________________________________________________________________
__________________________________________________________________________________________________________________________________________________________
__________________________________________________________________________________________________________________________________________________________

Allina Health
HOSPICE & PALLIATIVE CARE
Chapter 4: Caregivers

In This Chapter:
- What You Can Do and What Hospice Can Do
- Tips for Dealing with Caregiver Stress
- Depression
- How to Ask for Help
- Early Grief
- How Children Understand Death
- Additional Resources
- Allina Health Written Resources
Chapter 4: Caregivers

A caregiver is anyone who provides any type of physical or emotional care for a seriously ill or disabled person in the home. This type of care may include:

- helping with personal cares
- helping with meals
- giving medicines
- doing some medical procedures after being trained by the hospice team.

The role of caregiver may be new or one in which you might feel unprepared, anxious and even overwhelmed. You may have many mixed feelings including sadness, frustration and fear along with a strong desire to do whatever it takes to help the patient feel comfortable and cared for during this time of transition.

The hospice team wants to help you feel more confident in the care you provide. You are not alone! The hospice team wants to provide you with the information you need to be the best caregiver you can be.
What You Can Do and What Hospice Can Do

Hospice can help set reasonable goals and provide you with professional help when you need it most. The following are ways you can care for the patient and how the hospice team can help you.

- Help the patient with activities he or she can no longer do such as dressing, bathing, going to the bathroom, preparing food and eating. When you need more help with these activities, hospice can provide you with a hospice home health aide.

- Help the patient get to appointments, run errands, grocery shop and pick up medicine. When you need more help with these activities, hospice can provide you with a volunteer.

- Help the patient with managing finances, paying bills, putting legal affairs in order and finding resources to help him or her live safely at home. When you need more help with these activities, hospice can provide you with a social worker.

- Help the patient with emotional or spiritual support and companionship. Talk about living and dying and listen to his or her fears and concerns. Set aside time to read together. When you need help with these activities, hospice can provide you with a chaplain or social worker.

- Help the patient with issues of closure, forgiving, saying goodbye, asking for forgiveness and worrying about how the family will be after he or she dies. When you need more help with these activities, hospice can provide you with a grief counselor.
Tips for Dealing with Caregiver Stress

As the caregiver to a seriously ill person, you may at times feel overwhelmed. Remember, you are not alone. Here are some suggestions for dealing with the stress of being a caregiver.

Communicate

Talk about your concerns with a trusted friend, clergy or hospice team member. You may want to see a professional counselor who specializes in dealing with life events such as this.

Take time for activities you enjoy

Continue doing hobbies, participating in clubs or doing special projects. Consider having a friend or volunteer help you with caregiving during this time.

Say YES to people who offer help

If you do not want them in your home, ask them to do errands for you. This could include walking your dog, babysitting off-site or doing yard work.

Handle one thing at a time

Do this by dividing your tasks into smaller parts.

Set priorities

Do the things that are most important first. Then do the rest as you are able.

Solve problems like an expert

Use the following steps to help identify and create a plan to deal with problems.

- Write down the problem.
- List the pros and cons of each option you have.
- Choose the best option and create a plan.
- List the steps needed to accomplish the plan.
- Give yourself a deadline.
- Act.

Tip

No one expects you to do everything by yourself. Ask your family, friends and hospice team to help you.
Eat a small amount of healthful foods throughout the day

“Grazing” is a good approach. Be careful of comfort foods high in fat and sugar. Avoid alcohol, as it is a depressant. Depressants slow you down and prevent your body from working as it should.

Be physically active

It is a stress reliever, even if it is only a walk around the block. Being active will give you an overall feeling of well-being, and reduce feelings of depression and anxiety.

Get plenty of rest

Sleep whenever you can. You may want to ask for a volunteer to care for the patient so you can take a break to nap in your own home.

As a caregiver to a seriously ill person you may at times feel overwhelmed. Remember, you are not alone. In order to gain some control over the situation you may want to create a plan of action. Think about the following questions as you begin your plan of action.

- What activities must be done in order for the patient to be cared for and comfortable? Be specific.
- Which activities can you handle on your own and with which activities can your hospice team help you?
- Who else can you ask to help you so you can stay focused on the things important to you and the patient?
Depression

Depression, grief and guilt are natural and common feelings among caregivers as they provide daily care to patients, especially in the final stages of the illness. This may be the end of a long and difficult battle and it can be exhausting. Some caregivers may feel a loss of self-esteem when they feel they have not provided the quality of care that is expected of them. Feelings of helplessness and failure result from unrealistic expectations and trying to be all things to all people.

As the patient is in his or her last days, you may feel many types of losses (loss of friendship, companionship, and family and daily routines that provided some order in your life). This may be difficult to handle.

Remember, you are not alone. There are many ways to cope with the stress, depression and grief you feel as the patient’s illness naturally progresses.

- Be open and honest with your feelings and share them with someone (such as a family member, friend, spiritual counselor or a member of your hospice team).
- Review the goals and expectations that you set for yourself and make sure they are realistic.
- Try to accept the things that you can’t control and ask for help with the rest.

Tip

Some caregivers use this opportunity to find or build on their own personal beliefs about the meaning of life and death. They pass their wisdom and insight to the rest of their family as the generations move forward.
How to Ask for Help

Some people realize right away that the role of caregiver may be an exhausting effort and easily ask for help. The caregiver never knows for certain how long his or her role may be so it is good to ask for support sooner rather than later (before becoming physically, emotionally or spiritually drained).

Most family members, friends, neighbors, church members and professionals want to help you and the patient be as comfortable as possible but they may not know exactly what is needed or how to help. Realize that having someone do even a small task is one less thing you need to do.

Make a list of tasks with which you could use help. Make sure you are specific. Then sit down with the person or find some quiet time to speak on the telephone. Discuss what you are doing and find out with what he or she would have time to help. Specifically, talk about the things with which you think the person can help you and ask if there is something else he or she could do. Try to be as specific as you can so the person knows exactly what would be helpful to you and the patient.

Try asking like this: “Pearl, I am so busy taking care of Jim. I have no time to do everything I need to do. I could really use some help with picking up some groceries. If you can help us, we would really appreciate that. I can give you a list of what groceries we need once a week. Do you think you could help Jim and me by picking up some food?”

Tip
If you are not comfortable inviting someone into your home to help, ask the person to walk your dog, run errands or drive the patient to and from an appointment.
Early Grief

You or the patient may begin feeling the effects of loss and grief before a death actually occurs. These are normal reactions to current and future losses. Losses can include those involved with caring for someone with an illness, changes in relationship and expected loss of a loved one. This early grief may actually help you prepare for the losses and deal with the grief after the death occurs.

Causes of early grief

Some of the causes of early grief are related to fears of actual or possible losses, such as:

- loss of social life
- loss of companionship
- loss of usual eating, sleep, work and recreational habits
- loss of independence
- loss of control
  (such as being able to care for yourself or a loved one)
- fears related to life without that person
- fear of losing present family structure (such as head of the household or getting used to changing roles)
- fear of starting over
- fear of the unknown.
Signs and symptoms of early grief

It is normal to experience a specific symptom of early grief more than once or a combination of them at one time. Some of the signs and symptoms of early grief may include the following:

- feelings of guilt
- tearfulness
- constant changes in emotions
- anger
- depression
- feelings of emotional numbness
- anxiety or feelings of fear
- changes in sleeping and eating habits
- poor concentration
- forgetfulness or poor memory
- loneliness
- denial
- acceptance
- exhaustion or fatigue (feeling tired).
What you can do

There are things you can do which may be helpful for working through the early grief process.

- Go for short walk.
- Write in a journal.
- Plan for the future.
- Seek spiritual help.
- Talk to a friend or family member.
- Make changes only as needed and put off major decisions when possible.
- Do the things you want to do now, forget the chores you can do later.
- Spend time with your loved ones, friends and family.
- Seek help from your family, friends and hospice volunteers to arrange some time to spend doing things you enjoy.
- Call your hospice team if early grief feels overwhelming or you want to talk about your feelings.
- Talk to a clergy or counselor, or join a caregiver support group. For web and phone grief support services, visit allinahealth.org/griefresources or call 651-628-1752. This is not a crisis line. It is a resource about support groups, counselors and books for the community.

Important

For web and phone grief support services, visit allinahealth.org/griefresources or call 651-628-1752.
How Children Understand Death

It is important to understand a child’s emotions at each phase of development and how he or she may be affected by the death of a loved one. This will help to prepare for and manage the challenges that come along with the death and grieving.

Infants to age 2

At this age there is little understanding of what is happening. Infants and toddlers are very sensitive to the emotional environment of the home. They sense change and react to the emotions of those around them. While most often infants and toddlers cannot tell you in words what they are feeling, they may be crabbier than usual and need more holding, stroking, reassurance and calming.

It is important to provide confident and consistent reassurance for infants and toddlers. One- and two-year-olds are working toward more independence, but when they feel stress and changes in the environment, they may become more dependent, stubborn or run away.

Changes in the environment and overlooking basic needs can create a sense of mistrust in infants and toddlers. Healthy and consistent doses of love and affection will ensure their view of the world is one of trust and security.

Signs and symptoms of grief in this age group may include:

- not sleeping well
- wanting to nurse or drink from a bottle more than normal
- being crabby
- crawling rather than walking
- eating too little
- lack of interest in playing
- lack of emotions or eye contact.
Age 3 to 5

These are the ages when children are very aware of the emotional mood at home. If the normal routine is changed, children may go back to earlier behaviors such as thumb-sucking, wetting their pants or tantrums. Trying to stay on a routine can be very helpful.

Magical thinking is common with children of this age as well as a certain sense of power. Children may think they caused the death of a loved one. Reassure them that they didn’t do anything to cause the death. However, children of this age also think very concretely. They are scared by what they do not know or understand, so it is important to use real, simple language about death and grief.

Children at this age are not able to understand the permanence of death. They may believe the person who passed away will come back. It is best to continue to talk openly with children using real, simple language.

Signs and symptoms of grief in this age group may include:

- thumb-sucking or wanting a pacifier
- bedwetting or potty accidents
- not being able to sleep
- curling up in a corner
- clinging
- whining
- not being able to pay attention
- yelling
- anger
- stress from being apart.

Tip

Talk openly with children ages 3 to 5. Use real, simple language and remember that they may not understand their loved one is not coming back.
Age 6 to 9

These are the ages when children are interested in real things and are less interested in fantasy. They begin to understand that death is real and permanent.

Children’s attention spans increase. They stick more with a task and enjoy working at things. Asking them to do tasks such as drawing a picture or writing a poem or letter to place in the casket can be helpful.

This is also a social stage when children can have low self-esteem, especially if they feel different about themselves or the changes in their family. The neighborhood and school are becoming important, and family is a little less the authority.

Signs and symptoms of grief in this age group may include:

- thumb-sucking
- wetting the bed
- not being able to sleep
- withdrawal or isolation
- misbehaving
- irrational fears (fears that do not seem to “make sense”)
- obsessive-compulsive or ritualistic behaviors (repeated behaviors done to lower stress)
- psychosomatic complaints (complaining of physical pains caused by thoughts or emotions)
- tics (twitching, especially in the face)
- harmful behaviors
- eating too much or too little
- acting like the parent (needing to be mom or the “man of the house”).
Age 10 to 13

Children in their “tween” years are moving toward independence. They may feel vulnerable and feel a need to know that their parents are in charge. It can also be a time of great stress for parents as they allow their children to grow up while still feeling the need to protect them.

Since fitting in is important for preteens and teenagers, it is difficult for them to have a family that is “not normal,” which is likely how they view their situation. And since they are having a difficult time separating but still wanting and needing parenting, they may feel lost.

Children this age are beginning to understand what death and dying means. They may ask many questions about terminal illness and death.

Signs and symptoms of grief in this age group may include:

- anger or withdrawal
- poor schoolwork
- crying more than usual
- eating too much or too little
- mood swings
- spending less time with friends or not having many friends
- fears
- being caught up with fantasy
- needing to always be by a parent, relative or close friend
- psychosomatic complaints (complaining of physical pains caused by thoughts or emotions).

More Information

Turn to page 67 at the end of this chapter for Allina Health written resources about grief. Your hospice team members can get copies for you.
Age 14 to 17

This is the age when adolescents feel stress as they try to separate from their family and gain independence. Yet, they often feel all-powerful and all-knowing. They struggle between being involved in family matters and finding their independence.

Adolescents are loyal to their friends. They may turn to their friends for support even though friends may not know how to help someone who is grieving.

A sense of immorality may cause adolescents to prefer to deny the reality of death. Listening and talking openly to them can be helpful.

Signs and symptoms of grief in this age group may include:

- extreme anger or aggression
- withdrawal or isolation
- depression (feeling “down in the dumps”)
- eating too much or too little
- losing interest and energy for life
- getting poor grades and having behavioral problems in school
- spending less time with friends or not having many friends
- showing addictive, unhealthy or dangerous behaviors
- sleeping too much or too little.

Additional Resources

Allina Health Hospice & Palliative Care has additional resources available to help deal with grief and the dying process. If you would like more support, please speak with your chaplain, social worker or grief counselor.
Allina Health Written Resources

“As Death Draws Near”
This booklet offers more information on the physical, psychological, emotional, social and spiritual aspects of dying. The booklet also offers guidance about self-care for caregivers and the needs of children when a loved one is dying.

“When A Loved One Dies”
This booklet addresses the practical matters of funeral arrangements, getting copies of the death certificate and the legal and financial details about your loved one’s estate and survivor benefits.

“Ten Things to Know About Grief”
This fact sheet gives information about the common themes of death and grieving, as well as what to expect.

“Children and Grief”
This booklet goes through each childhood developmental stage and how it relates to grieving.

This booklet is intended for children ages 4 to 10. It is a helpful tool in the task of learning how to have a new relationship with the loved one who has died — a relationship that will continue and change as children grow and develop, and grieve.

These resources are available compliments of Allina Health Hospice & Palliative Care. Your hospice team members can get copies for you.

For web and phone grief support services, please contact:
Allina Health Hospice & Palliative Care
Website: allinahealth.org/griefresources
Phone: 651-628-1752
Chapter 5: Symptoms

In This Chapter:
- Anxiety, Agitation and Restlessness
- Confusion
- Constipation
- Dehydration and Thirst
- Eating Habit and Diet Changes
- Fatigue, Drowsiness and Sleep Problems
- Loss of Appetite and Weight Loss
- Nausea (Upset Stomach) and Vomiting
- Pressure Ulcers (Bedsores)
- Shortness of Breath
- Special Diet Circumstances
- Transportation by Ambulance
- Allina Health Pain Assessment Scale
Chapter 5: Symptoms

Anxiety, Agitation and Restlessness

What it is

Anxiety, agitation and restlessness is the state of uneasiness. These symptoms can be caused by emotional, physical and spiritual concerns.

The key to dealing with anxiety, agitation and restlessness is to recognize it early and report it to your hospice team. There are many ways to treat this symptom including medicines, therapies and things you can do at home.

What to expect

Anxiety, agitation and restlessness is usually not difficult to recognize, but many conditions can cause it. You can help by watching the patient's behavior and looking for a few simple things. This will help determine the most likely cause of the problem.

What to look for

Look for the following signs of anxiety, agitation and restlessness:

- **pain:**
  This includes any new pain or pain that gets worse.

- **shortness of breath:**
  Many anxious, agitated and restless people feel out of breath. This may appear as quick or labored breathing.

- **repeated behaviors:**
  This includes behaviors such as picking at clothing.

- **environmental changes:**
  This includes changes such as moving to a new home or room.

- **difficulty sleeping:**
  This includes not being able to fall asleep or stay asleep, tossing and turning or being afraid to close his or her eyes.
How to respond

Anxious, agitated and restless people often feel out of control. As a caregiver, staying calm and in control can reassure and calm the patient.

The following are some things that can help.

- **Give medicines.**
  Many medicines can help reduce the symptoms of anxiety, agitation and restlessness. Only give medicines as directed by members of the hospice team or the patient’s primary care provider.

- **Stay calm.**
  Be calm in your voice and actions.

- **Offer reassurance.**
  Let the patient know you are there to help. You can do this by calling the hospice nurse or being a good listener.

- **Offer companionship.**
  Being alone often makes anxiety worse. Try to stay with the person experiencing these feelings.

- **Use simple speech.**
  Keep your speech clear, simple, and direct. Don’t say too much at once.

- **Practice active listening.**
  Pay attention to what the patient is saying and respond with reassuring words and actions.

- **Get rid of extra noise.**
  Turn off televisions and radios while talking with the patient.

- **Turn on some music.**
  Play music the patient enjoys (when you aren’t trying to have a conversation).

- **Open up the room.**
  Opening up curtains or a window may be helpful.

- **Go for a walk.**
  If the person is restless and needs to move around, go for a walk with him or her around the house and then bring the patient back to bed.
Available support

The following people are here to help you:

■ hospice team:
The hospice team has a lot to offer, especially when it comes to preventing anxiety, agitation and restlessness.
  — The hospice team can help you determine some of the factors that are causing the patient’s agitation and come up with a plan to deal with them. They will also encourage you to use the proper medicines and will make sure the nurse is notified right away.
  — The social worker can help the patient and family discuss concerns about the living situation or finances. Sometimes these issues weigh heavily on the patient and can lead to anxiety, agitation and restlessness.
  — The chaplain and social worker are available to discuss the emotional and spiritual issues that come with a terminal illness. Family issues or concerns for the future may be part of the anxiety. Both the chaplain and social worker are available to talk with you and the patient about relaxation skills which can help prevent anxiety.

■ hospice nurse:
You can expect your hospice nurse or triage nurse to:
  — check and treat the patient for possible causes of anxiety, agitation and restlessness
  — make referrals as needed.

When to call hospice

Anxiety, agitation and restlessness are common symptoms at end of life. Tell the hospice nurse if:

■ the anxiety, agitation and restlessness is new or gets worse
■ medicine is given but not effective after 1 hour
■ the patient is at risk for injury from falling because of anxiety, agitation and restlessness
■ you cannot keep the patient from leaving his or her home.
You are not alone. The hospice nurse is available 24 hours a day, 7 days per week. Please do not hesitate to call with any of your concerns for the patient.

Anxiety, agitation and restlessness can almost always be made better by things you can do at home. The key to preventing serious problems is to call your hospice nurse as soon as symptoms appear. Your hospice team wants you to feel confident with the care you provide.

Notes

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
Confusion

**What it is**

Confusion prevents the patient from thinking clearly or at his or her usual speed. The patient may feel disoriented and have difficulty paying attention, remembering and making decisions.

Being confused is often a reaction to a situation, not a sign of mental illness in itself. The patient may feel confused if he or she is not sleeping enough or adjusting to a new environment. Some medicines can also cause confusion.

**What to expect**

Confusion may come on quickly or slowly over time, depending on the cause. If the patient already has memory loss, dementia or Alzheimer’s disease, he or she may develop confusion with even a small stress, such as an infection.

Confusion in the last days of life is common. Chemical changes in the brain occur when organs begin to fail. These chemical changes can cause altered perception (not being fully aware of what’s happening around you). The patient may have visions and conversations with people whom family and caregivers are not able to see. He or she may also talk about going home, going on a trip or being “ready.”

**What to look for**

Watch the patient’s behavior and thought patterns. If you notice a change, talk with your hospice team.
How to respond

Most confused individuals feel upset because they cannot put together all of the information in their head. You can help by being calm and letting them know where they are and that everything will be OK.

The following are some things that can help.

- **Offer companionship.**
  Touch the person and sit with him or her.

- **Use simple speech.**
  Keep your speech clear, simple and direct. Don’t say too much at once.

- **Get rid of extra noise.**
  Turn off televisions and radios while talking with the patient.

- **Practice active listening.**
  Pay attention to what the patient is saying and respond with reassuring words and actions.

- **Turn on some music.**
  Play music that you know the patient enjoys (when you aren’t trying to have a conversation).

- **Be alert.**
  Look for signs that the patient is trying to get out of bed and walk around.

- **Go for a walk.**
  If the person is restless and needs to move around, go for a walk with him or her around the house and then return the patient to bed.

Available support

The following people are here to help you:

- **hospice team:**
  The hospice team is experienced in helping families with the problem of confusion. They can help you:
  - sort out some of the factors that are causing the confusion
  - deal with your own reactions
  - come up with a plan to deal with the confusion
  - bring the symptoms to the nurse’s attention.
**hospice nurse:**
The hospice nurse will try to determine the causes and find the best treatment for the problem. The nurse will:
- assess and treat for possible causes of confusion and make referrals as needed
- talk with you about the possible causes of the confusion
- check the patient for signs of infection or taking too much medicine
- review medicines
- recommend specific treatment.

**When to call hospice**

Be sure to tell the daytime hospice nurse or the after-hours triage nurse if:
- the patient begins to feel confused or if the patient is more confused than before
- the patient is at risk for injury from falling caused by confusion
- you cannot keep the patient from leaving his or her home
- you feel unsafe in any way.

You are not alone. The hospice nurse is available 24 hours a day, 7 days per week. Please do not hesitate to call with any of your concerns for the patient.

Symptoms of confusion can almost always be made better by things you can do at home. The key to preventing serious problems is to call your hospice nurse as soon as symptoms appear. Your hospice team wants you to feel confident with the care you provide.

**Notes**

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
**Constipation**

**What it is**

Constipation means that a person has three or fewer bowel movements in a week. The stool can be hard and dry. It is usually painful to pass.

Here are some important facts about constipation.

- More than half of the stool (the bowel movement) comes from sources within the body, not from food. A person with a poor appetite should still have bowel movements.
- There is no “correct” number of bowel movements someone should have each day or week. In general, bowels should move about every 2 days.
- Liquid stool can be a sign of constipation. The liquid can move around an area of hard stool.
- If constipation goes on for a long time, the bowel muscles get weak and the person may have difficulty sensing that they are constipated.

**What to expect**

Constipation is almost always a concern for patients. It is a real concern for the hospice team too. Your hospice team will help you stay on top of the problem and make sure you feel confident as you care for the patient.

There are many factors that can lead to constipation. This includes:

- pain killers (which slow the bowels down)
- decreased appetite
- decreased activity.

Some factors can be treated, while others cannot. With the right treatment plan, it should always be possible to return to a regular pattern of bowel movements.
What to look for

Look for the following signs of constipation:
- hard stool (difficult to pass)
- liquid stool (can move around an area of hard stool)
- stomach cramps or bloating
- loss of appetite
- feeling full or uncomfortable in the abdominal area
- no bowel movements for 3 days.

How to respond

It is possible to prevent constipation. The following lists some things you can do to help prevent constipation.

- **Offer fluids.**
  Make sure the patient drinks plenty of fluids.

- **Encourage activity.**
  Being active (especially walking) will help with regular bowel movements.

- **Use laxatives.**
  Your hospice nurse can tell you how much to take and how often to take laxatives.

Available support

The following people are here to help you:

- **hospice team:**
  Your visiting hospice team knows that constipation is a serious problem. They will encourage you to take the medicines that are prescribed and contact the nurse for questions.

- **hospice nurse:**
  Your hospice nurse will likely bring up the subject of constipation before it is a problem. This way, you can begin taking medicines to prevent it. If the patient is constipated, the nurse may:
  - check for signs and symptoms of constipation
  - review medicines
  - prescribe a laxative or increase the dose of laxatives currently being used
  - do a rectal exam to check for hard stool.
The most common medicine for constipation is senna (Senokot®, Senokot-S®, Senna-Plus®, Smooth Moves® herbal tea and others). Senna goes to the nerves in the bowel that are dulled by pain killers and wakes them up. Senna is always started along with pain killers and should be taken every day while the patient is taking pain killers. Colace, fiber and over-the-counter laxatives do not take the place of senna.

**When to call hospice**

Call the hospice nurse right away if the patient has:

- abdominal pain, stomach cramps or vomiting that doesn’t go away
- a temperature of 101 F or higher
- not had a bowel movement for more than 3 to 5 days.

You are not alone. The hospice nurse is available 24 hours a day, 7 days per week. Please do not hesitate to call with any of your concerns for the patient.

Symptoms of constipation can almost always be made better by things you can do at home. The key to preventing serious problems is to call your hospice nurse as soon as symptoms appear. Your hospice team wants you to feel confident with the care you provide.

**Notes**
Dehydration and Thirst

What it is

Dehydration and thirst are different. It is helpful to understand the difference between the two. Dehydration means that the body is low on water. Thirst is the feeling that you want to drink water. There are many ways to treat this symptom.

What to expect

Thirst is a common symptom and one that can be easily treated. Patients will usually drink liquids until thirst is relieved. For some, a dry mouth produces thirst. This is typically relieved by giving liquids but many patients will want to drink just enough to moisten their mouth and no more. Even a few drops of liquid or ice chips can relieve thirst.

It is common in the final days or weeks of life for the person to become dehydrated because patients are not drinking as much as they usually do. Dehydration itself usually doesn’t show symptoms except the patient will produce less urine.

What to look for

Look for the following signs of dehydration and thirst:
- complaints of thirst
- complaints of dry mouth
- dry skin (may be a sign of dehydration but can occur for other reasons as well).

How to respond

The following are ways you can help reduce symptoms of dehydration and thirst.
- **Offer sips of liquid.**
- **Swab the patient’s mouth.**
  Wipe the inside of the patient’s mouth using a swab moistened with water.
- **Offer ice chips.**
  Try using ice chips, hard candies or sugarless chewing gum. Each of these help produce saliva.
Apply lip balm to the patient's lips.

Ask your hospice nurse about artificial saliva. This must be prescribed.

There are times when IV fluids are appropriate but this can also easily overload the system, producing gurgling in the lungs or causing stomach cramps. Moisten the patient’s mouth and offer whatever fluid he or she wants. If this relieves the feeling of thirst, it is the right amount of fluid to give.

Available support

The following people are here to help you:

- **hospice team:**
  Please do not hesitate to voice your concerns. The hospice team will want to help you with any questions you may have about thirst, dehydration, IV’s or other concerns. The staff will help you get comfortable with simple mouth cares. They will also make sure that the nurse knows about the patient’s symptoms.

- **hospice nurse:**
  A nursing assessment will help to understand and treat the symptom. The nurse will:
  - check vital signs
  - complete an exam, paying close attention to the mouth and skin
  - ask you about urine production over the last few days
  - ask about other sources of fluid loss such as loose stools or vomiting
  - talk with you about pros and cons of treating thirst and dehydration.

When to call hospice

Call the hospice nurse right away if the patient has:

- a sudden change in his or her ability to swallow, or take fluids or medicines
- vomiting or loose stools for more than 24 hours
- a low level of alertness.

You are not alone. The hospice nurse is available 24 hours a day, 7 days per week. Please do not hesitate to call with any of your concerns for the patient.
Symptoms of dehydration and thirst can almost always be made better by things you can do at home. The key to preventing serious problems is to call your hospice nurse as soon as symptoms appear. Your hospice team wants you to feel confident with the care you provide.

Notes

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Eating Habit and Diet Changes

When a person enters hospice, the goal of nutrition therapy shifts from a certain nutritional plan to providing comfort. A feeding schedule may no longer be appropriate and can take away from patient comfort. This can be a difficult transition for many families and caregivers.

It is natural for hospice patients to change their diets, eating habits and even the foods they like. While each patient’s situation is unique, there are some common themes about nutrition in hospice.

Decrease in appetite

This is very common among hospice patients. Most patients will notice a decreased appetite and will usually feel better if they have smaller amounts of food and liquids. Small meals cause less stress on body systems and can help to prevent or reduce feelings of nausea (upset stomach) and bloating.

Narrowing of food choices

Many patients will gradually narrow their food choices to a few foods that are well-tolerated. Some patients may find liquids easier to tolerate than solid foods. This is normal and should be encouraged as it provides comfort. Liquid supplements such as Ensure®, Boost® and Carnation® Breakfast Essentials™ can be used as meal replacements.

Starvation

Many families and caregivers are concerned that patients will “starve to death” if they are not able to take in enough food. True starvation is the denial of food to a body that can use nutrients. In a terminal illness, the body is not able to use nutrients as it normally would. It is important to remember that the illness is responsible for the patient’s appetite and it is not starvation. Eating more will not help the patient feel better or improve his or her condition. Remembering this can help the patient, family and caregiver cope better with this difficult situation.
**Important**

Appetite stimulants should not be taken if eating more food causes nausea (upset stomach), bloating or discomfort.

**Appetite stimulants**

An appetite stimulant is a prescription drug or herbal product the patient can take to increase his or her appetite. The goal of using an appetite stimulant is to help the patient be more comfortable. It may also help the patient enjoy his or her food more. It should not be expected that taking an appetite stimulant will improve the patient’s illness or that he or she will gain weight.

**Faster metabolism and weight loss**

Advanced cancer and AIDS (acquired immunodeficiency syndrome) can cause a patient’s metabolism to speed up. The patient will not be able to maintain or put on weight even if feeding is increased.

Weight loss occurs in at least 80 percent of patients with advanced illness and is due to the illness, not poor nutrition. Many patients feel that they fail if they don’t gain weight. It is important to remember that weight loss is a result of the illness, not a failure on the part of the patient.

**Notes**

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Fatigue, Drowsiness and Sleep Problems

What it is

Fatigue is a feeling of weariness, tiredness or lack of energy. Drowsiness refers to feeling more sleepy than usual during the day. Sleep problems are very common and can be caused by either too much or too little sleep.

What to expect

Loss of sleep (insomnia) can be caused by pain or nausea (upset stomach), from the side effects of medicines or from worrying. Sometimes it is a lifelong problem that gets worse with the stress of illness. Sleeping too much may be the result of medicine side effects or from the progress of the illness itself.

What to look for

Look for the following things that could be preventing the patient from sleeping as he or she normally does:

- **poorly-controlled pain:**
  This includes any new pain or pain that gets worse.

- **anxiety:**
  This could appear as restlessness (changing positions frequently), general feelings of nervousness, or being afraid to close his or her eyes.

- **caffeine:**
  Coffee, tea and soda have caffeine. Even decaffeinated coffee has caffeine. It has one-fourth the amount of caffeine of regular coffee.

- **stimulating medicines:**
  This includes decongestants, Prozac®, Prednisone and others.
How to respond

The following tips may help you to get better sleep.

- **Give medicines.**
  Many medicines can help reduce the symptoms of fatigue and drowsiness. Only give medicine as directed by hospice team members.

- **Offer warm, non-caffeinated drinks.**
  Serve these drinks in the evening. Milk has natural chemicals that help sleep.

- **Avoid bright lights.**
  Bright lights can turn off normal sleep hormones in the body. Try to only use dim lighting for several hours before the patient goes to bed.

- **Offer to give the patient a massage.**
  Massage the patient’s hands and feet before he or she goes to bed. This can help the patient to relax.

Available support

The following people are here to help you:

- **hospice team:**
  The hospice team will encourage you to use the appropriate medicines and alternative methods. They can talk with you about relaxation techniques that could be used early in the evening to help the patient feel calmer at bedtime.

- **hospice nurse:**
  The nurse will assess the patient and make changes in the medicines as needed. He or she will also:
  — assess and treat the patient for possible causes of fatigue and drowsiness
  — make referrals as needed
  — review medicines.
When to call hospice

Call the hospice nurse if the patient is not able to sleep during the night.

You are not alone. The hospice nurse is available 24 hours a day, 7 days per week. Please do not hesitate to call with any of your concerns for the patient.

Fatigue and drowsiness can almost always be made better by things you can do at home. The key to preventing serious problems is to call your hospice nurse as soon as symptoms appear. Your hospice team wants you to feel confident with the care you provide.

Notes

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Loss of Appetite and Weight Loss

What it is

Loss of appetite is a common symptom. Many people fear that it is a kind of starvation that makes death more likely. Research has shown that weight loss that occurs as part of a serious illness is very different from weight loss due to starvation. Hospice patients often do not want to eat.

What to expect

In cancer, advanced heart disease, chronic obstructive pulmonary disease (COPD) and other serious illnesses, there is a change in body chemistry. The change may cause:

- a loss of appetite
- weight loss from muscles and fat stores
- the body to have a difficult time using the energy from food in a useful way.

Forcing food into the body (through a feeding tube or IV) does not correct the problem in the body. Trying to give extra calories often causes the patient to have nausea (upset stomach).

What to look for

The answers to the following questions will help your nurse to find out what is causing the patient to lose weight.

- Is the weight actually falling? What does the patient weigh?
- Is it specific foods or all foods that are the problem?
- When was the last normal bowel movement?
- Have any new medicines been started recently?
- Are there ulcer symptoms such as burning, abdominal pain or a history of ulcers?
- Are abdominal pain and vomiting the main reasons for the weight loss or is it mostly loss of appetite?
How to respond

The following are things you can try that may help the patient’s loss of appetite and weight loss.

- **Avoid serving red meat.**
  Serve eggs or fish instead to provide protein.

- **Serve small portions.**
  Smaller portions are more appealing than large ones.

- **Offer cold drinks.**
  You can try offering a cold nutrition shake. This will provide extra calories for the patient.

- **Serve citrus fruit.**
  Try giving the patient lemon or orange slices.

- **Treat constipation.**
  Stool softeners and laxatives can help to control constipation. Talk with your hospice nurse if you have questions or concerns about constipation.

Available support

The following people are here to help you:

- **hospice team:**
  The hospice team wants to discuss your concerns and questions about nutrition. If different members of the family have different opinions about eating, the team can help your family discuss it. A plan of care will be developed according to the needs of the patient.

- **hospice nurse:**
  The hospice nurse can assess the situation and make recommendations. The nurse may:
  - measure weight loss with a scale or by measuring around the bicep with a tape measure
  - review medicines with the pharmacist or medical director to see if they might be the problem
  - suggest other foods to try
  - help relieve pain, medicine effects or constipation that are causing the patient’s loss of appetite
  - call in medicines as needed.
When to call hospice

Loss of appetite and weight loss is not usually an urgent need. Talk with your nurse case manager about loss of appetite and weight loss.

You are not alone. The hospice nurse is available 24 hours a day, 7 days per week. Please do not hesitate to call with any of your concerns for the patient.

Loss of appetite and weight loss can almost always be made better by things you can do at home. The key to preventing serious problems is to call your hospice nurse as soon as symptoms appear. Your hospice team wants you to feel confident with the care you provide.

Notes

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
Nausea (Upset Stomach) and Vomiting

What it is

Nausea (upset stomach) is the feeling that you want to throw up or vomit. It is a symptom that gets in the way of enjoying daily life. By controlling nausea, you improve the quality of both waking and sleeping hours.

What to expect

Nausea has many causes, but you can do something about the most common ones. Nausea and vomiting can almost always be made better by things you can do at home.

Pain medicines like morphine can cause nausea. The good news is that the patient's body adjusts to the nausea from pain medicines after 1 or 2 weeks. Starting at low doses and increasing the dose gradually can often help. Your hospice nurse may also recommend medicine that works well for this kind of nausea.

What to look for

The answers to the following questions will help your nurse to find out what is causing the nausea and vomiting.

- Did the nausea seem to start after a change in medicine?
- Does it come and go or does the patient always feel nauseated (upset stomach)?
- Does the patient have stomach cramps or diarrhea?
- If there is vomiting, does it come after a period of nausea or does the vomiting happen suddenly, with little warning?
- Does the patient have any stomach pain or heartburn?
- When was the last normal bowel movement?
- Does the patient get a little hungry but then feel nauseated after a few bites?
How to respond

The following are things you can try that may help to relieve the patient's nausea.

- **Give medicine.**
  Give nausea medicines as prescribed. Some medicine can be given rectally with a suppository if needed.

- **Offer clear, cold, flat liquids.**
  Offer clear, cold liquids without fizz such as ginger ale, apple juice, peppermint tea and Popsicles®.

- **Offer sour-tasting foods and beverages.**
  Sour foods and beverages (such as lemons) may help to relieve nausea.

- **Practice deep breathing with the patient.**
  Have the patient take slow, deep breaths.

- **Offer to give the patient a massage.**
  Hand and foot massages may help to relieve nausea symptoms.

Available support

The following people are here to help you:

- **hospice team:**
  The non-nursing hospice team wants to discuss any questions or concerns you might have about nausea and vomiting. They will encourage you to use treatments listed and any medicines that may be helpful. They will also make sure the nurse knows about the symptoms.

- **hospice nurse:**
  Nausea has many causes. The nurse will assess the patient to determine the most likely causes of his or her nausea. The nurse will:
  
  — want to know answers to the questions in “what to look for”
  
  — look for signs of infection, anything blocking the bowels and side effects from drugs
  
  — ask about the patient's bowels
  
  — talk with the patient’s primary care provider if needed
  
  — help you understand the treatments available.
When to call hospice

Call hospice if the patient starts feeling nauseated, begins vomiting or if he or she has the following symptoms:

- vomiting blood (other than just a few streaks of red)
- sudden pain, nausea or vomiting
- tarry stools (stools that are dark red or black in color)
- foul-smelling vomit.

Remember, you are not alone. The hospice nurse is available 24 hours a day, 7 days per week. Please do not hesitate to call with any of your concerns for the patient.

Nausea and vomiting can almost always be made better by things you can do at home. The key to preventing serious problems is to call your hospice nurse as soon as symptoms appear. Your hospice team wants you to feel confident with the care you provide.

Notes

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________
Pressure Ulcers (Bedsores)

What it is

A pressure ulcer (or bedsore) is a skin injury caused by sitting or lying in the same position too long or by sliding down in a bed or chair. Sores usually form over the bony parts of the body that press against a mattress, chair or other body part. These areas include the ankle, heel, knee, tailbone, hip, elbow, shoulder or back of the head.

What to expect

Hospice patients have a higher risk of getting pressure ulcers because their skin is weaker due to:

- age:
  The skin loses its thick padding with time.

- illness:
  Increased pressure on bony parts of the body during bed rest causes the skin to break down easily. It takes longer for the injury to heal because of illness.

Pressure ulcers are much easier to prevent than they are to treat. A pressure ulcer can appear after only a few hours of unrelieved pressure, but it may take months to heal.

There are four stages of pressure ulcers:

- **stage one**: reddened skin
- **stage two**: open skin surface
- **stages three and four**: deep layers of skin are affected.

When patients are within days or weeks of dying, the skin may break down easily. New ulcers may form and there may be several of them. The first goal of treatment in this situation is to make sure the patient is comfortable. The hospice team will work with you and the patient to decide whether more medicine, turning or both is needed.

What to look for

Look for the following early signs of pressure ulcers to prevent them from developing:

- areas of redness that do not go away
- open areas of skin
- pain on pressure points.
How to respond

The key to treating most pressure ulcers is prevention. If ulcers do occur, early treatment with the help of the hospice team gives the best chance of healing them.

Early treatment can help stage one ulcers heal quickly. At the first sign of an ulcer you should do the following.

- **Change the patient’s position often.**
  - If the patient is in a wheelchair, have him or her change sitting positions every 30 minutes.
  - If the patient is in a bed, change his or her position from one side to the other every 2 hours during the day and every 4 hours during the night.

- **Avoid sheet wrinkles.**
  Keep the bottom sheets smooth and tight to avoid wrinkles.

- **Elevate the patient’s bed.**
  Be careful not to raise the head of the bed more than 30 degrees.

- **Lift the patient.**
  Lift the patient to move him or her higher up in bed. Never pull the patient across the sheet.

- **Be careful when moving the patient.**
  This will help to protect the areas of pressure on the patient’s body.

Available support

The following people are here to help you:

- **hospice team**
  Pressure ulcers are usually a sign that the person’s care needs are increasing. The hospice team can help caregivers come up with a plan and look for outside help when it is needed.

- **hospice nurse:**
  The hospice nurse may:
  - examine the affected skin
  - look at the bed, sheets and patient’s body position to understand how the pressure ulcers started
  - recommend a special cushion to lie over the mattress, such as a Geo-Mat™
  - begin treating the pressure ulcer.
When to call hospice

Usually, pressure ulcers are not an emergency, but you should call your hospice nurse any time you think an ulcer is starting. Treatments should be started the same day and usually involve turning the patient more often. Signs of more serious problems will require the nurse to be in contact with the hospice primary care provider. These signs may include:

- a foul-smelling odor from the ulcer
- a temperature of 101 F or higher
- two or more ulcers showing up within a few days of each other or at the same time
- increased pain from a pressure ulcer.

Remember, you are not alone. The hospice nurse is available 24 hours a day, 7 days per week. Please do not hesitate to call with any of your concerns for the patient.

Pressure ulcers can almost always be made better by things you can do at home. The key to preventing serious problems is to call your hospice nurse as soon as symptoms appear. Your hospice team wants you to feel confident with the care you provide.

Notes

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________
Shortness of Breath

What it is

Shortness of breath usually involves the feeling of difficult breathing or not getting enough air.

What to expect

Shortness of breath can be just as troubling as pain. Most people will tell you if they are short of breath but if you are unsure, just ask. Sometimes shortness of breath builds up slowly and the patient becomes less active to avoid feeling short of breath.

What to look for

Look for the following signs of shortness of breath:

- **shortened speech:**
  The patient is not able to speak more than a few words at a time.

- **coughing or wheezing:**
  A new cough or wheeze or an increase in coughing or wheezing.

- **mucus:**
  The patient coughs up mucus (also called sputum or phlegm).

- **bluish-colored skin:**
  The patient may have a bluish color to his or her lips or fingertips.

- **feeling anxious:**
  This could appear as restlessness (changing positions frequently) or general feelings of nervousness.
How to respond

There are many things you can do to relieve shortness of breath.

- **Stay calm.**
  This will help the patient relax.

- **Give oxygen.**
  If the patient has oxygen, make sure it is turned on and hooked up correctly. The tubing should not be kinked or blocked.

- **Give medicine.**
  Many medicines can help reduce the symptoms of shortness of breath. Only give medicine as directed by a hospice team member.

- **Help the patient sit up in bed.**
  If he or she feels better sitting up at the side of the bed but is tired, place a pillow on the bedside table. The patient can lean forward and rest his or her arms on the pillow.

- **Make sure the patient's room has good air movement.**
  Turn on a gentle fan and aim it toward the patient’s face or run the air conditioner on hot days.

- **Open up the room.**
  Open up curtains or a window during nice weather.

- **Give nebulizer treatments.**
  If nebulizer treatments are prescribed, make sure to use them.

Available support

The following people are here to help you:

- **hospice team:**
  The non-nursing hospice team can help you move the patient and will encourage you to use the medicines prescribed. They will also make sure the nurse knows about the symptoms.

- **hospice nurse:**
  The hospice nurse will:
  
  - assess and treat the patient for possible causes of shortness of breath
  - make referrals as needed
  - have an open discussion with you and the patient about possible goals of treatment and the pros and cons.
When to call hospice

You will need to call the hospice nurse if:

- there is any significant change in the patient’s breathing
- medicine is given but not effective after 1 hour.

Remember, you are not alone. The hospice nurse is available 24 hours a day, 7 days per week. Please do not hesitate to call with any of your concerns for the patient.

Symptoms of shortness of breath can almost always be made better by things you can do at home. The key to preventing serious problems is to call your hospice nurse as soon as symptoms appear. Your hospice team wants you to feel confident with the care you provide.

Notes

____________________________________________________
____________________________________________________
____________________________________________________
____________________________________________________
____________________________________________________
____________________________________________________
Special Diet Circumstances

Diabetes

Patients with diabetes need special care if they are taking medicine to control their blood sugar. The goal is to prevent symptoms of too high or low blood sugar. This usually means keeping the patient’s blood glucose between 100 to 200 mg/dL. Hypoglycemia (low blood sugar) is more of a concern than hyperglycemia (high blood sugar) and diabetes medicines often have to be decreased or stopped.

Try to encourage the patient to eat any foods that appeal to him or her in reasonable amounts. It is not necessary to limit the patient to the foods on a certain nutrition plan.

Dementia

Most patients with dementia will gradually eat less, need softer foods and do well consuming very small amounts of food. Patients in the end stages of dementia do not need large amounts of food.

Tube feeding

Patients on tube feedings should have their feedings checked to make sure they are not being given too much formula. The right amount of formula should promote comfort. Most patients will feel better with smaller amounts of feeding as death nears. Tube feedings can be stopped, skipped or decreased as needed for convenience or comfort.

Total parenteral nutrition (TPN)

Total parenteral nutrition (TPN) is a way of giving patients all of the nutrients their bodies need through an IV instead of through food. It is used when patients are not able to eat.

There is no evidence that TPN is beneficial for patients or improves their quality of life during cancer therapy. For patients on TPN, the goal is to prevent or minimize complications.

The most common complication of TPN is giving the patient too much fluid. Decreasing the amount of fluid may help him or her to be more comfortable.
Amyotrophic lateral sclerosis (ALS)

Many patients with amyotrophic lateral sclerosis (ALS) are encouraged to start tube feedings early in the illness. This is because the muscles used to swallow may be some of the first affected. Eating and drinking may become difficult.

As ALS progresses, the following may help patients be more comfortable:

- **patients who are on tube feedings:**
  - The amount of formula and free water can be gradually decreased.

- **patients who are not on tube feedings:**
  - The amount of softer foods can be gradually decreased.

It is important to watch carefully for any signs of the patient having too much food or liquid during the last stages of ALS. Both can cause breathing problems for the patient.

Notes

____________________________________________________
____________________________________________________
____________________________________________________
____________________________________________________
____________________________________________________
____________________________________________________

Transportation by Ambulance

Did You Know?

Respite care gives caregivers a break from their responsibilities of caring for the patient. This gives the caregiver a chance to rest and take care of himself or herself.

Payment for transportation to and from the hospital will be provided to current hospice patients who have:

- been admitted for acute hospice care
- a terminal illness
- been pre-approved by hospice.

Costs of transportation to and from clinic appointments, emergency rooms visits, treatment or respite care stays are the responsibility of the patient.
Allina Health Pain Assessment Scale

Your hospice team will use the following tool to help measure your symptoms.

### Allina Health Pain Scale (0 to 10)

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td><strong>Worst Possible Pain</strong>&lt;br&gt;unbearable&lt;br&gt;crushing&lt;br&gt;devastating&lt;br&gt;excruciating</td>
</tr>
<tr>
<td>8-9</td>
<td><strong>Very Severe Pain</strong>&lt;br&gt;dreadful&lt;br&gt;overwhelming&lt;br&gt;horrible&lt;br&gt;agonizing</td>
</tr>
<tr>
<td>6-7</td>
<td><strong>Severe Pain</strong>&lt;br&gt;miserable&lt;br&gt;gnawing&lt;br&gt;fierce&lt;br&gt;piercing</td>
</tr>
<tr>
<td>4-5</td>
<td><strong>Moderate Pain</strong>&lt;br&gt;aggravating&lt;br&gt;grueling&lt;br&gt;upsetting&lt;br&gt;frustrating</td>
</tr>
<tr>
<td>1-3</td>
<td><strong>Mild Pain</strong>&lt;br&gt;bothersome&lt;br&gt;annoying&lt;br&gt;irritating&lt;br&gt;nagging</td>
</tr>
<tr>
<td>0</td>
<td><strong>No Pain</strong></td>
</tr>
</tbody>
</table>

© Allina Health System
Chapter 6:
Last Days of Life

In This Chapter:
- Signs and Symptoms
- Providing Comfort
Chapter 6: Last Days of Life

The last days of life can be extremely emotional and overwhelming. This may be the time to call in all of your support. Be sure to let family know that if they want to visit or say anything to their loved one, now is the time. It is difficult to say exactly when someone will die but there are a few common signs and symptoms that may help you to know when the patient’s last days of life are here.

Signs and Symptoms

Not all signs and symptoms happen at the same time and some never happen at all. Every death is as unique as the person who is experiencing it. However, the following symptoms are a normal part of the dying process.

Food

As the patient approaches death he or she often experiences a decrease in the desire for food or fluids. Some may even refuse both. The patient may only take a few sips of liquid to moisten his or her mouth and lips for comfort. When the body is shutting down, it does not need nourishment and can no longer use the food or fluids properly. "Feel good" chemicals (endorphins) are released to help the patient be more comfortable.

Skin color

The skin may become cool to the touch and color may change in the feet, legs, hands and arms because of slowed circulation. You may notice “mottling” (a bluish color with purplish splotches) on the feet or knees.

Fatigue

You may begin to notice extreme fatigue, drowsiness and more time sleeping during the day and night. This is a natural part of the dying process.
Confusion

The patient may begin to show signs of restlessness and confusion about the time of day and date. He or she may also have a difficult time recognizing people. As the patient’s body and organs begin to stop working, he or she may become restless.

Common behaviors caused by restlessness include:

- pulling at sheets or clothes
- talking to family members or friends who are already dead
- insisting on going somewhere.

Try to encourage the patient to talk about his or her experiences and feelings. Take time to explain things that are confusing and keep him or her comfortable.

Breath patterns

You may begin to notice irregular breathing patterns. A long pause between breaths (called apnea) is normal.

Rattling breath sounds

A rattle noise from the throat is common and caused by saliva collecting at the back of the throat. Being so weak makes it difficult to swallow saliva. This happens when there is a decrease in circulation and organ function.

Changing the patient’s position might help but do not be alarmed if it does not help. Try turning the patient on his or her side to keep the saliva from building up in the throat. Your hospice nurse can start some medicine that can reduce the amount of saliva made but it is not always possible to clear this up completely. It is expected and a normal part of the dying process.
**Pain**

At the end of life, the patient may not be able to tell you how he or she feels. The common signs of discomfort are:

- moaning when moved
- frowning
- grimacing
- rubbing certain areas of the body
- restlessness
- pulling at dressings or tubes
- agitation
- confusion.

Don’t be afraid to ask if he or she “hurts” on a regular basis.

Pain can be impacted by many things such as emotional or spiritual distress. Talking with a social worker, a spiritual counselor, listening to music or gentle touch may benefit the patient, along with regularly-scheduled medicines.

You and your hospice nurse can help manage the patient’s pain and symptoms that cause discomfort. Let your nurse know if you have noticed any increase in discomfort. The goal is to help you relieve suffering and make sure the patient is as comfortable as possible.
Providing Comfort

The patient may not be able to communicate with you about what he or she needs in the final days of life. Here are some suggestions that will help you keep him or her feeling comfortable and loved.

Communication

Everyone working with the patient should let him or her know what is being done and why. Talk softly and in a calm manner. If the patient cannot respond there is no need to speak loudly. There is no better time than now to say what you want or need to say. Let him or her know who is in the room, who is visiting and when.

Environment

It is important to try to create a space that is calm and pleasing. Bring in the patient’s favorite blanket, piece of furniture, photos of family and friends or play some calming music in the background.

Temperature

Keep the patient as dry and as clean as possible. He or she may be either very hot and sweaty or very cold, especially in the final days. The body is no longer able to control body temperature. Add or take away blankets as desired. Avoid electric blankets or hot pads as they may be on too long and burn. Some people do not like the weight of pajamas or blankets on their body. You can adjust the amount and weight of clothes to the patient’s comfort.

Private time

Consider giving the patient some private time. Let him or her know when you will be going into the next room and when you will return. Even 5 to 10 minutes of private time is welcome. Take this time to relax or pamper yourself as well.

Please remember that you are not alone. The entire hospice team has experts who will help you to create a plan of care to follow during this time. Your nurse case manager will coordinate your team to meet your needs. Please let the hospice team know what you need.
Chapter 7:
At Time of Death

In This Chapter:
- What You Need to Do
- What Happens Next
- Worksheet: At Time of Death Information
Chapter 7: At Time of Death

It is important that you take the time you need to grieve your loss. When you feel ready, make calls to family and friends to tell them of the death. This chapter explains the things you will need to know at this time.

What You Need to Do

When you are ready, you will need to do the following things.

- Note the time that you either observed or discovered he or she stopped breathing.
- Call hospice to tell of the death within 1 hour. Please call 651-635-9173 or 1-800-261-0879. Hospice will have a number of questions about the last 24 hours. When you call, you will be asked to give the following information:
  - time of death
  - location of patient
    (hospital bed, own bed, living room)
  - what he or she was wearing
  - who was present
  - last medicines (name, dose, time)
  - any fall with fractures in the last 6 months
  - funeral home information
    (name, location and phone number).

This information is reported to the coroner and is needed to release your loved one's body for funeral arrangements.
What Happens Next

You can expect the following after you tell hospice of the death.

- Hospice notifies the county coroner and gives the coroner the information on the previous page along with the funeral home information.
- Your loved one will be pre-registered with the county coroner if there has not been any fall with injury in the last 6 months. Some counties require your primary care provider to sign the pre-registration as well. If your loved one is not registered, the coroner may decide to send out the police to complete the process. The triage nurse will tell you if this needs to happen.
- Your loved one’s body is released to the funeral home.
- The funeral home will contact you about coming to pick up your loved one’s body. You can decide when you want them to come. You can have them come as soon as possible or you can tell them you need some time and call them when you are ready. Take the time you need to have family members, friends and clergy say their goodbyes and offer you support.
- The funeral home will set up an appointment at another time to meet with you at their office to finish making arrangements. Funeral home staff are very good at telling you everything you will need to know to finish the funeral arrangements.
At Time of Death Information

The following information will help you be more prepared at the time of death. Fill out the information below and keep it in a safe place.

Date of death: ____/____/_______  Time of death: ____:____ a.m. / p.m.

Whom to notify at time of death

Hospice team member: ______________________ Phone: ____ - ____ - ________

Legal next of kin: _________________________ Phone: ____ - ____ - ________

Family/friend: ____________________________ Phone: ____ - ____ - ________

Family/friend: ____________________________ Phone: ____ - ____ - ________

Family/friend: ____________________________ Phone: ____ - ____ - ________

Family/friend: ____________________________ Phone: ____ - ____ - ________

Family/friend: ____________________________ Phone: ____ - ____ - ________

Funeral home arrangements

Funeral home: __________________________________________________________

Phone: ____ - ____ - ________

Address: ______________________________________________________________

Notes: __________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Chapter 8: Documents

In This Chapter:

- Health Care Directives
- Provider Orders for Life-Sustaining Treatment (POLST)
- Combined Minnesota and Federal Hospice Bill of Rights
- Section 504 Grievance Procedure
- Your Privacy
- Notice of Privacy Practices
Chapter 8: Documents

Health Care Directives

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. 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 health care provider 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 a health care provider 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.
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 and dated
- 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
- include the appointment of an agent to make health care decisions for you and 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.

I prepared 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.

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 and preferences 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 medicines
- 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 your 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 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 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.

How to Get More Information

If you want more information about health care directives, please contact your health care provider, your attorney, or:

Minnesota Board on Aging’s Senior LinkAge Line®: call 1-800-333-2433 or visit mnaging.org
Provider Orders for Life-Sustaining Treatment (POLST)

What is POLST?

POLST stands for Provider Orders for Life-Sustaining Treatment. Your health care provider uses POLST to write medical orders indicating your health care wishes.

Who should have a POLST?

If you have a serious health condition, you may need to make advance decisions about life-sustaining treatment. Your provider can use the POLST form to document your wishes in a very clear, specific written medical order.

If I have a POLST form, do I need an advance directive?

An advance directive is recommended even if you have a POLST form. An advance directive will list your health care agent and describe your values and goals as they relate to your health care wishes. You can obtain information about advance directives from your provider, your health insurance provider or online at POLST.org.

Who completes and signs the POLST?

The form must be signed by a provider for it to be followed by other health care professionals. Health care professionals who work with our provider can complete this form.

Where is the POLST used?

The POLST remains with you if you are transferred between care settings regardless of whether you are in the hospital, at home or in a long-term care facility. If you live at home, keep the original yellow POLST form on the refrigerator where emergency responders can find it. If you live in a nursing home, the POLST will be kept in your chart.

Does the law require a POLST?

The POLST form is voluntary and is intended to:

- help you and your provider discuss and develop plans to reflect your wishes
- assist physicians, nurses, health care facilities and emergency personnel to honor and carry out your wishes for life-sustaining treatment.
What if my loved one can no longer communicate wishes for care?

Family members may be able to speak on behalf of their loved one. A physician or nurse can complete the POLST based on family members’ understanding of their loved one’s wishes.

To find out more information about POLST, call the Allina Health Care Navigation Help Desk at 651-635-9173 or 1-800-261-0879.
Combined Minnesota and Federal Hospice Bill of Rights

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 limitation on those services.

(7) Know in advance of receiving care whether the hospice 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 in 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 documents 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, or creates an abusive or unsafe work environment for the individual providing hospice

(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

(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 complaint.

(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 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
(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 YOUR HOSPICE, 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 or 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: 651-201-5797

Office Address:
Minnesota Department of Health
Office of Health Facility Complaints
85 E. Seventh Place
St. Paul, Minnesota 55164-0970

Ombudsman for Long-Term Care
651-431-2555 or 1-800-657-3591
Fax: 651-431-7452

Mailing Address:
Office of Ombudsman for Long-Term Care
P.O. Box 64971
St. Paul, Minnesota 55164-0971
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.

Information from:
Minnesota Department of Health
12/19/2008
Section 504 Grievance Procedure

Allina Health Hospice & Palliative Care has adopted an internal grievance procedure providing for prompt and equitable resolution of complaints alleging any action prohibited by the U.S. Department of Health and Human Services regulations (45 C.F.R. Part 84), implementing Section 504 of the Rehabilitation Act of 1973 as amended (29 U.S.C. 794). Section 504 states, in part, that “no otherwise qualified disabled individual...shall solely by reason of his/ her disability, be excluded from participation in, be denied the benefits of, or be subject to discrimination under any program or activity receiving Federal financial assistance...” The law and regulation may be examined in the office of Gayle Mattson, 1055 Westgate Drive Suite 100, St. Paul, MN 55114 who has been designated to coordinate the efforts of Allina Health Hospice & Palliative Care to comply with the regulations.

1. A complaint should be in writing, contain the name and address of the person filing it, and briefly describe the discriminatory act.

2. A complaint should be filed in the office of the Section 504 coordinator within 30 days after the person filing the complaint becomes aware of the alleged discriminatory act.

3. The Administrator, or designee, will investigate the complaint. The investigation will be informal but thorough, affording all interested persons and their representatives an opportunity to submit evidence relevant to the complaint.

4. The Administrator shall issue a written decision determining the validity of the complaint no later than 30 days after its filing.

5. The Section 504 coordinator shall maintain the files and records relating to all complaints filed. The Section 504 coordinator may assist persons with the preparation and filing of complaints, participate in the investigation of complaints, and advise the Administrator concerning their resolution.

6. An individual who files a complaint may pursue other remedies. This includes filing with Department of Health and Human Services, Office for Civil Rights.
These rules shall be liberally construed to protect the substantial rights of interested persons to meet appropriate due process standards and assure Allina Health Hospice & Palliative Care compliance with Section 504 and the regulations.

Section 504 Notice of program accessibility

Allina Health Hospice & Palliative Care and all of its programs and activities are accessible to and useable by disabled persons, including person with impaired hearing and vision. Access features include:

- convenient off-street parking designated specifically for disabled persons
- curb cuts and ramps between parking areas and buildings
- level access into first floor level with elevator access to all other floors
- fully accessible offices, meeting rooms, bathrooms, public waiting areas, cafeteria, patient treatment areas, including examining rooms and patient wards
- a full-range of assistive and communication aids provided to persons with impaired hearing, vision, speech, or manual skills, without additional charge for such aids. Some of these aids include:
  - qualified sign language interpreters for the deaf
  - a 24-hour telecommunication device for the deaf, which can connect the caller to all extensions within the facility and/or portable (TTY/TDD) units for use by hearing or speech impaired patient/clients,
  - readers and taped materials for the blind and large print materials for the visually impaired
  - flash cards, alphabet boards and other communication boards
  - assistive devices for persons with impaired manual skills.

If you require any of the aids listed above, please let the Allina Health Hospice & Palliative Care receptionist or a clinical staff member know.
Your Privacy

As we care for your health, we learn about you. Some of what we learn becomes part of your medical record and billing records. To protect your privacy, our organization follows certain rules about handling your health information. These rules and your health information rights are summarized on this page. The attached Notice of Privacy Practices (notices) provides more detail about these rules.

How we use and disclose your health information

We use your health information to treat you, to facilitate payment for services, to inform you of helpful services and to meet government requirements. We may share this information with people involved in your care. We may also share limited information for fundraising and to conduct research to better serve you. And we may disclose information to law enforcement and certain government offices if there is a threat to public health or safety.

See the enclosed notice for a complete list of ways we use and disclose health care information.

Your health information rights

We fully support your rights to manage your health information. A summary of these rights appears below and the attached notice reviews these rights in more detail.

1) In general, you can see your health information upon request.

2) You can request restrictions on who can see your health information.

3) You can request corrections to your health information.

4) You can request a list of certain disclosures we have made of your health information.

5) We must get your written permission to share health information for purposes other than those summarized in the section above. If you give us permission, you may withdraw it at any time.
6) You may ask questions about our privacy practices. If you disagree with any decision we make about your rights, you may contact us directly or contact the federal government, as provided in the attached document.

You may call or write us at any time with questions about your privacy rights. Please write to us at the address listed on page 84. Fulfilling some requests may result in a cost to you. We will let you know in advance which of these requests will be charged and the approximate amount of the charges.

We are pleased you have chosen us as your health care provider and we are committed to protecting your health information.
Notice of Privacy Practices

Our Health Information Responsibilities

- We have a duty to protect the privacy of your health information and to give you this Notice.
- We have a duty to follow our current Notice of Privacy Practices.

“Health information” means information about your past or present health status, condition, diagnosis, treatment, prognosis, or payment for health care. (There are some exceptions.)

Who Will Follow this Notice

This notice describes Allina Health’s practices and that of:

- all departments and units of Allina Health Providers
- all residents, medical students and other trainees affiliated with Allina Health
- all volunteers who may assist you while you receive services at Allina Health and
- all employees, staff and other Allina Health workers.

Your Health Information Rights

Restrictions on Use or Disclosure. This Notice describes some restrictions on how we can use and disclose your health information. You may ask us for extra limits on how we use or to whom we disclose the information. You need to make such a request in writing. If you request that information about a service not be sent to your insurer and pay for the service in full we will agree to this restriction. We are not required to agree to other requests. If we do agree, we will follow the restriction except:

- in an emergency where the information is needed for your treatment
- if you give us written permission to use or disclose your information
- if you decide or we decide to end the restriction, or
- as otherwise required by law.

If you restrict us from providing information to your insurer, you also need to explain how you will pay for your treatments and you will be responsible for arranging for payment of the bills.
Alternative Communication. Normally, we will communicate with you at the address and phone number you give us. You may ask us to communicate with you in other ways or at another location. We will agree to your request if it is reasonable.

Patient Access. You may request to look at or get copies of your health information. If you request a copy of your electronic health record or other health information we keep electronically we will provide it in an electronic format upon your request. You need to make your request in writing. If you ask for copies, we may charge photocopying fees, the cost of making copies of x-rays or other images, and postage if the copies are mailed. If you ask for another format we can provide, we may charge a reasonable fee based on our costs.

If your request is denied, we will send the denial in writing. This will include the reason and describe any rights you may have to a review of the denial.

Amendment. You may ask us to change certain health information. You need to make such a request in writing. You must explain why the information should be changed. If we accept your change, we will try to inform prior recipients (including people you list in writing) of the change. We will include the changes in future releases of your health information. If your request is denied, we will send the denial in writing. This denial will include the reason and describe any steps you may take in response.

Disclosure List. You may receive a list of disclosures of your health information – with some exceptions – made by us or our business associates. The list does not include:

- disclosures made for treatment, payment or health care operations (this term is defined in the next section)
- disclosures made before April 14, 2003, and
- other disclosures as allowed by law.

You need to make your request in writing. If you ask for a list more than once in a 12-month period, we may charge you a fee for each extra list. You may withdraw or change your request to reduce or eliminate the charge.

Paper Copy of Notice. You may receive a paper copy of our current Notice of Privacy Practices.
Uses and Disclosures of Health Information

To provide you the best quality care, we need to use and disclose health information. We safeguard your health information whenever we use or disclose it. We follow our notice of privacy practices and the law when we use and disclose health information. We may use and disclose your health information as follows:

Treatment, Payment and Health Care Operations. We may use and disclose your health information for:

- treatment (includes working with another provider)
- payment (such as billing for services provided), and
- our health care operations. These are non-treatment and non-payment activities that let us run our business or provide services. These include quality assessment and improvement, care management, reviewing the competence or qualifications of health professionals, and conducting training programs.

Medical Emergency. We may use or disclose your health information to help you in a medical emergency.

Appointment Reminders and Treatment Alternatives. We may send you appointment reminders, or tell you about treatments and health-related benefits or services that you may find helpful.

Patient Information Directory. We may disclose the following information to people who ask about you by name:

- location in the facility
- general condition
- religious affiliation (given only to clergy).

You may choose not to have us disclose some or all of this information. For example, if you do not want us to tell people your location, we will agree to your instructions. (In some cases, such as medical emergencies, we may not get your instructions until you can communicate with us.)

People Involved in Your Care. We may disclose limited health information to people involved in your care (for example, a family member or emergency contact) or to help plan your care. If you do not want this information given out, you can request that it not be shared. If appropriate, we may allow another person to pick up your prescriptions, medical supplies or X-rays.
Foundations/Fundraising. We may contact you or have our foundations contact you about fundraising programs and events. We will use or disclose only your name, how to contact you, demographic information, the dates we served you and other limited information about your care and services you received and the dates we served you. We may disclose this information to companies that help us with our fundraising programs. You have the right to opt out of fundraising communications.

Research. We may use or share your health information for research purposes as allowed by law or if you have given permission.

Death; Organ Donation. We may disclose certain health information about a deceased person to the next of kin. We may also disclose this information to a funeral director, coroner, medical examiner, law enforcement official or organ donation agency.

Health Care Workplace Medical Surveillance/Injury/Illness. If your employer is a health care provider, we may share health information required by state or federal law:

- for workplace medical surveillance activities, or
- about work-related illness or injury.

Law Enforcement. We may disclose certain health information to law enforcement. This could be:

- about a missing child, or
- when there may have been a crime at the facility, or
- when there is a serious threat to the health or safety of another person or people.

Correctional Facility. We may disclose the health information of an inmate or other person in custody to law enforcement or a correctional institution.

Abuse, Neglect or Threat. We may disclose health information to the proper authorities about possible abuse or neglect of a child or a vulnerable adult. If there is a serious threat to a person’s health or safety, we may disclose information to the person or to law enforcement.

Food and Drug Administration (FDA) Regulation. We may disclose health information to entities regulated by the FDA to measure the quality, safety and effectiveness of their products.
Military Authorities/National Security. We may disclose health information to authorized people from the U.S. military, foreign military and U.S. national security or protective services.

Public Health Risks. We may disclose health information about you for public health purposes, such as:
- reporting and controlling disease (such as cancer or tuberculosis), injury or disability
- reporting vital events such as births and deaths
- reporting adverse events or surveillance related to food, medications or problems with health products
- notifying persons of recalls, repairs or replacements of products they may be using, or
- notifying a person who may have been exposed to a disease or may be at risk for catching or spreading a disease or condition.

Health Oversight Activities. We may disclose health information to government, licensing, auditing and accrediting agencies for actions allowed or required by law.

Required by Other Laws. We may use or disclose health information as required by other laws. For example:
- we may disclose health information to the U.S. Department of Health and Human Services during an investigation.
- we may disclose health information under workers’ compensation or similar laws.
- we may disclose health information:
  - to social services and other agencies or people allowed to receive information about certain injuries or health conditions for social service, health or law enforcement reasons
  - about an unemancipated minor or a person who has a legal guardian or conservator regarding a pending abortion
  - about an emancipated minor or a minor receiving confidential services to prevent a serious threat to the health of the minor.

Notice. We are required to promptly notify you of a breach to your health information.
Legal Process. We may disclose health information in response to a state or federal court order, legal orders, subpoenas or other legal documents.

Health Records under State Law. Release of health records (such as medical charts or X-rays) by licensed Minnesota providers usually requires the signed permission of a patient or the patient’s legal representative. Exceptions include you having a medical emergency, you seeing a related provider for current treatment, and other releases required or allowed by law.

With Your Authorization

Your Authorization. We may use or disclose health information only with your written permission, except as described above. If you give written permission, you may withdraw it at any time by notifying us in writing. A form to revoke your permission is available from the Allina Health facility where you received services, or by contacting us. Your permission will end when we receive the signed form or when we have acted on your request.

Questions and Complaints

If you have questions about our privacy practices, please contact us:

For release of information questions (re: copy fees and release of records) contact 612-262-2300.

If you think your privacy rights have been violated, or if you disagree with a decision about any of your rights, you may file a complaint with us by contacting 612-262-4900 or submit your complaint in writing and mail to the following address:

Allina Health
P.O. Box 43
Minneapolis, MN 55440-0043

You also may send a written complaint to the U.S. Department of Health and Human Services – Office of Civil Rights (OCR). We will give you the address to file a complaint upon request. Please know you will not be penalized for filing a complaint.

If you have any questions or concerns about our privacy practices and specifically this notice please contact Health Information Management at 612-863-3664.
Organizations Covered by this Notice

This Notice applies to the privacy practices of the Allina Health providers and facilities listed below, and their related sites. These businesses are part of an organized health care system. We may share health information within our system for treatment, payment or health care operations.

Abbott Northwestern Hospital
Abbott Northwestern – WestHealth
Allina Health Home Care Services
Allina Health Emergency Medical Services
Allina Health clinics
Allina Health Pharmacy
Allina Medical Clinic
Allina Health Laboratory
Minneapolis Cardiology Associates
Buffalo Hospital
Cambridge Medical Center
Cardiovascular Surgeons of St. Paul
Courage Kenny Rehabilitation Institute
Crosby Cardiovascular Services
Mercy Hospital
Metro Cardiology
Metropolitan Heart & Vascular Institute
New Ulm Medical Center
Owatonna Hospital
Phillips Eye Institute
Quello Clinic, Ltd.
St. Francis Regional Medical Center
Southwest Surgical Center
United Heart & Vascular
United Hospital
United Neurosurgical Associates
United OB GYN Associates
Unity Hospital

River Falls Area Hospital, also part of the organized health care system, uses a different Notice because it is located in Wisconsin.

This Notice takes effect April 14, 2003. It will remain in effect until we replace it. We may change the terms of this Notice and make the new terms applicable for all health information we have. This includes health information we created or received before we made the changes to our Notice. We will make any revised Notice available in hard copy and display it in our facilities and on our web site. Also, you can request the revised Notice in person or by mail.