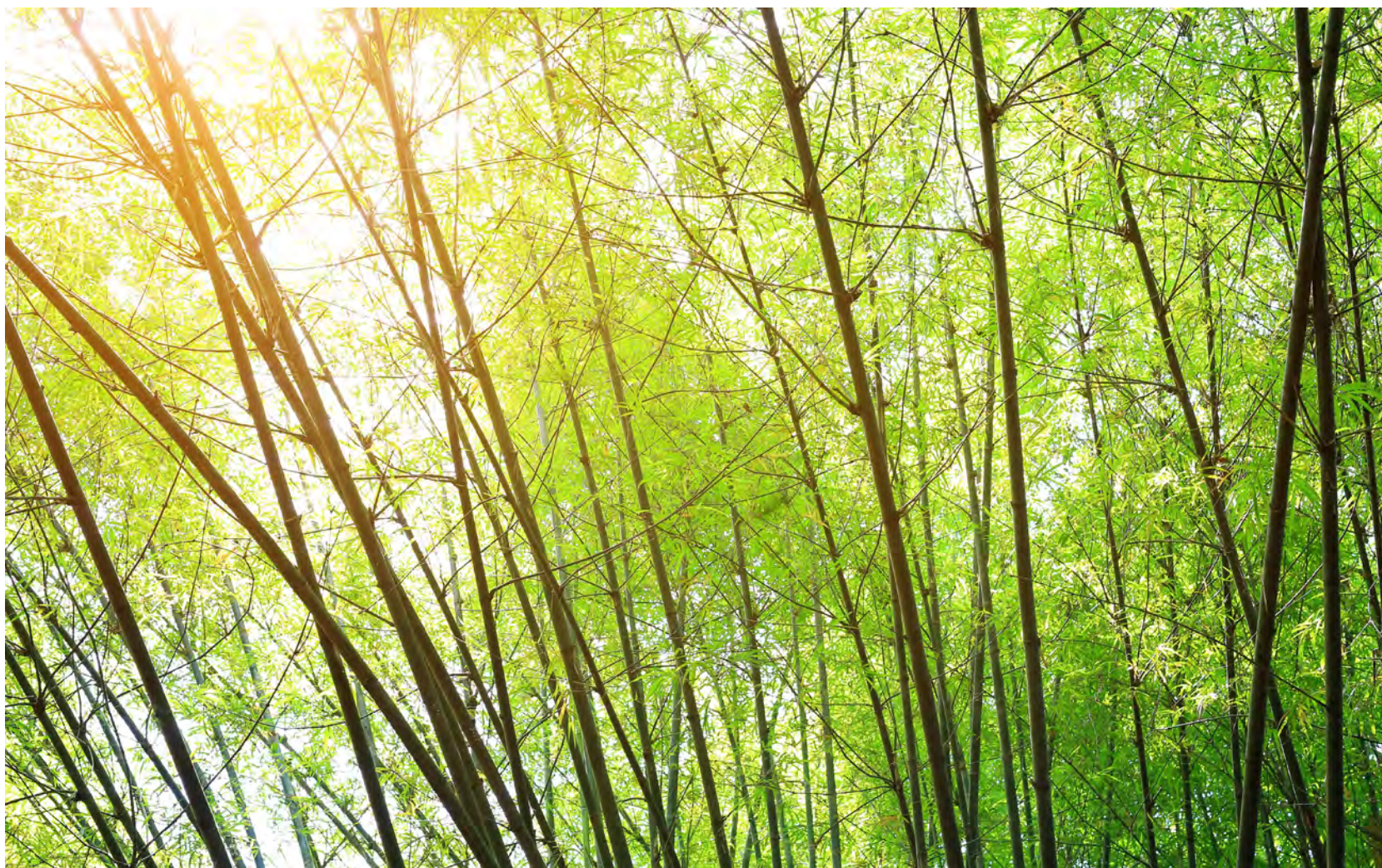


Allina Health Hospice

Information for You and Your Caregiver



To contact hospice anytime, call:

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

How to Reach Allina Health Hospice

A nurse is available anytime at 651-635-9173 if you have a question or need help right away.

The nurse has access to your complete chart and will try to help over the phone. If the issue cannot be resolved, an on-call nurse can make a home visit. Once the issue has been resolved, a message will be sent to your nurse case manager about what happened.

Allina Health Hospice

Information for You and Your Caregiver

Second edition

Developed by Allina Health.

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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rapidly changing state of scientific and medical knowledge, some of the facts and recommendations in the manual may be out-of-date by the time you read it.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.

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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.



Please keep this by your phone at all times.

Your Hospice Team

Nurse(s): _____

Home health aide(s): _____

Social worker(s): _____

Chaplain(s): _____

Volunteer(s): _____

Others visiting: _____

Primary care provider: _____

Phone number: _____ - _____ - _____

The name of your preferred hospital is: _____

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Chapter 1:

Welcome to Hospice

In This Chapter:

- Hospice Team
- Family Conference
- Worksheet: Plan of Care

Chapter 1: Welcome to Hospice

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

Hospice is a special way of caring for someone with a terminal illness and his or her caregiver. It cares for the whole person — body, mind and spirit. Hospice focuses on comfort and having the highest quality of life possible (known as comfort care).

Hospice keeps you comfortable and not suffering while “nature takes its course.” Only medicines and actions to make you 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 you choose to try treatments for reasons other than symptom control, you may stop hospice at any time.

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

Hospice Team

You and your caregiver are assigned to a hospice team. The names of your team members are written on page 3. Certain team members are assigned to provide care for you. This helps to build relationships between you and your caregiver, and the hospice team. You may see other team members if your assigned team member needs to take time off from work.

The hospice team provides comfort care in your home when possible. Your team may include:

- nurses
- a social worker
- a home health aide
- a chaplain
- your primary care provider
- a nurse practitioner (NP)
- a pharmacist
- volunteers (and a volunteer coordinator).

Grief counselors, therapists and dietitians may also be a part of this team if needed.

Nurses

The nurses check your health status, help with medical needs, treat and monitor your physical symptoms, and help your caregiver properly care for you. Nurses are available by phone 24 hours a day, 7 days a week and make home visits as needed.

The five types of nurses include:

■ **a nurse case manager:**

This nurse is your director of care. This person is a registered nurse (RN), and may also be a certified hospice and palliative care specialist.

■ **a licensed practical nurse (LPN)**

This nurse makes home visits and can make changes to your medicines if needed (and approved by your primary care provider).

Important

The term "hospice nurse" will be used throughout this book and may refer to any of the five types of nurses.

- **a triage nurse:**

This nurse helps the nurse case manager and answers the hospice phone line 24 hours a day, 7 days a week.

- **a visit nurse:**

This nurse helps the nurse case manager by doing home visits when the nurse case manager or LPN is not able to do them.

- **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 nurse case manager will tell you if continuous care is needed.

Social worker

Social work services are available to you and your caregiver. Services may include:

- counseling
- financial and legal information (power of attorney, Family and Medical Leave Act, money management, Social Security application)
- resources (discharge planning, community resources, children's support resources, advocacy).

Home health aide

Home health aides are trained and certified to help your caregiver with personal cares for you in your home. They are available to help you with personal hygiene matters such as:

- bathing
- shaving
- dressing changes
- linen changes
- household services to keep your living space safe and clean.

Home health aide services are supervised by the nurse case manager.

Chaplain

Spiritual care is available for you and your caregiver, and is tailored to your personal and spiritual points of view (regardless of your faith, religion or cultural background).

The chaplain can provide spiritual and emotional support by listening to your life stories and experiences, and talking about any spiritual concerns you may have. The chaplain also provides guidance and explores the role of spirituality in illness, suffering and healing. Together, the chaplain and your spiritual leader make sure you are getting the best spiritual care possible.

Primary care provider

Your primary care provider approves your admission to hospice. He or she continues to manage your medical needs and concerns while you are in hospice.

In addition to your primary care provider, your team will also include a:

■ doctor:

A doctor who meets weekly with your hospice team to give medical information and advice. Hospice will work with your caregiver and make sure your primary care provider knows how things are going at home.

■ medical director:

A doctor who is available to your primary care provider and hospice team for medical information and advice.

Nurse practitioner (NP)

The nurse practitioner is a registered nurse (RN) with advanced training. He or she will do an assessment after 6 months (during a recertification visit) to determine if hospice care is still needed. The nurse practitioner will talk with you and your hospice team to determine the best plan of care for you.

Tip

Turn to the end of chapter 3 to fill out the *My Medicines* charts. These will help you keep track of the medicines you are taking.

Did You Know?

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 your hospice team.

Pharmacist

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

Volunteers

Volunteers help you in many ways. They are available to:

- drive you to and from medical appointments
- give your caregiver a break
- provide companionship and emotional support
- do light housework
- prepare meals.

A volunteer coordinator on your hospice team will call you or your caregiver to talk about how a volunteer can help. The volunteer coordinators put a lot of effort toward matching your needs with the skills and interests of the volunteer. Some volunteers have special skills in massage therapy, healing touch therapy, music therapy and hair care.

Therapist(s)

You may also have therapies available to you such as physical therapy, music therapy, massage therapy and nutrition therapy. These therapies are used to help treat symptoms and increase comfort. Ask your nurse case manager if these therapies are available to you.

Grief support services and resources

Grief support services and resources are available for 13 months after death. Some of the resources include:

- lists of books
- information about local support groups
- grief counselors
- phone counselors
- volunteer grief support visitors
- referrals to community-based resources.

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

Family Conference

A family conference is a chance for you and your family to meet with your hospice team to talk about your comfort and care. You can request this at any time. A family conference is a good time to bring up any concerns, questions or specific needs you have. Together, you will create a plan of care that is right for you.

A family conference may include:

- talking about your needs (body, mind, spirit)
- developing a plan of care
- reviewing physical status, symptoms and symptom management
- discussing how volunteers and the entire hospice team can support you and your family.

You may also receive education materials and additional support during the conference.

Plan of Care

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

Hospice team member	Number of visits each week	Day and time of visits	Reason for visits
Nurse case manager Name: _____		Day: _____ Time: __:__ a.m. / p.m.	
Social worker Name: _____		Day: _____ Time: __:__ a.m. / p.m.	
Home health aide Name: _____		Day: _____ Time: __:__ a.m. / p.m.	
Chaplain Name: _____		Day: _____ Time: __:__ a.m. / p.m.	
Primary care provider Name: _____		Day: _____ Time: __:__ a.m. / p.m.	
Volunteer coordinator Name: _____		Day: _____ Time: __:__ a.m. / p.m.	
Volunteer(s) Name: _____ Name: _____		Day: _____ Time: __:__ a.m. / p.m. Day: _____ Time: __:__ a.m. / p.m.	
Other team member(s) Name: _____ Name: _____		Day: _____ Time: __:__ a.m. / p.m. Day: _____ Time: __:__ a.m. / p.m.	



Chapter 2: Safety

In This Chapter:

- Smoking
- Pets
- Firearms
- Oxygen Safety
- Medical and Self-help Equipment
- Home Safety
- Preventing Falls
- Emergency Planning
- Infection Control

Chapter 2: Safety

Smoking

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

Pets

Please have all household pets secured away during home visits. This will keep your pet and members of your hospice team safe.

Firearms

All firearms must be in a safe location during home visits. Please make sure to do this before members of your hospice team arrive.

Oxygen Safety

Important

If you choose to smoke with your oxygen on, your hospice team will not stay in your home for their own safety.

- Oxygen is not flammable. It will not start on fire by itself. When it mixes with flammable materials, it will help them burn hotter and faster.
- Oxygen will be in the air around you. Keep all flammable materials away from your oxygen concentrator.
- Do not use your oxygen around open flames, matches, stoves, barbecues or space heaters.
- If you smoke, you must be off oxygen for 15 minutes before smoking. It takes that long for the oxygen to leave your clothing, hair and skin.
- Stay at least 8 feet away from someone who is smoking.
- Keep the oxygen unit away from oil, grease or aerosol sprays.
- Be careful around anything that creates a spark (hair dryer, electric razor, kitchen appliances).

- Do not:
 - leave the oxygen concentrator on while you are not using it
 - leave the cannula in your bed or under furniture cushions.
Doing so could cause a fire if there is a spark or flame.
- Hang the “no smoking sign” (given to you by the person who set up your system) on the outside of the main entrance to your home or apartment unit.
- Never use petroleum-based products (petroleum jelly, diaper rash cream) in and around your nose. Mixing these with oxygen may cause burns. Instead, use water-based products and gels (lubricants).
- Do not use or store oxygen in an area without air flow such as a closet.

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
- waterproof pads for bed or chair
- adult underwear protection products
- cotton sleepwear.

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

Home Safety

Your safety and independence at home may be a concern. 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 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 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. 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.
- Do not wear loose-fitting, backless slippers or ones without covered toes.
- Wear an emergency alert system around your neck to make sure 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 nonskid 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 nurse about getting a bedside commode.
- Consider bath benches and shower curtains instead of shower doors.
- Use nonslip 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, nonslip tread on the hand rail to give yourself a warning that you are at the last step.
- Apply a nonslip 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 nonslip 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.
- Do not rush to the phone or door. Tell family and friends the phone may ring 10 or more times
- Do not pull 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.

Medicines, alcohol and balance

- Certain medicines (including tranquilizers, heart medicines, blood pressure medicines and mood-altering medicines) 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 interactions when taking more than one medicine (including over-the-counter medicines or alcohol).

Emergency Planning

Important

Disasters can strike quickly and without warning. You may be forced to leave your home or neighborhood. Learn how to protect yourself and cope with disasters by planning ahead. Even if you have physical limitations, you can still prepare yourself.

Work with your family to plan for an emergency before it happens.

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

- **Prepare a fire escape plan.**
Be familiar with more than one escape route.
- **Change the batteries in fire and carbon monoxide alarms every year.**
Consider changing them on a holiday such as New Year's Day to help you remember.
- **Keep a list of emergency numbers by each phone.**
Be sure to include the phone numbers for your:
 - health care provider
 - emergency contact
 - pharmacy
 - utility company
 - oxygen supplier.

Consider using preset buttons for emergency numbers on phones with automatic dialing.

Important

Hospice assigns an emergency code level to each person receiving care. You will be assigned to one of the following levels:

■ **High:**

Someone who requires uninterrupted services in case of a disaster or emergency. Great effort will be made to visit someone at this level within 24 hours.

■ **Moderate:**

Someone whose symptoms are managed and services may be replaced with a phone call. The caregiver is available to provide basic care for and assure the safety of someone at this level. The next visit may be delayed for 48 to 72 hours.

■ **Low:**

Someone whose symptoms are managed and he or she has others who can provide care. The visit can be safely missed.

Visit ready.gov for more information about emergency codes.

■ **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. Talk with your social worker or primary care provider for more information.

■ **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 have oxygen equipment in your home.

■ **Keep the phone close.**

Arrange the bedside with a phone, flashlight and extra batteries within reach. Carry a portable phone with you if you have one.

■ **Pay attention to changing weather conditions.**

Plan for help from family and friends before storms occur.

■ **If you need electricity to provide power for an important device in your home (oxygen concentrator, ventilator, suction machine), ask your utility company to place your home on a priority list for electricity.**

■ **Make sure you know how to access your backup oxygen tanks in case electricity is not restored quickly.**

■ **Keep at least a 3-day supply of your medicines at all times.**

The three steps to being prepared

1. **Create (or buy) a kit of basic items** you would need for 3 days.
2. **Make a plan** of what you will do, when you will do it, and who will help and support you. If it helps, you can write it down and share it with members of your family.
3. **Be well-informed.** Know how information about emergencies is communicated by authorities. Also be sure you know how you will communicate with members of your family and how they should communicate with you.

Infection Control

You are at a higher risk for infections because your body's natural defense against illness is 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, put a walnut-sized amount into your hand and rub until dry before touching anything.

Chapter 3:

Medicines

In This Chapter:

- Medicine Safety
- Medicine Waste
- Medicine Delivery
- Pain Medicines
- Radiation and Chemotherapy
- Keeping Track of Your Medicines
- Worksheet: My Medicines

Chapter 3: Medicines

Tip

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

Keeping track of your medicines and knowing how and when to take them is important to your health. Take time to learn about your medicines. Make sure to talk with your nurse, primary care provider or pharmacist to get the information you need.

Use the *My Medicines* charts at the end of this chapter to keep track of your medicines (prescription, over-the-counter, herbals, vitamins or other supplements). Ask your case manager if you need another copy.

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 beverages may react badly with medicines. Talk with your nurse about foods to avoid while taking certain medicines.
- Keep medicines in their original containers (unless your nurse wants to set up your pills in a pill box each day to help you).
- Do not mix alcohol and medicine. The effects of mixing alcohol and medicine vary with the medicine and the person taking it.
- Ask your pharmacist or 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 does not look like what you usually take, ask why. It might be a generic or the wrong medicine.

- **Read the label.**

Read the label every time and follow the instructions carefully.

- **Take as directed.**

Do not chew, crush or break any capsules or tablets unless your nurse or pharmacist says it is safe.

- **Take with water.**

Always take your medicine with 6 to 8 ounces of water, unless your nurse or pharmacist tells you other instructions.

- **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. Turn to the next page for more information about how to get rid of your medicines safely.

Ask your nurse or nurse case manager the following questions to make sure you understand your medicines.

- What is the name of the medicine? (Know both the generic and brand names of your medicine. For example, 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 protects the environment and 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/residents

— Type “medicines” in the search box.

— Click on *Medicine, Prescription Drugs, Needles and Sharps* from search results.

— Scroll down to find your county under Recycling & Disposal Information.

■ Wisconsin:

dnr.wi.gov

— Type “health care waste” in the search box.

— Click on the light-purple *Find* box.

— Scroll down to find take-back programs in your county.

You can also get information about your city or county government's household trash and recycling service by calling them at the number listed on their website.

Did You Know?

Many retail pharmacies offer drop-off containers for medicines.



Source: Minnesota Pollution Control Agency

Scratch off personal information but leave safety information on the bottle.



Source: Minnesota Pollution Control Agency

Add a small amount of vinegar to solid medicines to dissolve most of the medicine.

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 does not offer a take-back program and there are not any instructions on your medicine container.

How to prepare your medicine container for throwing it in the trash

Read the safety information on your medicine container and follow any special instructions.

If there are not any special instructions, take the following steps to prepare your medicine container for throwing it in the trash.

- Scratch off your name, your health care provider's name and the prescription number on the medicine label. You can also 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 medicine.
- Keep the medicine in its original container.

How to prepare your medicine for throwing it in the trash

- **Solid medicines such as pills tablets:**
Add a small amount of vinegar to dissolve most of the medicine.
- **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.



Source: Minnesota Pollution Control Agency

Put your taped medicine container in another container you cannot see through such as an empty yogurt container.

How to seal and disguise your medicine container to throw it away

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

Activated charcoal pouch

Another option for getting rid of your medicines is an activated charcoal pouch. Your health care provider may give you one or you may buy one at some pharmacies.

How it works

- Place your unwanted medicines (pills, patches, liquids) in the pouch.
- Add warm water to the pouch and seal it. The activated charcoal lining will dissolve the medicines.
- Throw the pouch in the trash (not the recycling bin).

Talk with your health care provider if you have questions about the activated charcoal pouch.



Source: Minnesota Pollution Control Agency

Many pharmacies sell sharps containers.

How to store your sharps at home

You will need to have a special container to store your used sharps at home. You can:

- buy a sharps disposal container from your pharmacy.
- make your own container. Visit fda.gov and type “sharps disposal container” into the search box for instructions.

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

- 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.

How to get rid of your sharps

When the container is three-fourths full:

- return the sharps to your county drop-off site
or
- send them to a mail-back program.
You will have to pay for this.

Allina Health hospitals and clinics do not accept sharps. Please do not bring them to your hospital or clinic.

Whom to call with questions

Please call your city or county government’s household trash and recycling service with questions. You can also visit the following websites for more information.

- If you live in Minnesota, visit pca.state.mn.us.
- If you live in Wisconsin, visit dnr.wi.gov.

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 your nurse if you have not received the medicine by 10 p.m.

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

Pain Medicines

Pain medicines can help when pain cannot be controlled on its own. Although medicine may not take away all pain, the hospice team's goal is to keep you as comfortable as possible.

To prevent pain from starting or becoming worse (some people call this "staying on top of the pain"), pain relievers may be given on a regular schedule around the clock. Tell your caregiver or nurse that you are having pain.

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

Some people have side effects from opiates. Common side effects you may have include:

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

These side effects can usually be treated as your pain is managed. Talk with your pharmacist or nurse about which options are best for you.

The following medicines may 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 medicines are only available with your primary care provider's (or hospice doctor's) written prescription. They may be given:

- by mouth (pill)
- through the skin (patch or shot)
- through the anus (suppository).

Not all pain medicines are available in each of these forms. Talk with your nurse case manager or nurse if your pain medicine is not working. The dose, type or form of medicine may need to be changed.

Common myths about opiate pain medicines

MYTH: You will have 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 rarely occurs during hospice care.

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, people 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 pleasure (euphoria). 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 maintain your level of independence and dignity. People 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.

Radiation and Chemotherapy

Radiation and chemotherapy are not usually used in hospice. In some cases, radiation and chemotherapy may help 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:

- hassle and discomfort of getting to and from appointments
- trouble with tolerating procedures due to weakness
- possible side effects such as upset stomach (nausea), throwing up (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. Your nurse case manager can help you with this.

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)

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 Medicine Information							When To Take My Medicine				
Start date	Medicine name	Why do I take it?	How much do I take?	How do I take it?	Morning	Noon	Evening	Bedtime	Other		
Feb. 25, 2018	<i>Metformin</i>	<i>Control blood sugar</i>	<i>500 mg</i>	<i>By mouth</i>	X		X				

My Medicines

My Medicine Information							When To Take My Medicine			
Start date	Medicine name	Why do I take it?	How much do I take?	How do I take it?	Morning	Noon	Evening	Bedtime	Other	

Notes: _____

My Medicines

My Medicine Information							When To Take My Medicine			
Start date	Medicine name	Why do I take it?	How much do I take?	How do I take it?	Morning	Noon	Evening	Bedtime	Other	

Notes: _____

My Medicines

My Medicine Information							When To Take My Medicine				
Start date	Medicine name	Why do I take it?	How much do I take?	How do I take it?	Morning	Noon	Evening	Bedtime	Other		

Notes:

My Medicines

My Medicine Information							When To Take My Medicine				
Start date	Medicine name	Why do I take it?	How much do I take?	How do I take it?	Morning	Noon	Evening	Bedtime	Other		

Notes: _____

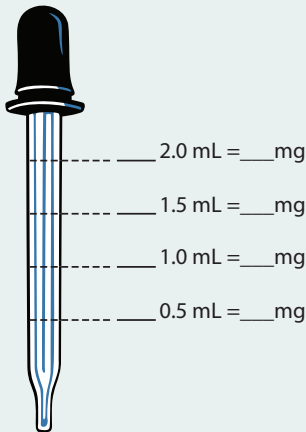
My Medicines

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 nurse case manager can help you with this.

Medicine dropper

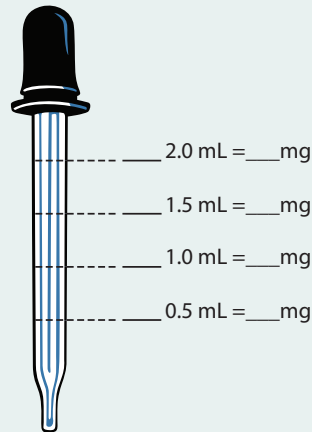
Medicine name: _____

Use for: _____
Start date: _____
Dose: _____



Medicine name: _____

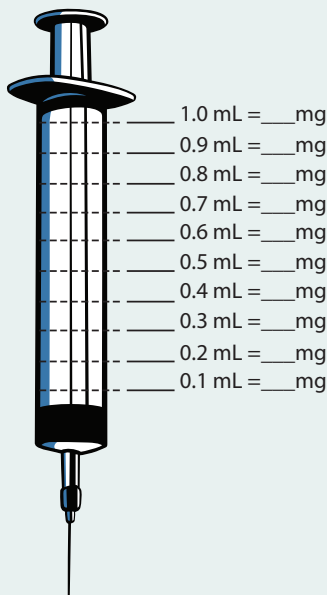
Use for: _____
Start date: _____
Dose: _____



Medicine syringe

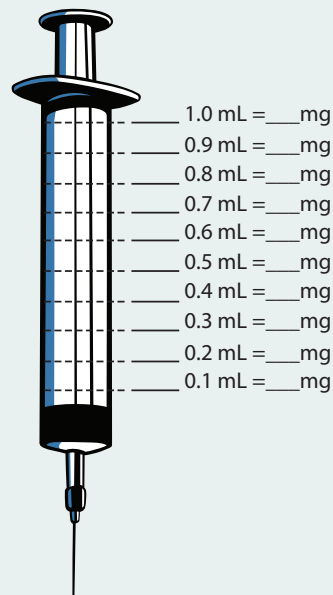
Medicine name: _____

Use for: _____
Start date: _____
Dose: _____



Medicine name: _____

Use for: _____
Start date: _____
Dose: _____



Chapter 4: Caregivers

In This Chapter:

- What You Can Do and What Hospice Can Do
- Tips for Dealing With Caregiving 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 person 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 guidance, as needed. You may need more or less help than others. Every situation is different. Help from hospice should not replace your role as caregiver.

The following are ways you can provide care and how the hospice team can help you.

- Help 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 home health aide.
- Help with getting to appointments, running errands, grocery shopping and picking up medicines. When you need more help with these activities, hospice can provide you with a volunteer.
- Help 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 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 with issues of closure, forgiving, saying goodbye, asking for forgiveness and worrying about how the family will be after he or she dies. A hospice team member is available when you need more help with these activities.

Tips for Dealing with Caregiver Stress

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

Communicate

Talk about your concerns with a trusted friend, spiritual counselor 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 with caregiving during this time.

Say YES to people who offer help

If you do not want them in your home, ask others 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. Do the rest as you are able.

Solve problems like an expert

Use the following steps to help identify and create a plan to solve 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 follow 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.

Tip

Eating small amounts of food throughout the day will help you have energy to do your everyday tasks. Try using smaller plates when you eat a meal or snack to help prevent overeating.

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. Alcohol is a depressant, which slows you down and prevents your body from working as it should. It is best not to drink alcohol.

Be physically active

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

Get plenty of rest

Sleep whenever you can. You may want to ask for a volunteer to help with caregiving so you can nap in your own home.

Action Step: Gaining a Sense of Control

You may at times feel overwhelmed as the caregiver to a seriously ill person. Remember, you are not alone. You may want to create a plan of action to help you feel more in control over the situation.

Think about the following questions as you begin your plan of action.

- What activities must be done to make sure the person feels 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 providing the best care?

Depression

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.

Depression, grief and guilt are natural and normal feelings with caregiving, especially in the final stages of 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 expected of them. Feelings of helplessness and failure result from unrealistic expectations and trying to be all things to all people.

You may feel many types of losses (loss of friendship, companionship, and family and daily routines that provided some order in your life) in the last days of life.

Remember, you are not alone. There are many ways to cope with the emotions you feel.

- 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 you set for yourself. Make sure they are realistic.
- Try to accept the things you cannot control and ask for help with the rest.

How to Ask for Help

Some people realize right away that the role of caregiver can be exhausting and easily ask for help. The caregiver never knows for certain how long he or she may be in the role. It is good to ask for support sooner rather than later (before becoming physically, emotionally or spiritually drained).

Tip

If you are not comfortable inviting someone into your home to help, ask the person to walk your dog, run errands or help with getting to and from appointments.

Most family members, friends, neighbors, church members and professionals want to help but they may not know exactly what is needed or how to help. Remember, someone doing even a small task for you is one less thing you need to do.

Here are some steps you can follow to ask for help.

- Make a list of specific tasks with which you could use help.
- Sit down with the person or find some quiet time to talk on the phone. Discuss what you are doing and find out with what he or she would have time to help.
 - Talk about the things with which you think the person can help you.
 - 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.

Here is an example of what you could say while following these steps.

“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?”

Early Grief

You or the person for whom you are caring may begin feeling the effects of loss and grief before death actually occurs. This is normal. Early grief may actually help you prepare for and deal with grief after death.

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 another person
- fears related to life without that person
- fear of losing family structure (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. Signs and symptoms of early grief may include:

- feelings of guilt
- tearfulness
- constant changes in emotions
- anger
- depression
- feelings of emotional numbness
- anxiety or feelings of fear
- changes in sleeping habits, eating habits or both
- poor concentration

- forgetfulness or poor memory
- loneliness
- denial
- acceptance
- feeling extremely tired (fatigue or exhaustion).

What you can do

There are things you can do to help work 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 and set aside the chores you can do later.
- Spend time with your family, friends and others close to you.
- 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 spiritual counselor or another counselor, or join a caregiver support group. Visit allinahealth.org/griefresources or call 651-628-1752 for online and over-the-phone grief support services. This is not a crisis line. It is a resource about support groups, counselors and books for the community.

Important

Visit allinahealth.org/griefresources or call 651-628-1752 for online and over-the-phone grief support services.

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 someone special. This will help to prepare for and manage the challenges that come along with the death and grieving.

Tip

Talk with your social worker for help with talking to children about death and grief.

Infants to age 2

At this age there is little understanding of what is happening. Infants and toddlers are sensitive to the emotional environment at 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 have a change in their usual behavior and need more holding, stroking, reassurance and calming.

It is important to provide confident and consistent reassurance for infants and toddlers. One- and 2-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:

- any change from the child's usual behavior
- 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.

Tip

Talk openly with children ages 3 to 5. Use real, simple language and remember that they may not understand the person is not coming back.

Age 3 to 5

These are the ages when children are more 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 helpful.

Magical thinking is common with children of this age as well as a sense of power. Children may think they caused the death. Reassure them that it is not their fault. However, children of this age also think concretely. They are scared by what they do not know or understand. 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.

For example, instead of saying *“Grandma is going to a better place,”* you could say *“Grandma has cancer and she will not get better. That means she is going to die.”*

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

- thumb-sucking or wanting a pacifier
- wetting the bed 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.

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
- fears that do not seem to "make sense" (irrational)
- repeated behaviors done to lower stress (obsessive-compulsive or ritualistic behaviors)
- complaining of physical pains caused by thoughts or emotions (psychosomatic complaints)
- twitching, especially in the face (tics)
- 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 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 trouble 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
- complaining of physical pains caused by thoughts or emotions (psychosomatic complaints).

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.

More Information

Turn to the next page for Allina Health written resources about grief. Your hospice team members can get copies for you.

Additional Resources

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

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 someone special 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.

“My Grief Journey: A Guided Journal for a Child Who Has Had Someone Special Die”

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 person 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.

Chapter 5:

Symptoms

In This Chapter:

- Hospice Team Support
- Anxiety, Agitation and Restlessness
- Bedsores (Pressure Injuries)
- Confusion
- Constipation
- Dehydration and Thirst
- Eating Habits and Changes
- Fatigue, Drowsiness and Sleep Problems
- Loss of Appetite and Weight Loss
- Shortness of Breath
- Special Diets
- Upset Stomach and Throwing Up
- Transportation by Ambulance
- Pain Management

Chapter 5: Symptoms

Hospice Team Support

For More Information

Turn to chapter 1 to learn more about the roles of each hospice team member.

The hospice team is experienced in helping families with symptoms common at the end of life. They can help determine some of the things that are causing the symptom and come up with a plan to deal with them. They will also help you with your own reactions.

You are not alone. The nurse is available 24 hours a day, 7 days per week. Please call any time with any concerns.

Important

The key to preventing serious problems is to **call your nurse as soon as symptoms appear.** Your hospice team wants you to feel confident with the care you provide.

Anxiety, Agitation and Restlessness

What it is

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

What to expect

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

What to look for

Signs of anxiety, agitation and restlessness include:

- **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, pacing or asking to be moved often.

- **environmental changes:**

This includes changes such as moving to a new home or room.

- **trouble sleeping:**

This includes not being able to fall asleep or stay asleep, tossing and turning, or being afraid to close his or her eyes.

What you can do

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

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.

- **Stay calm.**

Be calm in your voice and actions.

- **Offer reassurance.**

Let the person know you are there to help. You can do this by calling the 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. Do not say too much at once.

- **Practice active listening.**

Pay attention to what the person is saying and respond with reassuring words and actions.

- **Get rid of extra noise.**

Turn off TVs and radios while talking with the person.

- **Turn on some music.**

Play music the person enjoys (when you are not 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, bring him or her for a walk around the house and then back to bed.

Notes

When to call hospice

Call the nurse if:

- the anxiety, agitation and restlessness is new or gets worse
- medicine is given but not effective after 1 hour
- the person is at risk for injury from falling because of anxiety, agitation and restlessness
- you cannot keep the person from leaving his or her home.

Bedsores (Pressure Injuries)

What it is

A bedsore (pressure injury) 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

People in hospice have a higher risk of getting bedsores. Their skin is weaker because of:

- **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.

Bedsores are easier to prevent than they are to treat. A bedsore can appear after only a few hours of unrelieved pressure, but it may take months to heal. There are four stages of bedsores including:

- **stage one:** reddened skin

- **stage two:** open skin surface

- **stages three and four:** deep layers of skin are affected.

In the days or weeks before dying, the skin may break down easily. New bedsores may form and there may be several of them. The first goal of treatment in this situation is comfort. The hospice team will help decide whether more medicine, turning or both is needed.

What to look for

Early signs of bedsores include:

- areas of redness that do not go away

- open areas of skin

- pain on pressure points.

Notes

What you can do

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

Early treatment can help stage one bedsores heal quickly. Do the following at the first sign of a bedsore.

■ Change the person's position often.

- If the person is in a wheelchair, have him or her change sitting positions every 30 minutes.
- If the person 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.

■ Raise (elevate) the bed.

Be careful not to raise the head of the bed more than 30 degrees.

■ Lift the person.

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

■ Be careful when moving the person.

This will help to protect the areas of pressure on the body.

When to call hospice

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

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

Confusion

What it is

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

Being confused is often a reaction to a situation, not a sign of a mental health condition in itself. The person 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 person 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 the person to not be fully aware of what is happening around him or her (altered perception). The person 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 person's behavior and thought patterns. Talk with your hospice team if you notice a change.

What you can do

Most confused people 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.

Notes

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. Do not say too much at once.

■ **Practice active listening.**

Pay attention to what the person is saying and respond with reassuring words and actions.

■ **Get rid of extra noise.**

Turn off TVs and radios while talking with the person.

■ **Turn on some music.**

Play music the person enjoys (when you are not trying to have a conversation).

■ **Be alert.**

Look for signs that the person is trying to get out of bed and walk around.

■ **Go for a walk.**

If the person is restless and needs to move around, bring him or her for a walk around the house and then back to bed.

When to call hospice

Call the nurse if:

- the person begins to feel confused or is more confused than before
- the person is at risk for injury from falling caused by confusion
- you cannot keep the person from leaving his or her home
- you feel unsafe in any way.

Constipation

What it is

Constipation means having 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 trouble sensing he or she is constipated.

What to expect

Constipation is almost always a concern. Your hospice team will help you stay on top of the problem and make sure you feel confident in the care you provide.

Many things can lead to constipation, including:

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

Some things 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.

Notes

What to look for

Signs of constipation include:

- hard stool (trouble passing it)
- 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.

What you can do

You can help prevent constipation by:

- **offering liquids:**
Make sure the patient drinks plenty of liquids.
- **encouraging activity:**
Being active (especially walking) will help with regular bowel movements.
- **offering laxatives:**
Your nurse can tell you how much and how often to give laxatives.

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 taking pain killers. Docusate (Colace[®]), fiber and over-the-counter laxatives do not take the place of senna.

When to call hospice

Call the nurse right away if the person has:

- abdominal pain, stomach cramps or throwing up (vomiting) that does not go away
- a temperature of 101 F or higher
- not had a bowel movement for more than 3 to 5 days.

Dehydration and Thirst

What it is

Dehydration and thirst are different. **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. Most people will usually drink liquids until they are no longer thirsty. For some, a dry mouth produces thirst. This is typically relieved by giving liquids but many people 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 he or she is not drinking as much as usual. Typically, the only symptom of dehydration is producing less urine.

What to look for

Signs of dehydration and thirst include:

- comments about being thirsty
- comments about having a dry mouth
- dry skin. This may be a sign of dehydration but can occur for other reasons too.

What you can do

You can help reduce symptoms of dehydration and thirst by:

- **offering sips of liquid**
- **wiping the inside of the person's mouth using a swab moistened with water**
- **offering ice chips:**
Try using ice chips, hard candies or sugarless chewing gum. Each of these help produce saliva. You can also ask your nurse about artificial saliva. This must be prescribed.
- **applying lip balm to the person's lips.**

Tip

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

Notes

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 person’s mouth and offer whatever liquid he or she wants. If this relieves the feeling of thirst, it is the right amount of liquid to give.

When to call hospice

Call the nurse right away if the person has:

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

Eating Habits and Changes

In hospice, the goal of nutrition therapy shifts from a special diet to providing comfort. A feeding schedule may no longer be appropriate and can take away from comfort. Families and caregivers can have trouble with this transition.

It is natural for someone in hospice to have a change in his or her eating habits, including the foods he or she likes. While each situation is unique, there are some common themes about nutrition in hospice.

Decrease in appetite

Having a decrease in appetite is common. Most people will 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 upset stomach (nausea) and bloating.

Narrowing of food choices

Many people will gradually narrow their food choices to a few foods. Some may find liquids easier to tolerate than solid foods. This is normal and should be encouraged if it provides comfort. Ready-to-drink nutrition beverages such as Ensure[®], Boost[®] and Carnation[®] Breakfast Essentials[™] can be used as meal replacements.

Starvation

Many families and caregivers are concerned the person will “starve to death” if he or she is 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 appetite and it is not starvation. Eating more will not help the person feel better or improve his or her health problem. Remembering this can help everyone cope better throughout the illness.

Notes

Appetite stimulants

An appetite stimulant is a prescription medicine or herbal product taken to increase appetite. The goal of using an appetite stimulant is to increase comfort. It may also help the person enjoy his or her food more. It should not be expected that taking an appetite stimulant will improve illness or cause weight gain.

Faster metabolism and weight loss

Advanced cancer and AIDS (acquired immunodeficiency syndrome) can cause the metabolism to speed up. The person will not be able to maintain or put on weight even if food is increased.

Weight loss occurs in at least 80 percent of people with advanced illness. It is due to the illness, not poor nutrition. Many feel they fail if they do not gain weight. It is important to remember that weight loss is a result of the illness and not the person's fault.

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 common and can be caused by too much or too little sleep.

What to expect

Loss of sleep (insomnia) can be caused by pain or upset stomach (nausea), 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

Things that could be preventing the person from sleeping as he or she normally does include:

- **poorly controlled pain:**

This includes any new pain or pain that gets worse.

- **anxiety:**

This could appear as restlessness (changing positions often), 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, fluoxetine (Prozac®), corticosteroids (Prednisone®) and others.

What you can do

You can help the person get better sleep by:

- **giving medicines:**

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

Notes

- **offering warm, non-caffeinated drinks:**
Serve these drinks in the evening. Milk has natural chemicals to help sleep.
- **turning down bright lights:**
Bright lights can turn off normal sleep hormones in the body. Try to only use dim lighting for several hours before bedtime.
- **giving a massage:**
Massaging the person’s hands and feet before bedtime can help him or her to relax.

When to call hospice

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

Loss of Appetite and Weight Loss

What it is

Loss of appetite is a common symptom at the end of life. Many people fear 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. Most people in hospice 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 trouble 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 and can lead to other symptoms. For example, trying to give extra calories often causes upset stomach (nausea).

What to look for

The answers to the following questions will help your nurse determine what is causing the weight loss.

- Is the person actually losing weight? What does the person 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 throwing up (vomiting) the main reasons for the weight loss or is it mostly loss of appetite?

Important

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

Shortness of Breath

What it is

Shortness of breath usually involves the feeling of having trouble 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 slowly and the person becomes less active to avoid feeling short of breath.

What to look for

Signs of shortness of breath include:

- **shortened speech:**

The person 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 person coughs up mucus (sputum, phlegm).

- **bluish-colored skin:**

The person may have a bluish color to his or her lips or fingertips.

- **feeling anxious:**

This could appear as restlessness (changing positions often) or general feelings of nervousness.

What you can do

You can help relieve the person's shortness of breath by:

- **staying calm:**

This will help the person relax.

- **giving oxygen:**

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

Notes

- **giving medicine:**

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

- **helping the person sit up in bed:**

If the person feels better sitting up at the side of the bed but is tired, place a pillow on the bedside table. The person can lean forward and rest his or her arms on the pillow.

- **making sure the person's room has good air movement:**

Turn on a gentle fan and aim it toward the person's face or run the air conditioner on hot days.

- **opening up the room:**

Open up curtains or a window during nice weather.

- **giving nebulizer treatments:**

Make sure to use nebulizer treatments if they are prescribed.

When to call hospice

Call the nurse if:

- there is any significant change in the person's breathing

- medicine is given but not effective after 1 hour.

Special Diets

Diabetes

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

Try to encourage eating any foods that appeal to the person in reasonable amounts. It is not necessary to follow a certain nutrition plan.

Dementia

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

Tube feeding

People 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 people 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 all of the nutrients the body needs through an IV instead of through food. It is used when someone is not able to eat.

There is no evidence that TPN is helpful or improves quality of life during cancer therapy. For those on TPN, the goal is to prevent or minimize problems (complications). The most common problem of TPN is giving too much fluid. Decreasing the amount of fluid may help him or her be more comfortable.

Notes

Amyotrophic lateral sclerosis (ALS)

Many 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. The person may have trouble eating and drinking.

For those who are on tube feedings, the amount of formula and free water can be gradually decreased to increase comfort. **For those who are not on tube feedings,** the amount of softer foods can be gradually decreased to increase comfort.

Important: Watch for any signs of the person having too much food or liquid during the last stages of ALS. Both can cause breathing problems.

Upset Stomach and Throwing Up

Important

Only give medicine as directed by your hospice team. It is important to know which medicines are needed and how to safely give them. Talk with your pharmacist or nurse if you have questions.

What it is

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

What to expect

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

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

What to look for

The answers to the following questions will help your nurse determine what is causing the upset stomach and throwing up.

- Did the upset stomach seem to start after a change in medicine?
- Does it come and go or does the person always have an upset stomach?
- Does the person have stomach cramps or diarrhea?
- If there is throwing up, does it come after a period of having an upset stomach or does the throwing up happen suddenly, with little warning?
- Does the person have any stomach pain or heartburn?
- When was the last normal bowel movement?
- Does the person get a little hungry but then have an upset stomach after a few bites?

Notes

What you can do

- **Give medicine.**
Give medicines to relieve upset stomach as prescribed. Some medicine can be given through the rectum 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 flavored ice on a stick.
- **Offer sour-tasting foods and beverages.**
Sour foods and beverages (lemons) may help to relieve an upset stomach.
- **Practice deep breathing with the person.**
Have the person take slow, deep breaths.
- **Give a massage.**
Massaging the person's hands and feet can help relieve an upset stomach.

When to call hospice

Call the nurse if the person:

- starts having an upset stomach or throwing up
- throws up blood (other than just a few streaks of red)
- has sudden pain
- has stools that are dark red or black in color (tarry stools)
- has foul-smelling vomit.

Transportation by Ambulance

Did You Know?

Respite care gives a break from responsibilities of caregiving. This gives the caregiver a chance to rest and take care of him- or herself.

Payment for transportation to and from the hospital will be provided to people in hospice who have:

- been admitted for short-term (acute) hospice care
- a terminal illness
- been pre-approved by hospice.

Costs of transportation to and from clinic appointments, emergency department (ED) visits, treatment or respite care stays are your responsibility.

Pain Management

Important

Tell a member of the hospice team if you do not think the person's pain is being managed well. He or she will talk with you about his or her pain and pain management needs.

Types of pain

Pain can last less than 3 to 6 months (acute), last a long time (chronic) or be severe and intense (breakthrough). Pain can come and go with injury, recovery or illness.

Pain scale

Your hospice team will use the following number scale (0 to 10) to help measure symptoms.

Allina Health Pain Assessment Scale

10	Worst Pain You Can Imagine
7-9	Severe Pain Pain keeps you from doing your regular activities. ⑨ Pain is so bad that you can't do any of your regular activities, including talking or sleeping. ⑧ Pain is so intense that you have trouble talking. ⑦ Pain distracts you and limits your ability to sleep.
4-6	Moderate Pain Pain may interfere with your regular activities. ⑥ Pain makes it hard to concentrate. ⑤ You can't ignore the pain but you can still work through some activities. ④ You can ignore the pain at times.
1-3	Mild Pain Pain doesn't interfere with your regular activities. ③ You may notice the pain but you can tolerate it. ② You may feel some twinges of pain. ① You may barely notice the pain.
0	No Pain

Adapted with permission by Dr. Armaan Singh, 2015.

Treatments for pain

Managing your pain is more than taking prescription (opioid) pain medicine. There are many non-medicine ways to treat pain including:

- talking with a spiritual counselor or social worker
- listening to music
- relaxation techniques
- massage
- aromatherapy
- cold (ice packs) or warm packs.

The hospice team will work with you to help manage the person's pain and symptoms with medicines and other methods. Talk with a member of your hospice team if you have concerns.

Chapter 6: Last Days of Life

In This Chapter:

- What You Can Do to Help Your Loved One

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, now is the time. There is no way to know exactly when someone will die but there are a few signs and symptoms common in the last days of life.

What You Can Do to Help Your Loved One

Changes in the body

Dying is a natural process during which the body is shutting down and preparing to let go. As a result, your loved one will experience changes in his or her body, mind and spirit.

Important

The person may not be able to tell you how he or she feels at the end of life. Common signs of discomfort are:

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

Pain and discomfort

Emotional, psychological and spiritual pain can make physical pain worse. Physical pain can also worsen suffering that is caused by other sources. Your hospice care team can help your loved one feel more comfortable through music therapy, massage therapy, aromatherapy, supportive presence and medicine.

Talk with your hospice team if you have question about pain medicines.

What you can do:

- Offer supportive touch such as hand-holding if your loved one is OK with it.
- Sit in silence, as this may provide comfort.

Did You Know?

As death approaches, the person often experiences a decrease in the desire for food, liquid or both. The person 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 it properly. "Feel good" chemicals (endorphins) are released to help increase comfort.

Breathing

You may begin to notice a change in breathing. A long pause between breaths (apnea) is normal.

A gurgling noise from the throat is common and caused by saliva collecting at the back of the throat. Being weak makes it hard to swallow. It is likely more disturbing for you to hear than it is uncomfortable for your loved one.

What you can do:

- Change your loved one's position.
- Turn your loved one on his or her side to keep the saliva from building up in the throat.
- Clean your loved one's mouth with a swab.
- Use a fan or open a window to move air around the room.
- Respect your loved one's need to rest.

Restlessness or agitation

Restlessness comes and goes. Some days are peaceful, others less calm. It is all part of the normal process as the body makes the transition between the work of living and the process of dying.

Agitation is a symptom with many causes. It is common during the last few days of life.

Talk with the hospice team if restlessness seems extreme. You can also talk with a chaplain, social worker or friend to share thoughts and address anxieties.

What you can do:

- Keep voices calm and the room quiet.
- Dim the lighting.
- Allow your loved one to tell you about his or her dreams and visions. Reassure him or her that this is common.
- Try playing music with a gentle tone and soft volume in the background.



Chapter 7:

At Time of Death

In This Chapter:

- What You Need to Do When You Feel Ready
- What Happens Next
- Worksheet: At Time of Death Information

Chapter 7: At Time of Death

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

What You Need To Do When You Feel Ready

- Write down the time you noticed he or she stopped breathing.
- Call hospice at 651-635-9173 or 1-800-261-0879 within 1 hour to tell of the death. They will have questions about the last 24 hours. When you call, be prepared to tell them:
 - the time of death
 - where the body is
(hospital bed, own bed, living room)
 - what he or she was wearing
 - who was present
 - last medicines taken (name, dose, time)
 - any fall with fractures in the last 6 months
 - funeral home information
(name, location and phone number).

This information is given to the coroner and is needed to release the body for funeral arrangements.

What Happens Next

- Hospice contacts the county coroner and gives the information on the previous page along with the funeral home information.
- Pre-registration will be done with the county coroner if there has not been any fall with injury in the last 6 months. Some counties require the primary care provider to sign the pre-registration as well. If the person is not registered, the coroner may decide to send out the police to complete the process. The nurse will tell you if this needs to happen.
- The body is released to the funeral home.
- The funeral home will contact you about coming to pick up the 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 staff will set up an appointment to meet with you at their office. They will tell you everything you need to know to finish making 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 call 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: ___ - ___ - _____

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

What is a health care directive?

A health care directive is a written document of your health care choices. Members of your care circle (family, friends or others close to you) and health care providers use this to interpret and understand your wishes, goals and values for future health care needs if you cannot tell them yourself.

It will help them honor your wishes, especially before a medical crisis.

Who makes decisions on my behalf?

It is important to ask someone to make health care decisions for you if you cannot make them on your own. This person is called a health care agent.

Your health care agent should be:

- 18 years old
- willing, able and available to know and understand your wishes, goals and values
- able to make decisions under stress or crisis.

Ask this person if he or she agrees to be your health care agent.

Note: A health care agent is not a “financial power of attorney.” He or she cannot make decisions about your money or property.

Do I need an attorney to fill out a health care directive?

No. You can fill out a health care directive on your own. To make it valid, you will need two witness **or** a notary public to watch you sign your health care directive.

Should I fill out a health care directive if I have a chronic (long-lasting) illness?

Yes. This is a good place to list your health care agent(s), what kind of care you want, your wishes about the quality and length of your life, and what you want for treatment, including pain control.

What Do I Put in a Health Care Directive?

Your health care directive can include:

- a health care agent to make health care decisions for you
- alternate health care agents in case the first one is not available
- your health care choices based on your wishes, goals and values such as:
 - CPR (for restarting your heart and lungs if they stop)
 - ventilator or respirator (for help to breathe)
 - feeding tube (for nutrition)
 - organ donation
 - autopsy
- where you want to receive care
- funeral arrangements.

You may want to include other information in your health care directive as well.

Can I fill out a health care directive online?

Yes. Allina Health offers an interactive, online health care directive. Go to account.allinahealth.org and sign up for My Account, a secure area that can help you manage your health care goals, track preventive health recommendations and organize your family's health information.

Your health care directive can be as simple or as detailed as you want. After you print it and have it witnessed **or** notarized, you can scan it back into your My Account and share that link with whomever you choose.

I already have a health care directive and need to make changes, can I?

Yes. You can change your health care directive any time. You should review your health care directive at least every 5 years or if there are:

- personal health changes (including new diagnosis or major changes)
- change with a health care agent due to:
 - death
 - decline in health
 - divorce, separation or annulment
 - no longer willing or able.

Fill out a new document, make it valid and provide a copy to your health care provider and health care agents. Ask that they destroy the old copy.

Where do I keep my health care directive?

Keep your original health care directive in a spot where someone could find it. Give copies to your health care agent(s), health care provider(s) and members of your care circle.

For More Information

For more information about health care directives, call your social worker, health care provider attorney, or:

Minnesota Board on Aging's Senior LinkAge Line®:

Call 1-800-333-2433 or visit mnaging.org.

I need help filling out a health care directive. What should I do?

Allina Health offers free 75-minute classes to help you fill out a health care directive.

The class instructor will guide you through the process and notarize your document. He or she will help you with the final step of getting it into your electronic medical record.

Check out the class listings at 17 Allina Health clinics and hospitals at allinahealth.org/acp or call 612-262-2224 or 1-855-839-0005 to get scheduled. The classes are open to anyone. You do not need to receive your care at Allina Health.

I live in Wisconsin. Can I fill out a health care directive?

Yes. Allina Health offers Wisconsin options in both the online and print health care directives.

Is the health care directive I prepared in a different state still good?

Health care directives created in other states are legal if they meet the requirements of that state's law. If you set up residency in a new state, you should fill out a new health care directive for that state.

Provider Orders for Life-Sustaining Treatment (POLST)

What is a POLST?

POLST stands for "provider orders for life-sustaining treatment." Your doctor uses POLST to write medical orders indicating your health care wishes.

Who should have a POLST?

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

One decision you can make is whether or not you want CPR if your heart or breathing stops.

Do I need a health care directive?

A health care directive is recommended even if you have a POLST form. This document will list your health care agent and your values and goals as they relate to your health care wishes.

Allina Health offers a free, 75-minute class to learn how to fill out a health care directive. Go to allinahealth.org/acp to find out dates, times and locations. Call 612-262-2224 or 1-855-839-0005 to register 3 days before class.

Who signs the POLST?

The form must be signed by a doctor for it to be followed by other health care providers. Health care providers who work with your doctor or nurse practitioner can complete this form.

Where is the POLST used?

The POLST stays 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 doctor talk about and develop plans to reflect your wishes
- help doctors, 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 a loved one. A doctor, nurse or social worker can complete the POLST based on family members' understanding of their loved one's wishes.

When can I find a POLST form?

- **Minnesota:** Go to mnmed.org (Minnesota Medical Association). Click on the *Advocacy* tab, then *Key Issues* on the left-side menu. Choose *POLST Communications*. Scroll down and choose *POLST Form*.
- **Wisconsin:** Go to polst.org/educational_resource/wisconsin-polst/.

Reviewed date: ____/____/____

Signature: _____

Bill of Rights: _____

HIPAA: _____

Advance directives: _____

Combined Minnesota and Federal Hospice Bill of Rights



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 limitations on those services.**
7. Know in advance of receiving care whether the hospice services may be covered by health insurance, medical assistance, Medicare, or other health programs in which the individual is enrolled. **Receive information about the services covered under the hospice benefit.**
8. Receive, upon request, a good faith estimate of the reimbursement the provider expects to receive from the health plan company in which the individual is enrolled. A good faith estimate must also be made available at the request of an individual who is not enrolled in a health plan company. This payment information does not constitute a legally binding estimate of the cost of services.
9. Know that there may be other services available in the community, including other end of life services and other hospice providers, and know where to go for information about these services.
10. Choose freely among available providers and change providers after services have begun, within the limits of health insurance, medical assistance, Medicare, or other health programs. **Choose his or her attending physician.**
11. Have personal, financial, and medical information kept private and be advised of the provider's policies and procedures regarding disclosure of such information.
12. Be allowed access to records and written information from records according to sections 144.291 to 144.298. **Have a confidential clinical record. Access to or release of patient information and clinical records is permitted in accordance with 45 CFR parts 160 and 164.**
13. Be served by people who are properly trained and competent to perform their duties.
14. Be treated with courtesy and respect and to have the patient's property treated with respect. To have his or her property and person treated with respect.
15. Voice grievances regarding treatment or care that is, or fails to be, furnished or regarding the lack of courtesy or respect to the patient or the patient's property **by anyone who is furnishing services on behalf of the hospice.**

The patient has the right to not be subjected to discrimination or reprisal for exercising his or her rights.
16. Be free from physical and verbal abuse. **Be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property.**
17. Reasonable, advance notice of changes in services or charges, including at least ten days' advance notice of the termination of a service by a provider, except in cases where:
 - the recipient of services engages in conduct that alters the conditions of employment between the hospice provider and the individual providing hospice services, or creates an abusive or unsafe work environment for the individual providing hospice services.

- 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.
 - the recipient is no longer certified as terminally ill.
18. A coordinated transfer when there will be a change in the provider of services.
 19. Know how to contact an individual associated with the provider who is responsible for handling problems and to have the provider investigate and attempt to resolve the grievance or complain.
 20. Know the name and address of the state or county agency to contact for additional information or assistance.
 21. Assert these rights personally, or have them asserted by the hospice patient's family when the patient has been judged incompetent, without retaliation. **If a patient has been adjudged incompetent under state law by a court of proper jurisdiction, the rights of the patient are exercised by the person appointed pursuant to state law to act on the patient's behalf. If a state court has not adjudged a patient incompetent, any legal representative designated by the patient in accordance with state law may exercise the patient's rights to the extent allowed by state law.**
 22. Have pain and symptoms managed to the patient's desired level of comfort. **Receive effective pain management and symptom control from the hospice for conditions related to the terminal illness.**

The hospice must:

- **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.**
- **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.**
- **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.**
- **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,

COMBINED MINNESOTA AND FEDERAL HOSPICE BILL OF RIGHTS

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 provider or person providing hospice services, you may call, write, or visit the Office of Health Facility Complaints, Minnesota Department of Health. You may also contact the Office of Ombudsman for Long-term Care.

**MINNESOTA DEPARTMENT OF HEALTH
OFFICE OF HEALTH FACILITY COMPLAINTS**

85 East Seventh Place, Suite 300

P.O. Box 64970

St. Paul, Minnesota 55164-0970

Phone: 651-201-4201 or 1-800-369-7994

Fax: 651-281-9796

health.ohfc-complaints@state.mn.us

<https://www.health.state.mn.us/facilities/regulation/ohfc/index.html>

OMBUDSMAN FOR LONG-TERM CARE

PO Box 64971

St. Paul, MN 55164-0971

Phone: 651-431-2555 or 1-800-657-3591

Fax: 651-431-7452

mba.ooltc@state.mn.us

<http://www.mnaging.org/Advocate/OLTC.aspx>

**MEDICARE BENEFICIARY AND FAMILY CENTERED CARE QUALITY IMPROVEMENT
ORGANIZATION**

LIVANTA LLC

BFCC-QIO Program

10820 Guilford Road, Suite 202

Annapolis Junction, MD 20701-1105

1-888-524-9900, TTY 1-888-985-8775

https://livantaqio.com/en/Beneficiary/Immediate_Advocacy

Licensee Name: Allina Health Hospice & Palliative Care

Phone: 651-635-9173 or 1-800-261-0879 **Email:** julia.crist@allina.com

Address: 1055 Westgate Drive, Suite 100, Saint Paul, Minnesota 55114

Name/Title of person to whom problems or complaints may be directed:

Julia Crist, VP, Allina Health Hospice & Palliative Care

For informational purposes only and is not required in the Hospice Bill of Rights text:

MINNESOTA STATUTES, SECTION 144A.751

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

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

Minnesota Department of Health
Health Regulation Division
P.O. Box 64900
St. Paul, Minnesota 55164-0900
651-201-4101
health.fpc-licensing@state.mn.us

8/19

hospicecombined_eng_reg

To obtain this information in a different format, call: 651-201-4101.

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 the hospice director, 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.

Important

If you require any of the aids listed, 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 130. 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

District One Hospital

Mercy Hospital

Mercy Hospital — Unity Campus

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

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.

Nondiscrimination in Health Programs and Activities

Affordable Care Act – Section 1557

Allina Health complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, gender identity or sex. Allina Health does not exclude people or treat them differently because of race, color, national origin, age, disability, gender identity or sex.

Allina Health:

- provides free aids and services to people with disabilities to communicate effectively with us, such as:
 - ◊ qualified sign language interpreters, and
 - ◊ written information in other formats (large print, audio, accessible electronic formats, other formats)
- provides free language services to people whose primary language is not English, such as:
 - ◊ qualified interpreters, and
 - ◊ information written in other languages.

If you need these services, ask a member of your care team.

If you believe that Allina Health has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, gender identity or sex, you can file a grievance with:

Allina Health Grievance Coordinator
P.O. Box 43
Minneapolis, MN 55440-0043
Phone: 612-262-0900
Fax: 612-262-4370
GrievanceCoordinator@allina.com

You can file a grievance in person or by mail, fax or email. If you need help filing a grievance, the Allina Health Grievance Coordinator can help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Avenue, SW Room 509F, HHH Building
Washington, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.



- English: ATTENTION: If you speak English, language assistance services, free of charge, are available to you. Call 1-877-506-4595.
- Spanish: ATENCIÓN: Si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-877-506-4595.
- Hmong: LUS CEEV: Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. Hu rau 1-877-506-4595.
- Somali: LA SOCO: Haddii aad ku hadashid af Ssoomaali, adeegyo gargaar luqad, oo bilaash ah, ayaa lagu heli karaa. Wac 1-877-506-4595.
- Chinese: 注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1-877-506-4595。
- German: ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 1-877-506-4595.
- Arabic: ملحوظة: إذا كنت تتحدث انكر اللغة، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل برقم 1-877-506-4595.
- Russian: ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-877-506-4595.
- Korean: 주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-877-506-4595 번으로 전화해 주십시오.
- Vietnamese: CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-877-506-4595.
- Pennsylvanian Dutch: Wann du [Deutsch (Pennsylvania German/Dutch)] schwetzsch, kannsch du mitaus Koschte ebber gricke, ass dihr helft mit die englisch Schprooch. Ruf selli Nummer uff: Call 1-877-506-4595.
- Laotian: ໂປດຊາບ: ຖ້າວ່າ ທ່ານເວົ້າພາສາ ລາວ, ການບໍລິການຊ່ວຍເຫຼືອດ້ານພາສາ, ໂດຍບໍ່ເສັຍຄ່າ, ຄວນມີພ້ອມໃຫ້ທ່ານ. ໂທ 1-877-506-4595.
- French: ATTENTION: Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-877-506-4595.
- Polish: UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 1-877-506-4595.
- Hindi: ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। 1-877-506-4595 पर कॉल करें।
- Albanian: KUJDES: Nëse flitni shqip, për ju ka në dispozicion shërbime të asistencës gjuhësore, pa pagesë. Telefononi në 1-877-506-4595.
- Tagalog: PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-877-506-4595.
- Cushite: XIYYEEFFANNA: Afaan dubbattu Oroomiffa, tajaajila gargaarsa afaanii, kanfaltiidhaan ala, ni argama. Bilbilaa 1-877-506-4595.
- Amharic: ማሳሰቢያ: የሚናገሩት ቋንቋ አማርኛ ከሆነ የትርጉም እርዳታ ድርጅቶቻችን በነጻ ሊያገለግሉት ተዘጋጅተዋል። ወደ ሚከተለው ቁጥር ይደውሉ፡- 1-877-506-4595.
- Karen: ဟံသုဉ်ဟံသး- နမ့ကတိၤ ကညီ ကျိာအယိ, နမၤန့ ကျိာအတၢ်မၤစၢၤလၢ တလၢာ်ဘျဉ်လၢာ်စ့ၤ နီတမံၤဘျဉ်သ့န့ၢ်လီၤ. ကိး 1-877-506-4595.
- Mon Khmer: ប្រយ័ត្ន៖ បើសិនជាអ្នកនិយាយភាសាខ្មែរ, សេវាជំនួយផ្នែកភាសា ដោយមិនគិតថ្លៃ គឺអាចមានសំរាប់ប្រើអ្នក។ ចូរ ទូរស័ព្ទ 1-877-506-4595។





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