Our Mission: Partnering with patients and families to improve quality of life throughout serious illness

Please have this handbook available for each visit with your Agrace team.

agrace.org/caregiver

HospiceCare | PalliaHealth | Grief Support | Age at Home

An interactive resource for patients, families & caregivers

Please have this handbook available for each visit with your Agrace team.
Our Mission:
Partnering with patients and families to improve quality of life throughout serious illness
Welcome to Agrace

Thank you for choosing Agrace. It is a privilege to support you.

This handbook is for patients, their families, caregivers and Agrace staff to use together. You can refer to it whenever:

- You need more information about a symptom you're seeing/having
- You want to understand any part of the hospice process in more detail
- You want to take notes on conversations with your Agrace team
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Do you have a concern you would like to discuss with a manager? Please call Agrace and ask to talk with your care team’s manager:

_____________________________________________________________

Call Agrace at: __________________________

Online help for caregivers is available at agrace.org/caregiver.

Your Agrace Team

You are being served by the _______________________________ Team.

Registered Nurse (RN) Case Manager: _______________________________

Social Worker: _____________________________________________________

Your Doctor: ______________________________________________________

Certified Nursing Assistant(s): ______________________________________

Spiritual & Grief Counselor: _________________________________________

Call Agrace if you:

• fall,
• need to go to the emergency room,
• need to be admitted to a hospital,
• have pain or other symptoms that are getting worse, or
• need your medication changed or refilled before your next nurse visit.
Agrace Does Not Discriminate

Agrace does not exclude people or treat them differently on the basis of race, color, national origin, age, disability or sex. Agrace provides assistance—without charge and in a timely manner—to people with disabilities and people whose primary language is not English, to help them communicate effectively with us. This assistance includes qualified interpreters and information in alternate formats and languages. If you need these services, please call Agrace at 1-800-553-4289, TTY: 711.

If you believe that Agrace has failed to provide reasonable assistance or has discriminated in another way, you can file a complaint with: Agrace—Grievance Coordinator, 5395 E. Cheryl Parkway, Madison, WI 53711, Tel: 1-800-553-4289, TTY: 711 –or– Office for Civil Rights, U.S. Dept. of Health and Human Services, 200 Independence Avenue, SW, Room 509F, HHH Building, Washington, D.C. 20201, Tel: 1-800-368-1019, TTY: 1-800-537-7697, Web: https://ocrportal.hhs.gov
Hospice Care from Agrace—A Circle of Care

Hospice care is “whole-person” care that addresses the physical, emotional and spiritual concerns of people with illnesses that cannot be cured. This model of care emphasizes comfort and quality of life, and it respects each patient’s goals, preferences and choices.

In addition to serving our patients, Agrace extends support to their caregivers, family and other loved ones. **We define “family” as being whomever the patient considers to be their “family.”**

**As an Agrace HospiceCare patient, you are at the center of our circle of care.** Hospice care is provided by a team of professionals from various disciplines who are experienced in end-of-life care. Think of this interdisciplinary team as a “circle of care.” You are the center of this circle, and your needs and preferences guide your care. Your Agrace team can respond to your needs 24 hours a day, seven days a week.
Team Members and Their Role in Your Care

The Agrace care team members communicate with you and your family—as well as with each other—to ensure that your needs are being met. Each member of the care team is crucial to the process of providing consistent, coordinated, quality care.

Nurse (RN)

The nurse is primarily responsible for managing your care, which includes:

- assessing your physical condition and comfort
- working with your physician to coordinate their role in your care
- training you and your family on physical care, medication administration, equipment use, skin care and nutrition

Social Worker

The social worker provides several essential services to you and your family/support person, such as:

- assessing your need for emotional and spiritual support and making a referral to a spiritual & grief counselor for help addressing grief and/or spiritual concerns
- helping you complete advance directives (living will, power of attorney for health care)
- helping you complete applications for medical assistance, when appropriate
- referring you to community resources such as therapists (for adults and children), caregivers, Meals on Wheels and Lifeline
- facilitating difficult conversations about concerns of the patient/family members

Certified Nursing Assistant (CNA)

A CNA provides basic physical care, such as bathing, grooming, dressing, mouth care, skin care, transfers and repositioning. CNAs also train family caregivers about basic physical care. The Agrace team works with you and your family to decide how a CNA might help you and to arrange a schedule for visits.

Licensed Practical Nurse (LPN)

A licensed practical nurse provides additional nursing support under the direction of your primary nurse (RN). An LPN also reinforces the training you receive from your RN.

Agrace Doctor or Nurse Practitioner

Agrace’s doctors and nurse practitioners specialize in hospice and palliative medicine. They are expert advisors who collaborate with the other members of your team—including your personal doctor—when help is needed to manage symptoms that are complex or difficult to keep under control. They also meet with patients in person to provide education, talk about goals for care, assess their condition and ensure that each patient remains medically eligible to receive hospice care. When patients receive acute care for urgent or serious symptoms at the Agrace inpatient units, our doctors and nurse practitioners oversee this care.
Patient-Care Volunteer

Agrace’s patient-care volunteers are trained to support you and your family in a variety of ways, based on your needs and requests. This support may include companionship, delivering medications, running errands, driving you to appointments, taking you on outings, shopping, hairdressing, light housekeeping, light meal preparation and providing caregiver relief (companionship for patients while their caregiver does errands). Specially trained volunteers support grieving families and friends; others are trained to keep a vigil when a patient is actively dying.

Please note that volunteers do not give hands-on care (the care that is usually provided by a nurse or nursing assistant).

Spiritual & Grief Counselor

The spiritual & grief counselor provides grief and spiritual support. They can guide and comfort you if you’re having feelings of sadness, loneliness, regret, fear, despair or anger, or have spiritual questions. Spiritual & grief counselors are non-denominational and highly trained to work with people of all faith practices and with people who do not have formal religious beliefs.

- Your counselor is available to listen, affirm and educate you and your family (including children) about what may be helpful during this time.

- They can also connect you with spiritual resources in the community.

- Spiritual & grief counselors also provide grief support for family members, both during the illness and for 12 months after the death.

Qualified Medical Interpreter

If needed, Agrace will provide a qualified medical interpreter, without cost to you. The interpreter makes sure Agrace staff members are able to communicate effectively with you, using the language you and your family understand. For your well-being and privacy, we do not use family members who speak your primary language to interpret (nor would we want to put them in an uncomfortable role).

Patient’s Doctor/Health Care Provider

Your doctor or other health care provider (such as a nurse practitioner) is also part of the Agrace team. They support your referral to Agrace and continue to order medication, treatments and other symptom-management support.

Consulting Team Members

Based on your unique needs, others may be a part of your Agrace team. They may be specialists, therapists or other professionals. These team members may consult on your care and/or provide direct services for you or your family.

For more details about how social workers, spiritual & grief counselors and volunteers can assist you, please see the “Caregiver Support & Resources” section of this handbook.
Welcome to Agrace

The Four Levels of Hospice Care

Hospices provide four different levels of care to support you as your needs change. Most, but not all, insurance plans cover all four levels of care. Your care team will work with you to determine your specific coverage.

Routine Home Care is the most common form of hospice care, by far. But when Routine Home Care is not enough to meet your needs, three other levels of hospice care are available.

1. Routine Home Care
What is Routine Home Care? End-of-life care provided wherever you live. It includes services provided by your Agrace care team and also typically includes medications, medical equipment and supplies.
Who is Routine Home Care for? Hospice patients whose symptoms can be managed in a home or residential setting.
How long can you receive Routine Home Care? You may receive Routine Home Care as long as you continue to be eligible for hospice.
What is residential hospice care? Some Agrace patients choose to live in the residential rooms at our campuses in Madison or Janesville and receive Routine Home Care there. If you are interested in learning more about living at Agrace, please see page 9 of this handbook, and ask your care team if you have other questions.

2. Respite Care
What is inpatient Respite Care? An opportunity for your caregiver to have a break from caregiving.
Who is Respite Care for? Hospice patients whose caregivers (such as family members or friends) need a break and will resume caregiving at the end of the respite stay.
Where is it provided? At Agrace in Madison or Janesville, or at another contracted facility.
How long can you stay? Up to 5 days.

3. General Inpatient Care (GIP)
What is General Inpatient Care? Short-term, “acute” care to treat serious, urgent or complex symptoms that cannot be controlled in another setting.
Who is General Inpatient Care for? Hospice patients who have uncontrolled pain, severe shortness of breath, persistent restlessness or agitation, or other complex symptoms that cannot be managed in another setting.
Where is it provided? At the Agrace inpatient units (IPUs) in Madison or Janesville, or at a contracted hospital.
How long can you stay? Until your symptoms are under control, then you return home or transition to another setting. The usual length of stay for GIP care is a few days.

4. Continuous Care
What is Continuous Care? Short-term, increased nursing and personal care (between 8 and 24 hours a day) intended to help you stay in your home when extra care is needed to control your symptoms.
Who is it for? Hospice patients who are receiving Routine Home Care—and want to remain at home—but need intensive skilled nursing care, such as monitoring and treatment of acute pain or other complex symptoms.
How long can you receive Continuous Care? For brief periods of time (usually a few days), from 8 to 24 hours within a 24-hour day.
### Who Pays for Your Care?

Your “hospice benefit” is a special part of your health insurance that pays for most services, treatments, medicines and equipment you will receive once you enroll in end-of-life care. Your Agrace team will use this chart to explain how care is covered in your specific situation.

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<thead>
<tr>
<th>Your health insurance* is responsible if:</th>
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<tr>
<td>HOSPICE BENEFIT typically covers services, treatments, medicines and equipment if:</td>
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<tr>
<td>They are related to your terminal illness +</td>
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<tr>
<td>The goal is comfort +</td>
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<tr>
<td>They are provided or arranged for by Agrace</td>
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<th>EXISTING POLICY continues to cover services, treatments, medicines and equipment as before, if:</th>
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<tr>
<td>They are medically necessary and are NOT related to your terminal illness</td>
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<th>You are financially responsible if:</th>
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<tr>
<td>It is a premium, co-pay or a deductible</td>
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<tr>
<td>The goal is cure</td>
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<tr>
<td>It is NOT medically necessary</td>
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<td>You decline Agrace’s recommendation of a similar effective medication</td>
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* including Medicare and Medicaid

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**Care for All:** When patients who need hospice care do not have insurance coverage and cannot pay for the care they need, Agrace may be able to offer help paying for hospice services through our “Care for All” program. Please ask your Agrace nurse or social worker for details.
How long can I be an Agrace patient?
There is no limit on the length of time you can receive Agrace services, provided you are still medically appropriate for hospice (meaning a life expectancy of six months or less) and the goal of your care remains comfort and control of symptoms, rather than a cure for your illness. While you are an Agrace patient, your team regularly reviews your health status. In addition, patients whose hospice services are covered by Medicare will have a face-to-face visit with an Agrace doctor or nurse practitioner prior to reaching six months on our service and at least every 60 days after that.

If we notice changes that might affect your eligibility to receive hospice services (such as a steady improvement in your health), we will discuss them with you. If you improve to the point that you are no longer eligible and will be discharged from Agrace, your team will work with you to make the transition.

If I am discharged, can I be readmitted in the future?
Yes. If you are discharged from Agrace and your health later declines, you may be eligible to be re-enrolled in hospice care. You or your doctor may contact Agrace at any time to start the process. We will gather the information needed to assess your eligibility, and verify that your life expectancy is six months or less and that you are not receiving curative treatment. There is no limit to the number of times you can go on and off Agrace’s service.

Can my personal doctor be involved in my care now that I am an Agrace patient?
Yes. When you enroll with Agrace, you designate an “attending” doctor, who is always considered a part of the Agrace team. Agrace works closely with your personal doctor to ensure you get the best care possible.

Now that I’m on hospice, how do we decide which medications I will take?
Some of the medications you take as a hospice patient may be different from those you were taking before you enrolled. That’s because the purpose of your medications—and the focus of hospice care—is to keep you comfortable.

• Your Agrace team will review your medications with you and make recommendations, with input from our pharmacist, a hospice doctor and your doctor. The primary goal is to choose medications that help control your pain and other symptoms related to your illness, with the fewest side effects.
• Agrace may ask you to switch from a medication you have been taking to a similar, effective medication that is on our list of approved medications.
• You may keep taking other medications that are not related to your terminal illness, if they are medically necessary to treat a different health problem.
• Agrace will recommend that you stop taking medications that:
  › were taken to try to cure your illness,
  › are no longer effective, or
  › are not medically necessary for a person on hospice.

If you choose to continue taking a medicine even though Agrace offered a similar drug, or if you continue medicines that are not medically necessary, you may have to pay the full cost of them.

More details about who pays for medications can be found on page 5 of this handbook. More details about taking medications can be found on page 33.
Can I be hospitalized while I am an Agrace patient?
Agrace staff are experienced at managing the symptoms and problems that would normally require hospitalization. However, if hospitalization is necessary for the management of your symptoms, it can be arranged without discontinuing Agrace services. Agrace’s inpatient units are also a choice your team may discuss with you if you need intensive symptom management but prefer not to be hospitalized.

Can I receive treatment such as chemotherapy, radiation therapy and blood transfusions while I am a hospice patient?
All treatments are evaluated on an individual basis and are approved by your Agrace team. In order to be approved, treatments must be palliative in nature (for relief of pain and other symptoms), rather than for the purpose of curing your illness. The appropriateness of treatments will be evaluated on an ongoing basis.

Does Agrace HospiceCare provide around-the-clock nursing care?
Agrace provides intermittent in-home nursing visits and assistance with other activities of daily living. There is also 24-hour access to a nurse for information, support and problem-solving, either over the phone or by a home visit. If you need in-home assistance for extended periods or around-the-clock, several agencies in southern Wisconsin provide this type of support on a private-pay basis. Your hospice team can help you arrange this support, and we will work closely with any caregivers you hire.

Can I travel if I’m an Agrace patient?
Yes. However, if you plan to travel outside of Agrace’s service area, please notify your team (see map). Advance notice will allow your team to try to arrange for backup hospice services in the area you are visiting or to connect you with other available services.

If I have a medical emergency, should my caregivers or I call 911?
You always have the right to call 911; however, in most situations, we ask that you or your caregivers call Agrace first about any urgent medical matter. If you are unsure what to do, please call Agrace; we can help you determine what care is needed and what to do next.
If you do call 911, please also call Agrace to tell us what has happened. We will make every effort to meet you at the emergency department to talk through treatment decisions.

There are two times when we advise patients and their families to call 911 first:
1. When a patient who wants to be resuscitated is having a cardiac or respiratory arrest (their heart or breathing has stopped).
2. When a patient has an obvious physical injury that requires emergency care, such as a bone fracture or a wound with severe bleeding.

Agrace’s Service Area
What are Agrace’s hospice residences?
They are two beautiful, peaceful places—in Madison and Janesville, Wisconsin—where you can choose to live while you are having hospice care from Agrace.

What care is provided?
All of the staff are specially trained to care for people who are receiving hospice care.

• Your Residence registered nurse case manager and social worker oversee and coordinate your care.
• Certified nursing assistants (CNAs) and licensed practical nurses (LPNs) help with your personal care and give you your medications.
• A counselor is available to talk with you about feelings, worries or spiritual concerns.

What is it like to live there?
• You have a large, private room with your own accessible bathroom and a patio where you can enjoy gardens, scenery and fresh air. (See photo galleries at agrace.org/residence.)
• Your meals are created to be comforting and satisfying. We use many locally sourced foods to support local farms and food producers.

• Family and friends can visit anytime and stay overnight in your room. You can use one of Agrace’s family/common rooms to share a meal with them, or celebrate a special event.
• Volunteers can visit to keep you company, read to you, play games or take you on walks or wheelchair rides. While services vary by location, volunteers may also offer:
  o therapy dog visits,
  o hand massages and Reiki,
  o haircuts and hair styling,
  o musical performances, and
  o help with hobbies, art and crafts.

What does it cost?
You pay a $365 daily fee for your room, utilities, housekeeping and meals. Your hospice care is covered by your health insurance, as it would be if you were at home. Financial assistance is available through Agrace, if needed.

What if you need urgent medical care?
If a higher level of care becomes necessary, you can have “acute” inpatient care at Agrace—usually staying in the same room while the staff adjust your care to meet your more complex needs.
Living at Agrace
It’s much more than medical care.

Ask your Agrace social worker for details about living at Agrace.
Tracking Your Questions and Symptoms

It is very important to ask your Agrace care team your questions and tell us your concerns or worries, so we can try to make you more comfortable. During our visits, we will ask you often whether you have concerns with pain, constipation, difficulty urinating or other symptoms. We will also ask if you need any medical supplies or medicine refills.

This section includes places for you to write down your questions and anything else that is concerning you between (or during) visits with your Agrace team.

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## Questions for Your Agrace Team

Please write your questions and the date below. Your team will check this book on every visit to make sure we address your concerns.

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# Bowel Movement Tracker

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Patient Support & Personal Care

Our goal is to make you as comfortable as possible. This section explains some of the symptoms you may experience, their potential causes and what can be done to help you find relief.
# Patient Support & Personal Care

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Food and Nutrition

It is common for people with life-limiting conditions to lose their appetite or desire to drink. Some people experience taste changes; favorite foods no longer taste good. Occasionally, people report that foods have an “off flavor” or “metallic” taste.

You may feel full or have no taste for food for many reasons:

- As body functions slow down, it signals the brain that food and fluids are no longer needed.
- You may feel nauseated by movement, medications or blockages due to tumors.
- Cancer cells can release chemicals that affect the appetite center of the brain.

As your condition declines, you may take only sips of liquids or small bites of foods that are swallowed easily. At some point, you may not take in anything at all.

What can caregivers do to support a person who is eating or drinking less?

- Ask the person what tastes best and how much food or fluid they want—then respect their wishes.
- Encourage them to rest before and after a meal.
- Make mealtime a quiet, pleasant time—candles, flowers, soft music and good conversation may help.
- Offer small meals and use smaller dishes.
- If nausea is a problem, serve small portions of salty (not sweet), dry foods and clear liquids.
- Offer drinks or sips often, but do not pressure them to eat or drink. Eating when not hungry may cause vomiting, nausea, choking or increased swelling of the hands or feet.
- To prevent choking, offer food and fluids only when they are awake and alert enough to eat and swallow.
- Offer a sipper cup or drinking straw if weakness makes it difficult to hold a cup steady.
- Clean their mouth often—a pleasant tasting mouth may make food taste better. If they are not eating or drinking, keep their lips and mouth moist for comfort.
- Let your loved one know it is OK to say “no” to food and fluids.
- Understand that delivering nutrition or fluids through an IV or feeding tube is not effective for people who are close to death. These measures may make a dying person more uncomfortable. Gradual dehydration at the end of life is not painful; it is the body’s natural response to the dying process.
- Find other ways to show love and concern, such as giving a massage, playing cards or reading aloud. Comfort and loving care are the most important things you can offer.
- Help other family members and friends understand why eating and drinking may cause a person who is dying to be uncomfortable. (See the back of this page for details.)
Patient Support & Personal Care

Continued from previous page

Intravenous artificial nutrition and fluids:

When a person is nearing the end of life, adding artificial food and fluids intravenously is not likely to make the person stronger or prolong their life, and it may cause discomfort.

- Artificial food and fluids given intravenously may make some symptoms worse because the body systems are slowing and the body cannot process the food and fluids it does not need. This may increase fluid in the lungs, create difficulty in breathing, and cause nausea, vomiting and urinary incontinence.
- Feeding tubes may put a person at increased risk for pneumonia and may also cause pain, nausea and vomiting.
- Tubes for food and fluids are potential sites for infection.

What happens if intravenous artificial food and fluids aren’t given near end of life?

- Dehydration from being unable to take in food or fluids does not affect the dying patient in the same way as a healthy person who feels thirsty on a hot day. (EPEC Project, 19991)
- The lack of fluids seems to produce a natural anesthetic effect, often allowing for a reduction of pain medication. (Printz, 19882)
- Dehydration will reduce urine output and often provides a decrease in awareness of pain and other uncomfortable symptoms. It may help contribute to a peaceful, comfortable death for many persons. (Printz, 19882)
- Near the end of life, if the person is unable to take any food or fluids, they will gradually become weaker and sleep more.

Will the person nearing death who does not receive artificial food and fluids be thirsty?

- Usually, the person does not experience thirst or hunger.
- If a person has thirst, it will only last a day or so, and ice chips or small sips of fluid with good oral care should relieve it.

What can be done to provide comfort?

- If the person is awake, it may be comforting to offer ice chips if they can be tolerated.
- The person will also benefit from frequent oral care with a mouth swab or sponge to relieve any dryness in the mouth.
- Moisten the person’s eyes or use a warm, damp cloth over them a few times each day.
- Moisten the person’s lips and apply lip balm or K-Y Jelly to prevent dryness.
- Use lotion without alcohol to maintain skin comfort.

1 EPEC Project, Module 11, 1999: “Withholding, Withdrawing Therapy.”
Confusion
Confusion is a mental clouding with less awareness of one’s environment, including uncertainty about time, place and person. It can be a sudden change in mental status, often occurring over a period of hours to days, and it can even change throughout the day.

Signs and symptoms:
- Reversal of sleep and awake cycles
- “Sundowning” or confusion that is worse at night
- Mood swings that may change over the course of a day
- Difficulty focusing attention or shifting attention
- Hallucinations or seeing, hearing or feeling things that are not there
- Agitation and irritability
- Drowsiness and sluggishness
- Disorientation
- An unawareness of surroundings

What can help address and reduce confusion?
Confusion is common at the end of life. It has many causes. Your Agrace team will try to find out what is causing the confusion, and they will discuss treatment options with you.

Here are a few things caregivers can do to help:
- Keep the patient safe.
- Remind the patient who you are when you assist with caregiving. Tell them what you are going to do. For example, “I am going to help you get out of bed now.”
- Try to maintain a routine and structure.
- Avoid asking the patient a lot of questions.
- Provide a quiet, peaceful setting without TV and loud noises.
- Play the patient’s favorite music.
- Keep a nightlight on at night.
- If the patient is starting a new medication, watch for improvement, worsening or side effects, and report to your Agrace team.

Notify your Agrace team anytime you have questions or concerns about confusion.
**Constipation**

Let’s face it: It’s no fun to talk about constipation or frequency of your bowel movements. But to keep you comfortable, your Agrace team must ask you about your bowel habits—often—because what is normal may change while you are ill and on medication. We will ask what words you prefer to use to talk about bowel movements (for example, “stool,” “poop,” “BM”). There is a bowel movement tracker in the “Tracking” section of this handbook where you can record information for your care team.

**Signs and symptoms:**

If you are constipated, you may experience these symptoms:

- No bowel movement for more than two or three days
- Change or decrease in your regular pattern of bowel movement
- Having bowel movements that are uncomfortable and difficult for you to pass
- Passing small, lumpy and hard stools
- Straining to have a bowel movement
- Moving your bowels, but still feeling uncomfortable—such as having abdominal discomfort, bloating, nausea, hemorrhoids or even diarrhea

The following may cause less frequent bowel movements and difficulty passing stools:

- Decreased activity
- Older age or weakness
- Eating and drinking less
- Medication use (Your care team will discuss your medications and tell you which ones may cause constipation.)

**What you can do to help prevent or relieve constipation:**

- Talk to your Agrace team about your bowel movement patterns (it may help to use the tracker in the “Tracking” section of this handbook).
- Drink more fluids, if you can—especially water. Or try hot lemon water, warm prune juice and other juices. Drink as much fluid as is comfortable.
- Increase your fiber intake, if you can. High-fiber foods include fresh fruit and vegetables, oatmeal, wheat breads and grains, or brown rice.
- Use bowel medications as recommended by your care team and doctor.

**When should you call your care team about constipation?**

- You have a change in the color, texture, smell or frequency of your bowel movements.
- You are having difficulty passing stool.
- You have gone longer than two to three days without having a bowel movement.
- Your belly is firm or painful.
Emotional Distress

Are you feeling nervous, upset, sad, depressed, restless or anxious? When you are seriously ill, it is natural and expected to have some of these unpleasant feelings. “Emotional distress” can affect your sleep, mood, energy level, appetite, mental focus, memory, desire to take care of yourself and your ability to be with other people.

Anytime you are having unpleasant feelings, no matter what kind, please talk to your Agrace care team about what is happening. We may not be able to make the feelings go away, but we can help you manage better. There are medicines that can help manage distressing feelings, and many other ways to find relief without using medicine that you and your caregivers can try at home.

Signs and symptoms of anxiety, sadness, depression and restlessness:

Anxiety

Feeling nervous, bothered, worried or filled with dread can all be “anxiety.” These emotions are natural as you go through changes to your body, your mind and your life that are beyond your control. Anxiety can be hard to recognize because there are many ways you may react to it:

- Feeling tense, not able to relax
- Feeling of butterflies in stomach or lump in throat
- Muscle tension, aches, soreness
- Feeling very tired or exhausted
- Trouble falling asleep or staying asleep, or having nightmares
- Worrying about what could or may happen
- Sweating/flushing
- Headache
- Cold, clammy hands
- Dry mouth
- Diarrhea
- Urinary frequency
- Trouble concentrating
- Feeling that small tasks seem hard to do
- Getting upset about things that normally would not upset you
- Feeling that heart is beating too fast
- Panic or extreme nervousness, feeling something needs to be done but unable to do anything
- Trouble breathing
- Increase in pain

Feeling anxious can be uncomfortable, but if you and your Agrace care team can discover what is causing your anxiety, we can help you try to find relief. Please let us know what you are feeling.

Sadness

The losses you experience during your illness—loss of self-worth, of hope, of the ability to do the things you like to do, of the ability to communicate and care for yourself—may make you sad or “down.” Sadness may come and go. You may show sadness by crying or:

- Getting upset about things that normally would not upset you
- Feeling very tired or exhausted
- Having trouble concentrating
- Feeling that small tasks seem hard
- Wanting to be alone more than usual
- Having less interest in activities you once enjoyed

Continued on next page
Agrace can offer support that may help you find some relief from sadness. Please talk with any member of your care team about what you are feeling.

**Depression**

Depression is sadness or hopelessness that seems like it will never end. It gets in the way of your daily functioning and may cause you physical pain. You may have some of the signs of sadness shown on the previous page, as well as sleeplessness, sleepiness or lack of appetite.

*The most serious sign of depression is having thoughts of suicide.* Depression lasts, but it is treatable. Please ask your Agrace team for help.

**Restlessness/Agitation**

Some people become restless or physically agitated during a serious illness. Depending on your diagnosis, this may happen in the last days—or it could start much earlier. Regardless of when these feelings start, they may cause you to:

- Not be able to relax
- Pull/pick at clothing or bed linens
- Cry out/moan
- Make faces, clench your teeth
- Have trouble breathing
- Attempt to remove clothing
- Constantly move in bed or try to get out of bed
- Sleep very little

Restlessness and agitation can be related to fear or emotional/spiritual concerns about the end of life, or it may have an **underlying, treatable cause**, such as pain, constipation, inability to urinate, lack of oxygen, trouble breathing, infection (urinary or pneumonia), low blood sugar or medication side effects. Your Agrace team will look for both physical and emotional causes if you are feeling restless or agitated.

**What can be done to relieve emotional distress?**

**Feelings**

- Talk about your feelings, fears and concerns with someone who will listen and provide support, including family, friends, doctor, clergy and/or your Agrace care team.
- Allow yourself to cry.
- Keep a journal and write about your fears, feelings, concerns and/or things that are happening in your life. If you have difficulty writing, speak into a recorder, record on a smartphone or ask someone to write for you.

**Relaxation**

- Enjoy a relaxing activity: take a hot bath, color, read a good book or watch a favorite movie.
- Listen to soothing music.
- Take a short walk or find a place where you can relax for a while.
- Take slow, deep breaths.
- Take time to rest, and practice being kind to yourself.
- Try to keep to a regular routine.
Comfort

• Find new ways to enjoy your favorite activities, and surround yourself with things that feel good. For example, if you enjoy gardening, put flowers in your home.
• Read, have someone else read to you, or listen to an audiobook. Put books you enjoy—or have always wanted to read— around you.
• Let the sunshine in, and enjoy sunny days when possible.
• Talk with someone you trust, pray, use relaxation techniques or get a massage.

Interaction with People

• Keep in touch with your friends by phone, text, email or writing letters, if you are able. Have a volunteer write for you if you cannot write yourself.
• Invite family and friends to visit when possible.
• Ask for help when you are unsure about what you need.
• Continue making your own choices and decisions about your care.
• Make a list of things you want to do, break the list into small jobs, and ask friends to help. Celebrate small progress.

Suggestions for family/caregivers:

• Treat your loved one with respect, empathy and patience. Gently reassure them and give them time to talk about any worries.
• Continue to offer hope, and find joy in all victories, no matter how small. If your loved one has had a good day, offer encouragement: “You did have a really good day,” and “I’m proud of you.”
• Be flexible. Your loved one may want to talk one day and need quiet the next.
• Listen without minimizing their thoughts or feelings. Say, “Tell me more about that.”
• Be willing to be with your loved one without having to “do” something. Hold their hand or otherwise use touch, as appropriate, to comfort them.
• Provide a calm, relaxed setting if this is comforting to your loved one.
  › Turn down bright lights.
  › Keep the room as peaceful and quiet as possible.
  › Try playing soft, soothing music.
  › Explain to visitors the need for quiet, soothing surroundings.
• Talk in a calm voice. When giving care, softly explain what you are doing.
• Take time for yourself. Ask someone to stay with the patient while you rest, go for a walk, run an errand or do an activity you enjoy.

If your loved one is restless or agitated:

› Help them change positions (such as from sitting to lying down).
› Change their location/environment, if possible—help them move to a different room or open a window.
› Pad their sides with pillows or place pillows against the bedside rails for safety.
› Make sure someone is always with them; ask family and friends to help.

Anytime you are concerned about emotional distress, no matter what kind, please talk to your Agrace care team about what is happening.
Fatigue

Fatigue can be described as tiredness, exhaustion or lack of energy. It is a condition that affects the ability to perform any activity. This symptom can have many causes (including being a side effect of some pain medications) and is experienced by many of our hospice patients. It may also be associated with depressed feelings.

Signs and Symptoms:

- Unable to perform your normal activities
- Lack of appetite—do not have the energy to eat
- Sleepiness
- Not talking
- Feeling depressed

What can help relieve fatigue?

Because fatigue is a complex problem, it takes a group of actions to help reduce the symptoms. The Agrace team will work with you, your caregiver and your health care provider to find the causes for the fatigue and discuss treatments.

Here are some steps you can try:

- Gradually increase your activity.
- Conserve energy:
  › Plan, schedule and prioritize activities for the best times of day.
  › Keep a log of which time of day seems to be your best time.
  › Eliminate or postpone activities that are not a priority today.
  › Change your position. Do not just stay in bed.
  › Use sunlight/light source to help your body feel energized.
  › Try activities that restore your energy.
  › Encourage your family to be accepting of your new energy level.
  › Rearrange your environment to reduce exertion. For example: move your phone next to where you sit or lie, move your chair or bed as close as possible to the bathroom.
- Rest and sleep better:
  › Listen to your body. Rest as needed.
  › Establish and continue a regular bedtime and waking time.
  › Avoid interrupting sleep time to get continuous hours of sleep.
  › Plan rest times or naps during the late morning and mid-afternoon.
  › Avoid sleeping later in the day, which could interrupt your nighttime sleep.
  › Ask Agrace if using oxygen when you sleep would help you sleep better.
- Increase food intake:
  › Try nutritious, high-protein, nutrient-rich food.
  › Eat favorite foods or drinks.
  › Have small, frequent meals.
  › Add protein supplements to foods or drinks.
  › Do frequent mouth care (before and after meals).
  › Ask your Agrace team about possible use of medications to stimulate your appetite. A dietician is available if more information or assistance is needed.

Notify your Agrace team anytime you have questions or concerns about fatigue.
Nausea and Vomiting

Nausea is an unpleasant feeling that may occur in the back of the throat or stomach prior to vomiting. Vomiting is the emptying of the stomach contents. Nausea and vomiting are symptoms that can prevent you from getting enough food and nutrients, rest and comfort. Fortunately, nausea and vomiting can often be prevented and treated.

Signs and symptoms:

Nausea and vomiting may be caused by:

- Medications, such as chemotherapy, antibiotics, aspirin and many others; Ask your Agrace nurse if the medications you are taking could cause nausea and vomiting
- Damage to the stomach and intestinal lining from the disease process or treatments for the disease
- Anxiety
- Uncontrolled pain
- Motion sickness (travel-related)
- Some infections
- Constipation or diarrhea
- Coughing—thick secretions and/or coughing may trigger vomiting
- Some foods
- Strong odors

What can help prevent or relieve nausea and vomiting?

There is much you, your caregivers and the Agrace team can do for nausea and vomiting. The team will always try to discover the underlying cause and discuss treatments with your health care provider. If you can control nausea, you can often prevent vomiting.

Here are some suggestions to prevent and control nausea:

- Caregivers should provide small, frequent meals of foods chosen by the patient. Large meals can feel overwhelming.
- Try foods such as:
  - Toast and crackers
  - Sherbet
  - Pretzels
  - Angel food cake
  - Chicken without skin (baked or broiled)
  - Fruits or vegetables that are soft or bland (potatoes, canned peaches)
  - Ginger, herbal remedies
  - Carbonated drinks that have gone flat
  - Sports drinks (such as Gatorade®); with children use Pedialyte®

- Do not offer these foods:
  - Fatty, greasy or fried foods
  - Spicy, hot foods
  - Dairy products, such as milk or ice cream
  - Foods with strong odors
  - Citrus foods, such as oranges and grapefruit, and acidic juices, such as cranberry, grape and apple
  - Foods containing caffeine, such as coffee or chocolate

Continued on next page
You can also try these tips:

- Eat foods at room temperature or cooler. Hot foods may trigger nausea.
- Suck on ice chips or take frequent sips of a liquid such as ginger ale.
- Avoid drinking liquids with meals.
- Caregivers should provide frequent mouth care to the patient.
- Avoid strong odors such as perfume and deodorizers.
- Maintain a comfortable room temperature.
- Avoid constipation.
- Choose a quiet, relaxing, pleasant atmosphere for meals. Avoid eating in a room that is stuffy, too warm or has cooking odors or other strong smells.
- Caregivers may need to avoid cooking strong-smelling foods in the patient’s presence.
- Try relaxation techniques, such as deep, controlled breathing and focusing on pleasant thoughts.
- Don’t force eating—even favorite foods—when nauseated. This may cause a permanent dislike of those foods.
- Rest after meals because activity may slow digestion. It is best to rest sitting up for about one to two hours after meals.
- If nausea is a problem in the morning, try eating dry toast or crackers before getting up. Keep a supply next to the bed.
- Wear loose-fitting clothes.
- Try to keep track of when nausea occurs and what causes it (specific foods, events, surroundings). If possible, make changes in diet or schedule. Share the information with your Agrace team.
- Ask your doctor or Agrace nurse about specific medications to help control nausea.

Here are some suggestions for coping with vomiting:

- Caregivers: Turn the patient’s head to the side to prevent choking.
- After vomiting, rinse your mouth with water and brush your teeth.
- Place a damp, cool cloth on your forehead, neck and wrists.
- Do not drink or eat until the vomiting has stopped.
- Once the vomiting has stopped, try small amounts of clear liquids (apple juice, bouillon, gelatin). If you are unable to tolerate any fluids, please call your Agrace nurse.
- Once clear liquids stay down, try non-clear liquids. Gradually work up to a regular diet. Your Agrace nurse can help with ideas and suggestions.

Notify your Agrace team anytime you have questions or concerns about nausea and vomiting.
Pain

We all know that pain is hurting or discomfort. We think of pain as physical suffering, but it can also be emotional or spiritual suffering. In any case, it is an experience that can only be felt and described by the person with the pain.

Understanding your pain:

Pain should be reported to the Agrace team. Use these suggestions to communicate effectively:

• Report the severity or intensity of the pain as a number, using a scale from 0 as no pain to 10 as the worst possible pain imaginable. Other ways of reporting pain are also available, such as faces or descriptive words. Ask your nurse to tell you more about these options.
• Where is the pain?
• Is it new pain?
• Try to describe the pain. Here are some words you might use: shooting, dull, burning, constant, squeezing, aching, pressure, gnawing, stabbing or deep.
• Does the pain keep you from doing usual activities?
• What makes the pain worse?

What can help relieve and prevent pain?

There is much you, your caregivers and the Agrace team can do to manage your pain. The team will try to find the reason for the pain and discuss treatments with you.

• Medications are often necessary to relieve pain. Your Agrace nurse will give you information about the medicines, when they should be taken and what you should know about them. It is important for the medicines to be taken as ordered.
• Report any medication side effects to your nurse. Side effects can often be treated and may stop after you have taken the medication for a few days.
• In addition to medication, there are many other things that might help the pain; a few are listed here. Consider trying them, and ask your Agrace team if you want information about these or other ideas for pain relief:
  › Relaxing activities
  › Distracting activities, such as watching TV, humor, listening to music, playing with a pet or playing a game
  › Breathing exercises
  › Soaking in a tub
  › Guided imagery ( picturing relaxing scenes to distract the mind from the pain)
  › Heating pads or warm compresses
  › Cold, such as an ice pack
  › Smells of certain essential plant oils (aromatherapy)
  › Light massage
  › Acupressure or acupuncture
  › Reiki

Continued on next page
Helpful pain medication facts:

- For hospice patients, opioids (narcotic pain relievers) are the most commonly used medications for managing moderate to severe pain because of their effectiveness, ease of dosing and very minimal risk of severe side effects compared to their benefits.
- Many people have concerns and fears about taking morphine and other opioids. This is often because of misconceptions or a lack of information.
- Morphine and other similar medications are very safe when used correctly. Hospice patients are able to utilize these medications safely for many reasons.
  - All Agrace staff receive extensive training in how these medications work in the body to relieve pain, how to give safe doses of the medication and which patients would benefit from taking these medications.
  - After patients have been on medications like morphine for a while, their bodies adjust and higher doses may be needed to provide relief. This can be done safely without causing long-term side effects. Just as people often need changes in blood pressure medicine over time, people often need changes in their pain medication.
  - Unlike other pain relievers, such as acetaminophen (Tylenol) and ibuprofen (Motrin, Advil), there is no limit to an opioid dose. Therefore, dosages can safely continue to increase throughout the progression of the disease.
  - Addiction very rarely, if ever, occurs in patients who take medications for pain. Research has shown that less than 1 percent of all patients who take medications like morphine for pain develop any signs of addiction.
  - Agrace staff, along with your physician, follow dosing standards suggested by the World Health Organization, the Agency for Health Care Policy and Research and the American and International Pain Societies. These dosing standards have been proven safe in numerous studies.
  - It is important to keep track of how much extra or “breakthrough” pain medication you take. Ask your Agrace team about the best way to do this.

Medication (narcotic) side effects:

All medicines can have some side effects. Not all people get side effects from their medications, and some people have different side effects than others. Most can be easily managed.

Many side effects happen in the first few hours of treatment and gradually go away. You should not stop taking pain medicines—if you have side effects, call your Agrace nurse for help finding relief.

Here are some common side effects of pain medicines:

- **Constipation** (not being able to have a bowel movement). See page 14 for tips to relieve constipation.
- **Nausea and vomiting.** This sometimes happens when you start a new medication or have your dosage changed. It usually only lasts for the first day or two, while your body adjusts. See pages 19 and 20 for tips.
- **Sleepiness.** Some people who take pain medicines may feel drowsy or sleepy when they first take the medicine.

*Notify your Agrace team if you have concerns about pain, medication or alternative treatments for pain.*
**Trouble Breathing (Shortness of Breath)**

Shortness of breath is an uncomfortable feeling of having trouble breathing. You may feel like you cannot catch your breath, like the room is closing in or like there is not enough air in the room. It is a unique experience for each person.

**Signs and symptoms:**

- A restless or anxious feeling
- A feeling as though you are not getting enough air
- Tiredness
- Fast breathing
- Shortness of breath may also cause feelings of fear, nervousness, helplessness, anger, frustration or sadness

There are also some things that may cause or increase feelings of shortness of breath:

- Anxiety
- Movement
- Exercise
- Posture
- Coughing
- Secretions
- Climate, especially heat and humidity
- Infection

**What can help relieve breathing trouble?**

The Agrace team will try to discover the underlying cause of your breathing trouble and discuss treatments with your doctor. There are several ways to help decrease these feelings:

- **Medications:** Many different types of medicines can help improve shortness of breath such as narcotics, steroids or inhalers.
- **Oxygen therapy:** Not everyone will benefit from oxygen. Your nurse will assess your breathing comfort at each visit and discuss the need for oxygen with your doctor. Use oxygen only as directed by your Agrace team.
- **Try to identify what increases your feeling of breathlessness and let your Agrace team know.** They can then help you to plan activities so you can breathe easier.
- **Conserve energy.** Rearrange your environment to reduce exertion. For example, move your phone next to where you sit or lie. Move your chair or bed as close as possible to the bathroom.
- **Plan activities to conserve energy.** Schedule activities so that you have rest time. For example, eat first, then rest, then bathe. Also, try to conserve energy so that you can do those things you find enjoyable; for example, rest before going out.
- **Position yourself to help with chest expansion.** Sitting upright and leaning forward helps air to move in and out of the lungs. You may also find that lying on one side more than the other helps. Try placing pillows under both arms when in bed.
- **Eliminate allergens like smoke, dust and mold.**
- **Use a cool mist humidifier to increase the moisture in the room.** Increase air movement by using an open window or fan.
- **Focus on your breathing; take slow, deep breaths or use breathing exercises that the Agrace team has taught you.**
- **Try relaxation techniques, music and visualization.** Your Agrace team can suggest techniques and teach you how to use them.
- **Be sure clothing around the neck and chest is loose and lightweight.**
- **Breathing through your mouth may cause dryness.** Try ice chips or a cold, moist washcloth to relieve feelings of dryness of the mouth.
Infection Prevention

Infections are caused by germs such as bacteria or viruses. They cause common illnesses, such as colds and the flu, and serious diseases like whooping cough and tuberculosis. Most germs are spread by contact, often on unclean hands.

Having clean hands is the single most important way to prevent any infection. You may clean your hands by washing with soap and water or by using an alcohol-based rub.

Traditional soap and water:
- Soap and water must be used when your hands are visibly dirty, before handling food, when there is an infection that causes diarrhea, and after assisting others to the restroom or using it yourself.
- Wet your hands with warm water and liquid soap (if available) and then scrub for 10 to 15 seconds. Rinse well with warm water.
- Dry your hands with either paper towels or a clean towel.

Alcohol-based hand rub:
- Alcohol-based hand rubs are the preferred method to clean your hands when your hands are not visibly soiled.
- They must contain at least 70 percent alcohol to be effective.

Other strategies for preventing infections:
- Instruct visitors to clean their hands before and after visiting you. Do not allow entry to a visitor who has a cold, an uncontrolled cough or a fever, or is not feeling well.
- If your caregiver is ill, it is best to relieve that person of caregiving duties until they are well again. If this is not possible, the caregiver must use good hand hygiene, wear gloves and even wear a mask. Your Agrace team can provide these materials if you need them.
- Standard precautions: These procedures are used by the Agrace team and should also be used by caregivers.
  - Agrace staff will wear gloves for contact with blood, body fluids, secretions and excretions (except sweat), mucus membranes (eyes, nose, mouth, vagina and rectum) and non-intact skin (wounds, scrapes, cuts, etc.), as well as for handling contaminated equipment or supplies. Family caregivers should do the same. Throw gloves in the trash immediately after use, and clean your hands.
  - Gowns, masks and eye protection are worn by our staff during procedures that may generate a splash of blood or body fluids.
  - Contaminated equipment and supplies will be disposed of appropriately and disinfected prior to re-use.
  - Surfaces, especially those frequently touched by the patient, should be routinely cleaned and disinfected. Products like Lysol® or bleach wipes work well for this.
  - Handle used bedding, towels and clothing minimally and keep them away from your body. Rolling them into a ball works well. Launder with detergent and warm water; bleach can be added if you choose.
  - Do not recap, bend, break or hand-manipulate used needles. Use safety needles as your first choice. If that is not possible, scoop the cap to cover the used needle without using your other hand. Dispose of used needles and other contaminated sharp objects in a puncture-resistant red sharps disposal container as soon as possible. Learn about safe disposal of needles at home at http://dnr.wi.gov/ (search for “household sharps”), or www.epa.illinois.gov/ (search for “needle disposal”).
  - Find a list of places in Wisconsin where you can drop off filled sharps containers at http://dnr.wi.gov/ (search for “sharps collection stations”).
  - In Illinois, see www.knib.org/recycling/green-guide/needles-sharps/ for information on safe disposal of needles.
Preventing Falls and Related Injuries

Falling in your home can lead to serious, painful injuries, including head trauma and broken bones. Your Agrace team wants to help you stay safe and maintain your independence by following the important steps below to prevent falls and injuries.

Safety where you live:

• Arrange furniture so there is a clear path for walking.
• Remove throw rugs or secure them with non-slip backing.
• Remove objects from the floor, such as shoes, papers, books, towels and blankets.
• Clear wires or cords from walkways.
• Ensure lamps, night lights and light switches are within easy reach.
• Install handrails on stairs.
• Add grab bars in your bathtub/shower and near your toilet.
• Add a non-slip mat to the floor of your tub or shower.
• In the kitchen, move items to low shelves to avoid having to use a step stool. If a step stool is necessary, use a sturdy stool with a bar to hold.

Getting to the restroom:

• Set up a schedule for using the toilet, so you don’t have to rush to get there.
• Talk to your team about testing for a urinary tract infection if you have increased urgency or more frequent incontinence.
• Talk to your team about the pros and cons of a urinary catheter.

Improving your vision:

• Make sure your eyeglasses are clean and placed where you can reach them.
• See your eye doctor for a vision check to ensure you have the appropriate prescription.

Safety when standing or walking:

• Talk to your Agrace team if you have concerns about your steadiness or safety when walking or standing up. Your team can assess your needs and make recommendations.
• Follow your team’s advice for walking and transferring out of bed/chairs safely (see pages 26 – 27 for details).
• Ask your team for devices that might increase your function and safety, such as a walker, a lift or a bedside commode.
• If you have moments of sudden weakness, use extra assistance to keep your balance.

If you fall, please call Agrace as soon as you can. A nurse will visit you to look for any injury, treat your injury and discuss ways to prevent you from falling again.
Mobility Techniques & Caregiver Tips

Due to physical decline and/or weakness, you may have limited mobility or only be comfortable when in bed. This section contains instructions for your caregivers that can help keep you—and them—safe from injury while they are helping you transfer from one position to another.

Universal tips for caregivers assisting a patient with mobility:

• Clear clutter to create a safer environment for movement.
• Transfer on the strong side of the person receiving assistance.
• When lifting or moving people, always face them, and keep them—as well as equipment and supplies—close to your body.
• Bend your knees, and kneel or squat to lower your body to the height where you are working. Keep your back straight, and distribute weight to your thighs and buttocks rather than your back.
• Do not twist when turning; pick up your feet and pivot your whole body in the direction of the move.

Using a gait belt to improve stability and balance:

When a person with balance problems needs help transferring from one position to another, a gait belt can be used to aid the patient’s stability and balance, reduce the risk of falls and improve safety for the caregiver. A gait belt should not be used to lift a person who is too weak to stand on their own for a brief period of time.

• Bring the belt around the middle of the patient’s waist.
• The teeth of the gait belt buckle should be on the outside. Feed the belt through the teeth and tighten.
• Buckle the belt and ensure it is snug, with enough room for your hand to comfortably grasp belt. Two fingers should fit snugly under the belt.
• Hold onto the belt to provide the patient extra support while moving.

Using a hospital bed:

• Make sure the brakes are locked at all times, except when moving the bed.
• Raise the bed to waist height when providing care, to avoid reaching and bending.
• Always put the bed in the lowest position when getting the patient out of bed.

Continued on next page
Repositioning a patient in bed, from back to side:

- If necessary, give the patient a dose of pain medication before moving them.
- If using a hospital bed, lower the head of the bed, and raise the rail on the side toward which the patient will turn.
- Then, move to the opposite side of the bed; lower the rail, if applicable.
- If possible, slide the patient closer to you, so you can reach them without overextending your arms.
- Place your hands on the patient’s closest shoulder and hip, and gently roll them away from you; they may be able to assist by grabbing the opposite rail.
- Place a pillow behind the back for support, and add others between the legs, if needed to hold this side position. Move to face the patient, then pull their bottom shoulder slightly out and toward you.
- Adjust the head pillow for comfort, and provide blankets.
- If the patient cannot help in turning, a friction reducing device (aka “FReD”) and a lift sheet can be used to help move them without pulling on their body. Your Agrace team will instruct you on use of the “FReD” and lift sheet, if those aids are needed.

Changing bed sheets with the patient in the bed:

- If using a hospital bed, have the patient grab the side rail to roll away from you, and position them with pillows for stability.
- Remove the dirty sheet and roll it under the patient.
- Attach the top and bottom corners of a clean sheet to the mattress.
- Smooth the clean sheet, and fold and tuck both sheets under the patient.
- Roll the patient back to the clean side, over the clean and dirty sheets.
- Pull out the dirty sheets. Pull the clean sheet tight and attach the corners.
- A lift sheet and/or bedpan can be added at this time while the patient is still on their side.

Assisting the patient from lying to sitting:

- Go to the side of the bed where the patient will sit.
- If possible, raise the head of the bed so the patient is in a sitting position.
- Roll the patient toward you, with their arm reaching for the side rail (if using a bed with rails) and with their legs by edge of bed. Use your body to prevent them from coming off the mattress.
- Ask the patient to push up with their arms and swing their legs over the edge of the mattress at the same time.
- If possible, lower the bed to the patient’s sitting height.
- Provide verbal countdown and cues. Keep your knees flexible and your back straight. To assist the patient, lift their shoulders with one hand and use your other hand to move their legs off the bed. Keep your body in front of the patient.
- Ensure the patient is stable before having them scoot forward so their feet can touch the floor.
Rising from sitting to standing position:

- Ensure that the patient is wearing non-skid socks or shoes.
- Put the gait belt onto the patient, and then stand facing them, as close as possible.
- Place one foot slightly behind the other for balance, with your weight equally distributed between both feet.
- Have the patient scoot forward until their feet are flat on ground.
- Bend your knees and keep back straight. Grasp the gait belt from underneath.
- Use a gentle rocking motion to take advantage of momentum to aid them to standing position by pulling on the gait belt (not lifting). Use verbal cues such as “On three, I want you to push up with your arms from the bed/chair to stand.”

If you are moving to any type of chair after standing, incorporate the following steps:

- Place the chair to which the patient is transferring at a 90-degree angle on the patient’s strong side.
- While standing, rock back and forth in a dancing motion to pivot the patient until the back of their knees touches the surface of the chair.
- Have the patient reach back to hold the armrests. Lower them by bending your knees, but keep your back straight. Remove the gait belt after they are seated.

Walking assistance:

- Put the gait belt onto the patient and allow them to stand for a few seconds to establish balance and reduce dizziness before walking.
- Support the patient by placing one arm around the waist and holding the gait belt. Walk alongside the patient and move at their pace, looking for signs of needed rest (breathing difficulty, unsteadiness).
- Keep path clear from items, including oxygen tubing. While walking, if you find that you can no longer manage assisting or if the patient feels like they are unable to remain standing, ease them to the floor slowly and get help.
- A patient should not use a walker or a cane alone until shown how to use it properly.

Using a shower chair or a bath bench:

- When weakness prevents the patient from standing for long periods, a shower chair or bath bench can be used for safety when bathing.
- The patient should never use a shower chair or bath bench when alone, if they are too weak to do so independently.
- Make sure a chair or a bench is secured in the tub, and dry the equipment before use to reduce slipping.
- Placing a towel on the seat can help prevent the patient from sliding off.
Protecting the Skin

Your skin is your immune system’s first line of defense against infection, so protecting skin from injuries or breakdown is very important, especially if you are staying in the same position for much of the day.

Watch daily for signs or risks of skin breakdown:

- reddened areas that do not fade
- open areas or blisters on the skin
- a worsening of any open area of skin
- any changes in your ability to turn or change position
- difficulty in changing position because of weakness or pain

What can help keep your skin healthy?

- Wash with warm water and mild soap.
- Avoid friction or rubbing.
- Clean your skin after each soiling.
- Use alcohol-free lotions to moisturize dry skin.
- Do not massage reddened areas.
- Apply moisture barrier creams or ointments to fragile skin that comes in contact with moisture.
- Raise heels off of the bed by placing pillows under calves and knees for support.
- Change position at least every two hours while in bed and every one hour if sitting up in a chair.
- Keep the angle of the head of your bed at less than 30 degrees when you are not eating or drinking.
- Remove restrictive clothing, such as TED stockings, to allow your skin to breathe.
- Use pillows to protect bony prominences from extended periods of pressure (i.e., between ankles, knees, behind back, under elbows, under calves to float heels).
Oral (mouth) Care

Good oral (mouth) care may help prevent bad breath, dryness, infections and irritation and may help increase appetite. Keeping the mouth moist and clean is important for comfort. The membranes of the mouth and the lips are very sensitive and can become uncomfortable when dry. A dry mouth can be caused by decreased fluid intake, decreased saliva, mouth breathing, using oxygen, some medications and some treatments.

Watch daily for signs of dry mouth:

- Dried, flaky, whitish-colored saliva in the mouth.
- Dry, cracked or chapped lips.
- Difficulty swallowing.
- Thick saliva or mucus that stays attached to the lips like strings.

What can help your mouth stay healthy?

Try these oral care tips and techniques, with a caregiver’s assistance, if needed:

- Clean mouth and lips with a soft toothbrush or toothette every morning, after meals and at bedtime. Avoid abrasive and alcohol-based mouth rinses. Use a solution of one teaspoon of baking soda and ¼ teaspoon of salt in a glass of warm water to rinse the mouth.
- Use mouth swabs to keep mouth moist and clean. Dip a sponge in water and gently rub on gums, teeth and tongue. You also may be able to suck on the sponge.
- Eat cold, soft, bland foods, such as popsicles, shaved or crushed ice, frozen juices and ice cream, if able.
- Drink fluids with and between meals.
- If swallowing is difficult, place ice chips or frozen juices in a washcloth and suck on it.
- Avoid alcohol; tobacco; rough foods such as hard bread, toast, crackers, potato chips and pretzels; spicy foods and citrus juices, all of which can cause irritation.
- Suck on sugarless hard candy.
- Rinse mouth frequently with water.
- Do not lick lips; this can cause chapping. Apply K-Y Jelly or lip balm to lips every two hours.
Incontinence & Toileting

Patients with limited mobility may need assistance with toileting and may have issues with urinary incontinence. Here are steps you and your caregivers can take to manage these personal care issues.

Managing urinary incontinence:

Urinary incontinence is the inability to control urination. You may leak urine or may not be able to hold your urine at all. These are some causes of urinary incontinence:

- Use of medications such as diuretics (water pills), sedatives (sleep aids) or alcohol
- Inability to reach the bathroom quickly
- Constipation
- Confusion
- Anxiety or nervousness
- Urinary infections
- Side effects of radiation treatments

What can help you manage incontinence?

Managing urinary incontinence can prevent discomfort, skin problems and possible infection. Your Agrace nurse and CNA can help you determine what may be the most helpful. Here are some suggestions:

- Take diuretics, if ordered, early in the day.
- Use adult briefs (Depends/Attends), pads, shields and/or protective bed pads to catch the urine.
- Change soiled briefs, pads or linens immediately to prevent skin breakdown.
- Clean the area with soap and water after each incontinent episode. Dry well. A barrier cream may be helpful to prevent skin irritations. Your Agrace nurse can recommend creams to help prevent skin problems.
- Check for wetness every two hours.

Caregivers can assist by:

- Asking you frequently if you need to use the urinal, bedside commode or bedpan. Place these items close by, for convenience.
- Moving you closer to the bathroom, if possible.
- Offering assistance in taking you to the toilet.
- Encouraging you to drink less fluid late in the day.
- Offering reassurance and understanding of the problem.

Caregiver tips for assisting the patient with use of a bedpan:

- Use gloves when assisting the patient on and off a bedpan.
- Roll the patient to one side.
- Place the bedpan squarely under the buttocks with the thinner end of the pan near their waist.
- Place a towel or Chux (disposable plastic pads) under the bedpan to protect the sheets.
- Roll the patient back over on top of the bedpan.
- Check to make sure the bedpan is in the right position.
- If able, place the patient in a sitting position.
- Stay nearby for safety.
- When the patient is done, lay their head down and carefully roll them to one side.
- Remove the bedpan.
- Help cleanse the area, if assistance is needed, and pat dry.
- Roll the patient back.
- Dispose of waste in toilet and clean out bedpan.
- Remove gloves and wash hands. If the patient has assisted, they may need to wash their hands as well.
Managing a urinary catheter:

A urinary catheter drains urine continuously from the bladder through a plastic tube into a bag. It is held inside your bladder by a small balloon filled with sterile saline. The catheter eliminates the need to use a bedpan or toilet for urination, but a bedpan is still needed for a bowel movement.

What caregivers can do to help:

- Wash your hands with soap and water before and after handling the catheter, tube or bag.
- Keep the bag below the level of the patient’s bladder at all times.
- Check frequently to be sure there are no kinks or loops in the tubing and that the patient is not lying on the tubing.
- Do not pull or tug on the catheter.
- Wash around the place where the catheter enters the body with soap and water twice each day and after each bowel movement.
- Do not use powder around the catheter entry.
- Periodically check the skin around the catheter entry site for signs of irritation, redness, tenderness, swelling or drainage.
- Offer fluids frequently, especially water or cranberry juice.

Emptying the catheter bag: The catheter bag should be emptied as often as needed or at least every 12 hours. Leg bags, which are smaller bags attached to the leg, should be emptied every three to four hours.

- Gather gloves, a container to collect urine and an alcohol swab.
- To empty the bag, follow these steps:
  › Put on gloves.
  › Remove the drainage tube from its sleeve (on the bag) and point it into the container.
  › Unclamp the drainage tube. Try not to touch the end of the tube to any surface.
  › Let the urine drain into the container.
  › Reclamp the tube.
  › Clean the tip of the drainage tube with an alcohol swab.
  › Re-insert the tube into the sleeve.
  › Empty the container into the toilet.
  › Rinse container to prevent odor.

Common catheter concerns and suggestions:

- After catheter insertion, you may feel mild burning or a need to urinate. This is a common feeling.
  › Try deep breathing, relaxation exercises or a diversion such as reading or watching TV.
  › Call the Agrace nurse if these symptoms persist for more than a day or two.
- The urine is dark or amber-colored. This can be caused by some diseases and medicines, or can occur when you do not drink a lot of fluids.
  › Encourage and increase fluids as tolerated.
  › Ask the Agrace nurse whether your illness or medications can cause dark urine.
  › Monitor for fever and discomfort.
- No urine has drained into the tubing or bag.
  › Try changing your position.
  › Check for leaking around the site where the catheter enters the body.
  › Check to see if there is fullness, pressure or pain in the lower abdomen.
  › Call the Agrace nurse if there is leaking, discomfort, pressure or you have tried everything else and you still see little or no urine in the bag six to eight hours after you emptied it.

Notify your Agrace team anytime you have questions or concerns about incontinence, bedpan use or catheters.
How to get your medications:

As an Agrace patient, you can continue to get medications from your pharmacy. Some will be billed through Agrace. Others may be billed the way they were before you enrolled with Agrace; your care team will review this with you. Agrace will tell your pharmacy that you are in our care, and we will work with them to make sure medications are billed correctly. If you have any trouble getting your medications or think you were charged incorrectly, please ask your care team.

Crushing medications and giving them under the tongue:

If it becomes hard for you to swallow pills, you may need a different way to take your medications. Crushing pills, mixing in a small amount of water and then giving that mixture under the tongue is a helpful option. Before using this method, be sure talk with your Agrace nurse, because some pills should not be crushed.

Follow these steps to crush medicines:

1. Wash your hands with soap and water, or use hand sanitizer. Try not to touch the medication with your bare hands (wear medical gloves, if available).

2. Use clean, dry equipment, such as:
   a. a pill crusher (preferred)
   b. a clean plastic sandwich bag and a heavy cup/small hammer, or
   c. a small cup/bowl and a sturdy spoon.

3. Crush the pill, then put ALL of it into a small bowl or cup.

4. Draw from 0.5 to 2 mL (milliliters) of water into your syringe. If it is difficult to swallow, use the smaller amount.

5. Add the water from the syringe to the crushed pill in the bowl. Use just enough water to dissolve the medicine.

6. Mix the crushed pill and water together until the medication dissolves.

7. Draw up ALL of the dissolved mixture into the syringe.

8. Sit up or have your caregiver raise the head of your bed up to at least a 30-degree angle.

9. Drop by drop, place all the dissolved medication under the tongue.

10. Wash your hands with soap and water, or use hand sanitizer.

Allow time for the medicine to absorb. Do NOT swab or moisten the mouth for at least 30 minutes.
Changing or stopping medications:

There are many reasons Agrace might suggest that you change or stop certain medicines. As your condition declines, some medicines are no longer helpful or appropriate. A medicine’s side effects may become worse than its benefits, or it might not be on Agrace’s formulary [a list of approved medications]. Agrace’s pharmacist and physicians, along with your personal doctor, oversee all medication recommendations and changes.

Disposing of unused medications:

To prevent harm, it is important to quickly and safely dispose of all unused medications, especially those which are considered “controlled substances.” If not disposed of properly, medications could be taken accidentally by children or pets, or be taken illegally by someone for whom the medicine was not prescribed. If disposed of improperly, medications can be bad for the environment, contaminating water and harming wildlife.

**Agrace cannot accept unused medications for return or reuse.** Your care team will teach you about safe disposal. Options may include drug take-back programs, drug donation programs (see below), proper disposal in household trash, or flushing down the sink or toilet. The federal government has a list of medications for which flushing is recommended if take-back programs are not available. Agrace’s Medication Disposal Policy, which can be found in the “Forms & Policies” section of this handbook, has more information about Agrace’s ability to assist you with disposing of unused medications.

If you live in a skilled nursing or assisted living facility, the facility will have its own policies about the disposal or return of unused medications.

Donating medication in Wisconsin:

You may be able to donate medication that will not expire soon and is in its original, unopened, tamper-evident packaging. The state of Wisconsin’s drug donation program accepts certain medicines, which are given to people with cancer or other chronic diseases who need short-term assistance with medication. Controlled substances cannot be donated. You can find details and a list of participating pharmacies on the website of the Wisconsin Department of Health Services: [www.dhs.wisconsin.gov/guide/cancer-drugrepo.htm](http://www.dhs.wisconsin.gov/guide/cancer-drugrepo.htm)

Other donation programs may also be available; ask your nurse or social worker for information.

*We appreciate your understanding and support of our Medication Disposal Policy. If you have any questions or comments, please ask your Agrace team.*
Safe Use of Medical Equipment

Your Agrace care team may supply you with medical equipment to help you stay safe and more comfortable. The medical equipment Agrace supplies is not an extra cost to you; it is part of your hospice care.

This section explains how you get this equipment and how to use several of the most commonly used pieces of medical equipment. If you have urgent questions about any medical equipment from Agrace, please call (800) 553-4289. This number is answered 24 hours a day.
Instructions and Safety Guidelines

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Safe Use of Medical Equipment

While you are a hospice patient, your Agrace team may recommend that you use certain medical equipment to aid in your comfort and safety. Walkers, wheelchairs, hospital beds, shower chairs and oxygen concentrators are all examples of durable medical equipment (also called “DME”). The following pages explain how you get the equipment you need, and how to use several types of common equipment safely.

Who decides what equipment I need?

Your Agrace team will talk with you and your family or other caregivers about equipment that may be helpful for you. After your needs have been determined, your team will arrange to have the equipment delivered to you. The equipment Agrace provides will become part of your hospice “plan of care.” You should use it as prescribed or directed by your doctor and your Agrace care team.

Who provides the equipment?

Agrace provides your equipment. An Agrace medical equipment technician delivers it to you, assembles and adjusts it to meet your needs. The technician and your Agrace care team will show you how to use your equipment and review your home for safety, as related to using the equipment.

**IMPORTANT:** If your medical equipment from Agrace does not arrive by the time it was scheduled, or if you have other questions about using your equipment, please call (800) 553-4289. This number is answered 24 hours a day.

If the medical equipment Agrace provides does not meet your needs, do not try to modify it. Please talk with your team at their next visit (if it can wait) or call the number above. Someone from Agrace will help make sure the equipment works or send a replacement.

Who pays for the equipment?

Equipment related to your hospice diagnosis (the medical reason you are receiving hospice care) is part of your insurance policy’s hospice benefit. You do not pay for it separately.

Who will pick up the equipment when I no longer need it?

When you no longer need equipment that Agrace has supplied, your care team will arrange to have it picked up.
Instructions and Safety Guidelines

Here are instructions for safely using some of the medical equipment most commonly prescribed for people receiving hospice care.

- Hospital bed
- Alternating pressure pad (APP) mattress overlay
- Over-the-bed table
- Walker
- Wheelchair
- Oxygen concentrator, humidifier and portable oxygen tanks
- Bathroom safety equipment: shower chairs, transfer bath benches, standard bedside commodes

If your doctor has given you instructions for equipment use that are different from the information in this handbook, follow their instructions instead.

Hospital Bed

An adjustable electric hospital bed is higher than a regular bed, and it rolls easily on wheels. It allows you to sit up in bed to eat, read, talk and do other activities while staying in bed. Sitting up may help you breathe and swallow food and liquids. Being able to change positions can also help minimize pressure sores and help you rest more easily.

An electric bed is easy to operate without a caregiver’s help. It may be raised or lowered to give your caregiver easier access to you and make it easier for you to transfer to a chair. Your bed rails keep you from accidentally falling out of bed and can be used as a handhold when you want to change your position.

Lock the wheels: The bed has two wheel locks, on opposite corners of the bed. Lock the wheels to keep the bed securely in place. Unlock the wheels only when moving the bed. After repositioning the bed, re-lock the wheels.

Raising or lowering the bed: The hand-held controller with buttons lets you raise and lower the bed’s head and foot and change the overall bed height. Raising the whole bed can make it safer and easier for you to reach a stable standing position. Your caregiver can concentrate on assisting you, rather than struggling to lift you to a standing position. Raising the bed also prevents your caregiver from having to bend and stoop while helping you with bathing, feeding and other bedside care.

- Raise the foot section slightly before raising the head of the bed. This prevents you from sliding down in the bed. Most people find it more comfortable to raise their thighs and flex their knees while lying on their back for long periods of time.
- If the power goes out, take the hand crank from beneath the footboard. Insert it into the top of the footboard and turn it to raise/lower the bed.

Keep the side rails up, for safety. When someone is helping you turn in bed, the upper side rails should be up and locked. Set the bed at a height that permits the caregiver to reach over the rails and roll you toward them, never away from them. The upper side rails may be lowered when someone is caring for you or making the bed, but they should remain up at most other times.
• To move the rails, lift the black hook bar, slide the rail up or down, and replace the hook bar to keep the rail in position.
• Use the knob on the rail to tighten the rail to the bed if it feels loose.

**Caution:** While using the upper rails improves safety, it is recommended that you do not have all four siderails up at the same time, unless you have discussed this with your Agrace care team. It may not be safe if you are agitated, confused or restless while in bed.

**APP Mattress Overlay**

An alternating pressure pad and pump (APP) mattress overlay goes on top of a mattress. It works by changing the pressure in its internal air chambers at regular intervals. This may help reduce pain and prevent pressure on your skin while you are in bed.

• Cover the pad with a cotton flat sheet; if uncovered, it can increase friction with your skin. (A flat sheet is suggested because a tighter, fitted sheet could prevent the overlay from working properly.)
• Hang the pump over the bedframe or footboard of your bed, or set it on the floor where you won’t step or trip on it.
• Connect the overlay’s tubes to the inflating nozzles, and make sure they are securely attached. Check to make sure the tubes are not kinked or flattened.
• Plug the power cord into an electrical outlet. It will take about 10 minutes for the overlay to inflate the first time it is used. Use the dial to adjust the firmness to a level that is comfortable for you.
• Turn the power switch ON.

**Safety and maintenance:**

• The mattress overlay may be slippery when covered with a flat sheet. Be careful while sitting on the side of the bed or transferring out of bed. To prevent a fall, take extra precautions such as holding the bed rails, leaning on your walker or making sure you have extra support from a caregiver.
• If the overlay gets soiled, wipe it clean with soap and water.

**Over-the-bed Table**

An over-the-bed table has wheeled legs, and the height is adjustable. You can position it to give you easy access to items while you’re in bed. You can prevent falls by having what you need within reach on your table: glasses, water, hearing aids, a favorite book, and a mobile/wireless phone or a bell (to get your caregivers’ attention).

• To raise the table, pull UP on the adjustment lever (located underneath the table top) with one hand and raise the table to the desired position. Then release the adjustment lever.
• To lower the table, pull UP on the adjustment lever with one hand and push DOWN on the table on the same side as the lever. Then release the adjustment lever.
• Never lean or apply pressure to the end of the table opposite the vertical adjustment bar, as this could cause the table to tip.
Walker

A walker lets you bear some of your weight on your arms and hands, taking weight off your legs and feet. It also helps you balance and remain stable as you walk or stand. **Do not attempt to stand if you cannot do so safely. Using your walker properly may help prevent falls.**

The Agrace equipment technician who delivers your walker will adjust its height and make sure the legs are secure. When properly adjusted, the hand grips will be slightly above your wrists when you are standing with your arms hanging at your sides.

Your Agrace team will demonstrate how to use your walker safely. When using a walker for the first time, have someone else assist you.

- Follow slightly behind the walker. Do not step all the way into the front of the walker frame; you could lose your balance and fall forward.
- If your walker has wheels, push it slightly ahead of you as you walk.
- If your walker does not have wheels, lift the walker and place it forward so that the rear legs are a few inches ahead of your toes. Then step forward so your legs are about even with the rear of the walker. This gives you four stable legs to lean on, if necessary.
- Never use a walker on stairs. Always use stair handrails.
- Be very careful using a walker around throw rugs or cords, on uneven floors, and where flooring changes from carpet to vinyl, wood or tile. When obstacles are present, lift up slightly on walker to avoid catching the legs.
- To fold the walker, push down on the red release buttons and swing/fold the sides toward the inside of the walker.
- When opening the walker, make sure the sides click into the locked position before using it.
- To adjust the walker height, use the push button locks on the legs. Make sure all four legs are adjusted to the same height.

Wheelchair

A wheelchair makes transportation easier and more comfortable if you are unable to walk on your own for long stretches of time or just want to conserve your energy. It gives you greater independence and keeps you from getting too tired.

**SECURELY LOCK THE WHEELS EVERY TIME** before you sit in or get up from the wheelchair. To lock the wheels, push forward on the lock tips (found on either side of the chair seat) until the locks snap into the locked position.

Adjusting the foot rests: The foot rests on your chair should be adjusted for your comfort. An Agrace equipment technician will do this at the time of delivery, if possible.

If the foot rest is too low, you will feel a line of pressure under your thigh, at the front edge of the seat. If the foot rest is too high, your knees will raise up and you’ll bear more weight on your buttocks. Either situation increases the risk of pressure sores.
**Adjusting the elevating leg rests:** If your wheelchair has elevating leg rests, they should also be adjusted for your comfort. An Agrace equipment technician will do this at the time of delivery, if possible. Most people find it comfortable to use the chair with their knees bent.

- The angle of the elevating leg rests can be raised by lifting up on them until you reach a comfortable position.
- To lower the leg rest, push down on the small release lever and support the leg so it does not drop quickly.

**Moving the foot rests/leg rests** away from the front of the chair allows you to transfer more easily and safely from the chair to a bed, toilet or car.

- Pull the release lever and swing the foot/leg rest outward, to the side of the wheelchair.
- Return the rests to the front position by swinging them back from the side of the chair to the front. The rests will lock automatically in the front position.
- While in the swing-away position, the rests can also be removed from the chair entirely by lifting up on them. To replace them, put them back onto the chair in the swing-away position. Line them up on the metal prongs, then swing them back to the front position.

**To fold the wheelchair:**

- Pull the heel loops forward over the rear of the foot rests.
- Lift the foot rests and calf rests on their inside edges, into the vertical position OR remove them from the chair.
- Then lift the front center edge of the seat.

**To unfold the wheelchair:**

- Press DOWN on the seat rails (the bars that hold the outer edges of the seat). This will force the wheels apart, opening up the seat.
- You may need to tilt the chair to one side while you push down on the seat rails.
Oxygen Therapy

Oxygen Concentrator

Oxygen is classified as a drug and must be prescribed by a doctor. It is important that you use oxygen **exactly** as your doctor or your Agrace care team directs.

Your oxygen concentrator separates the oxygen from the nitrogen in the air, concentrates it, and stores it for you to breathe. A concentrator does not reduce the oxygen in the room, because it requires only a small amount of oxygen to generate enough for you to use.

A prescription for oxygen includes a “flow rate,” measured in liters per minute. **Never change your flow rate of oxygen from what your doctor has prescribed without first calling an Agrace nurse to discuss why you think you need more oxygen.** Too much oxygen can be just as harmful as too little.

**Turning ON oxygen**

- Plug the concentrator into a properly grounded electrical wall outlet. Do not use an extension cord.
- Turn the switch to the ON position.
- Adjust the flow adjustment knob until the flow meter registers the flow rate prescribed by your doctor (measured in liters per minute).
- Attach the tubing from your cannula (nasal prongs) to the oxygen outlet.
- Put the cannula up to your nose, insert it with the prongs curved downward, and adjust for comfort.

**Making sure oxygen is flowing**

- At a low rate (2 – 3 liters per minute) you will not feel much air coming out of the cannula.
- Raise the cannula to your cheek to feel air flow, or raise to your ear to hear the flow.
- You may also place your cannula in a glass of clean water. If bubbles come from the tubing, you know the oxygen is flowing.

**Turning OFF oxygen**

- Remove the nasal cannula.
- Turn the concentrator power switch to the OFF position.
- It is not necessary to turn the flow control OFF after it has been set properly; however, it should be checked each time the concentrator is turned ON, and again periodically during use. The flow control may require adjustments from time to time.
If the alarm sounds
Your oxygen concentrator has an alarm to alert you if there is a power failure or the equipment malfunctions. If the alarm sounds, quickly look to see if:

- the tubing is blocked/kinked,
- the power cord is unplugged from the electrical wall outlet, or
- the power is out in the whole house.

If the power is out, turn OFF the concentrator to stop the alarm.

Then turn ON your back-up system and connect your oxygen tubing to it. Agrace provides you portable oxygen tanks to use if your concentrator is not functioning properly (see directions below).

After you’ve connected to a tank, notify Agrace of the concentrator malfunction immediately.

Opening and using portable oxygen cylinders (tanks)

To use your back-up portable tank during a power failure, follow the written directions below. If you have trouble with this process, please watch a video of these steps at agrace.org/caregiver or call (800) 553-4289.

1. Place the oxygen tank securely upright in a stand.
2. Remove the plastic safety seal that covers the valve stem at the top of the tank.
3. Find the regulator. It has a T-handle at one end, a hole through the middle, and a round gauge on the side that shows how much oxygen is in the tank.
4. Look inside the center hole for two small metal alignment pins. They will need to line up with two holes on the tank’s valve stem.
5. Hold the regulator with silver hose barb pointing downward. Hold the tank’s valve stem upright and slide the regulator down over the valve stem until the pins slide into the holes. You may hear them click into place.
6. Hold the regulator still with one hand, and use your other hand to turn the T-handle at the end of the regulator clockwise (to the right) to tighten it in place.
7. Fold the valve stem to create a lever that can be turned. Slowly turn it two full turns counterclockwise (to the left). Now the tank is open.
8. The round pressure gauge on a full “E-cylinder” tank should read 2,000 psi—the needle will point to the green section of the gauge.
9. Connect your oxygen tubing to the silver hose barb that is pointing down from the regulator.
10. Turn the flow selector on the end of the regulator to the flow rate prescribed by your doctor.
Medical Equipment

Troubleshooting a leak:
If you notice the tank is leaking (you hear a hissing sound), make sure the regulator has been connected according to the directions above. A leak sometimes happens if a black seal washer is not securely in place. The washer should be inside the “hole” in the regulator (next to the two metal alignment pins). If you continue to have trouble with the tank leaking, call Agrace for assistance.

How long does oxygen last in E cylinders?
As you open an oxygen cylinder (tank), check the pressure gauge to ensure that you have enough back-up oxygen. When the needle on the gauge nears the RED zone (less than ¼ full), it is time to change the tank.

<table>
<thead>
<tr>
<th>Liter Flow Per Minute Continuous Flow</th>
<th></th>
<th>Approximate HOURS of Oxygen Left</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Full Cylinder</td>
<td>3/4 Full</td>
</tr>
<tr>
<td>1 LPM</td>
<td>8.00</td>
<td>6.00</td>
</tr>
<tr>
<td>2 LPM</td>
<td>4.00</td>
<td>3.00</td>
</tr>
<tr>
<td>3 LPM</td>
<td>2.70</td>
<td>2.00</td>
</tr>
<tr>
<td>4 LPM</td>
<td>2.00</td>
<td>1.50</td>
</tr>
<tr>
<td>5 LPM</td>
<td>1.60</td>
<td>1.20</td>
</tr>
<tr>
<td>6 LPM</td>
<td>1.30</td>
<td>1.00</td>
</tr>
<tr>
<td>7 LPM</td>
<td>1.10</td>
<td>0.84</td>
</tr>
<tr>
<td>8 LPM</td>
<td>1.00</td>
<td>0.75</td>
</tr>
</tbody>
</table>

Removing the regulator from a tank:
1. Close the tank by turning the valve stem lever clockwise (to the right) until it stops.
2. The needles on the pressure gauge will gradually reduce to “0”. When they reach 0, turn the flow selector counterclockwise until it stops.
3. Loosen the regulator by turning the T-handle counterclockwise (to the left). Remove it from the tank valve stem. You may keep the regulator to use with other back-up tanks.

Cleaning and Replacing Oxygen Supplies

Cannula and extension tubing: The cannula is a nose piece (nasal prongs) that delivers oxygen. The prongs fit into your nostrils. The other end attaches to the extra tubing or the humidifier, if one is used.
• Clean the cannula every day. Wipe the prongs with a clean, damp cloth. Do not use other cleaning products.
• Use a new cannula once every two weeks, and whenever yours becomes dirty or clogged. Throw away the old one. If you are alternating use of two cannulas, use them for two weeks only, then throw both away.
• Extension tubing should never be longer than 50 feet, or you may not get the proper flow of oxygen. Change your extension tubing every three months; your Agrace nurse or CNA can help.

If you have questions or concerns about your medical equipment supplied by Agrace, call (800) 553-4289. This number is answered 24 hours a day, every day.
Air filter (10-liter concentrators only): The sponge-like inlet air filter on your oxygen concentrator should be cleaned once a week, or as needed. Your Agrace nurse or CNA can help with this. Remove the filter and wash it under running tap water. Shake out the excess water and dry it by squeezing it in a towel before replacing it. The concentrator should never be used without this filter in place.

Humidifier: A humidifier is a bottle that is filled with water and attached to the oxygen system to moisten the oxygen before you inhale it. Medical oxygen is dry. Use the humidifier if your nose is dry or irritated.

- Add distilled water or clean, cool boiled water to your humidifier every day, but keep water below the “Max Fill” line. Overfilling will cause water to build up in your tubing.
- Keep the humidifier clean, and sanitize it once a week to prevent bacteria growth and infection.
- To clean your humidifier, you will need dish-washing detergent (like Dawn®), white vinegar, a small brush (a bottle brush or tooth brush) and two basins or large bowls.
  › In one basin, wash the disassembled humidifier in warm, sudsy water containing dish-washing detergent. Use a brush to remove any residue.
  › Rinse all parts thoroughly under clear, hot running water.
  › In the other basin, soak all parts in a mixture of equal parts white vinegar and water for 30 minutes. Make sure all parts are completely covered by the water and vinegar solution.
  › Rinse all parts thoroughly under clear, hot running water.
  › Lay the parts on a paper towel in a clean area and allow to dry.
  › When dry, reassemble and reconnect the parts.

Water trap: If your tubing has a water trap, change it when you change your tubing, or more often, as needed. Your Agrace team can help with this.

Oxygen Therapy Safety Precautions

There must be enough space around your oxygen equipment to allow air to circulate freely around all sides of the unit. You may notice some heat from the unit, but this is normal.

Oxygen does not explode, but it will make a fire burn much faster and hotter. Portable oxygen tanks must be handled with great care. To avoid the chance of fire and other hazards associated with oxygen, follow these rules:

- **DO** use a stand for all oxygen tanks, or lay them down on their side where they cannot fall or roll around.
- **DO** keep oxygen equipment out of reach of unsupervised children.
- **DO** use water-based lubricants (K-Y Jelly or lip balm) on your lips or nostrils to prevent discomfort due to the drying effect of oxygen.
- **DO** wrap gauze around the tubing if it rubs uncomfortably at the top of your ears.
- **DO** let your Agrace team know if you need more oxygen to cover an upcoming holiday or stretch of bad weather—or if you are planning to travel, especially outside of the Agrace service area.
- **DO NOT** allow open flames, lit smoking materials or spark-producing equipment to be in the room where oxygen is being used or stored.
- **DO NOT** use electrical equipment around your oxygen (examples: electric shavers, electric blankets, etc.).
Medical Equipment

electric heating pads. Keep these items at least five feet away from any oxygen source.

• **DO NOT** place oxygen equipment near any source of heat, including radiators, heat ducts and stoves.

• **DO NOT** store oxygen equipment in an enclosed space, like a closet. Wipe the back of the concentrator with a damp cloth several times a week to make sure the air intake panel does not clog with dust.

• **DO NOT** use any petroleum-based products such as oily back rubs, lip balms, lotions, creams or Vaseline® while receiving oxygen. **DO NOT** handle or allow others to handle oxygen equipment with these substances on their hands.

• **DO NOT** use aerosol sprays, alcohol, alcohol-based products, products containing ether or other flammable components near oxygen.

• **DO NOT** oil or grease your oxygen equipment.

• **DO NOT** allow oxygen tubing to be covered by bedding or any other objects.

• **DO NOT** route oxygen supply tubing under carpet or furniture.

• **DO NOT** leave oxygen on when it is not in use.

• **DO NOT** attempt to repair oxygen equipment or allow untrained people to use or adjust your equipment. Call Agrace if you need help adjusting your equipment.

• **DO NOT** transport oxygen tanks in an enclosed area such as the trunk of your car.

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**Bathroom Safety**

Agrace staff may suggest equipment for you to use in the bathroom to promote safety and independence. The layout of your bathroom may determine which equipment is the best option for you. It may be easier to use a handheld shower head to shower while seated.

**Shower Chair with or without Back**

- Place the shower chair completely in the tub or shower stall. Make sure all chair feet are flat on the floor and the seat is level before using the chair.

- When using in a shower, set the chair seat at a comfortable height. Adjust the height by pushing in the snap button locks and moving the leg extensions up or down.

- When using the chair in a bathtub, place it toward the back, away from the faucets. Adjust the seat height so it matches or is higher than the side of the tub. This makes transfers easier.

**Safety**

- Keep the tub/shower clean and free of soap film to help prevent slipping.

- Exert force only straight down when sitting down or rising from the seat. Shower chairs are lightweight and not anchored; pushing horizontally could cause the seat to slip or even tip over.

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If you have questions or concerns about your medical equipment supplied by Agrace, call **(800) 553-4289**. This number is answered 24 hours a day, every day.
Transfer Bath Bench

A transfer bath bench allows you to move into a bathtub from a seated position.

- Place the bench so the two legs with suction cups are inside the tub.
- The backrest and seat should face the faucet. If the seat back is on the wrong side for your tub, slide the seat out and move it to the other side of the bench.
- The seat depth can be adjusted on the underside of the bench.
- To adjust the seat height, push in the snap button locks and move the leg extensions up or down.
- For safety, make sure the seat is level and stable before using the bench. To level the seat, the legs outside the tub may need to longer or shorter than the legs inside the tub.

Standard Commode

A commode is a portable toilet that can be used different ways to save energy and enhance safety. It can be used at the bedside, as an elevated seat when placed over the toilet, or as safety arm rails when placed over the toilet.

- Make sure the commode is adjusted to the proper height for use. Adjust the seat height by pushing in the snap button locks and moving the leg extensions up or down.
- Ensure all legs are even on the floor.
- To use the commode at the bedside, place the removable bucket on the frame underneath the seat. Keep a small amount of water in the bottom bucket to make cleaning it easier.
- Using the commode over the toilet provides greater stability and safety for getting on and off the toilet. The higher seat and arm rests make transfers easier. When using the commode over the toilet, remove the bucket and use the splash guard instead.
Equipment and Supply Donation

When you no longer need it, Agrace will pick up the durable medical equipment (DME) we supplied to you, such as walkers, wheelchairs and hospital beds.

We may accept donations of unopened containers of adult briefs (such as Depends®) and unused, current containers of nutritional supplements (such as Ensure® and Osmolite®). However, due to the laws and regulations that govern Agrace HospiceCare, we cannot accept donations of other used medical equipment. If you have other equipment or supplies that you are no longer using, we encourage you to contact one of the agencies listed below. The agency will give you instructions on pick-up/delivery of the items and what is accepted. Agrace staff cannot transport items being donated to these organizations.

• **Agrace thrift stores—East and West Madison and Janesville.** Accepts donations of gently used clothing, accessories, books, furniture and home goods. agracethriftstore.org
  
  • **Central Lutheran Church—Edgerton.** Accepts donations of medical equipment and supplies. (608) 884-9418

• **St. John Lutheran Church—Evansville.** Accepts donations of medical equipment and supplies. (608) 882-4044 or stjohns-lc.org

• **First Lutheran Church—Janesville.** Accepts donations of medical equipment and supplies. (608) 752-7434

• **St. Vincent de Paul—Madison.** Accepts donations of clothing, books, furniture and household items. Donation pickup service available in Madison and surrounding areas. Call (608) 278-2920 to arrange pickup.

• **West Madison Senior Coalition—Madison.** Accepts walkers, wheelchairs and shower chairs/benches in good working condition. Location: 517 N. Segoe Rd., #309, Madison. (608) 238-7368; M–F 8 a.m. – 4 p.m.

• **Middleton Outreach Ministry—Middleton.** Accepts clothing, housewares, pans, dishes, bedding, sheets, towel, and unopened canned goods. Donations can be delivered to 3502 Parmenter St., Middleton. (608) 836-7338 or momhelps.org

• **Milton Seventh Day Baptist Church—Milton.** Accepts donations of medical equipment and supplies. (608) 868-2741

• **Oregon Senior Center—Oregon.** Accepts donations of unopened Depend and Chux pads. (608) 835-5801 or oregonareaseniorcenterwisconsin.com

• **St. Vincent de Paul locations in Baraboo, Prairie du Sac, Reedsburg, Sauk City and Wisconsin Dells.** Call your local store to confirm whether they will take the medical equipment you have to donate.

• **Good Neighbor Clinic of Sauk Prairie—Prairie du Sac.** Accepts medical supplies. Located at 95 Lincoln Avenue, Prairie du Sac. (608) 643-4749 or gnccrc@gmail.com. Call ahead for open hours. goodneighborclinic.org

• **Stoughton Senior Center—Stoughton.** Accepts donations of Depend and Chux pads. (608) 873-8585 or ci.stoughton.wi.us/senior
What types of equipment are available through Agrace?

Agrace provides the following categories of durable medical equipment. The equipment you receive is based on your plan of care and need, as determined through discussions with your care team and doctor (hospice attending physician).

- Hospital bed
- Broda chair
- Quad cane
- Commode (portable toilet)
- CPAP and BiPAP machines (to help with breathing)
- Cushion
- Enteral feeding pump
- Fall mat
- Foam mattress, alternating pressure pump (APP) overlay
- Low-air-loss mattress
- Nebulizer
- Over-the-bed table
- Oxygen concentrator, nasal cannula, tubing
- Portable oxygen tank
- Patient lift
- Wheeled shower chair, transfer bath bench, shower chair
- Shower commode chair
- Suction supplies
- Trach supplies
- Transfer disc, transfer board
- Walker, rollator
- Wheelchair

Medicare Supplier Standards

The medical equipment products and/or services provided to you by Agrace HME, LLC through Agrace HospiceCare are subject to the supplier standards contained in the Federal regulations shown at 42 Code of Federal Regulations Section 424.57(c). These standards concern business professional and operational matters (such as honoring warranties and hours of operation). The full text of these standards can be obtained at http://ecfr.gpoaccess.gov. Upon request, we will furnish you a written copy of the standards.
As a caregiver, you may need support from many different sources throughout this hospice experience. This section describes a variety of support options and resources available through Agrace and other community organizations. Please explore these pages and let your care team know if you have any questions.
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Use our caregiver website: agrace.org/caregiver. It has many additional resources for you, including instructions for using medical equipment, links to suggested articles and a comment/concern form. There is also an online version of this handbook, which makes it easy for you to share information with other family members.

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Social Work Support

The journey at the end-of-life can be a smooth or a rough road—or something in between. Social workers help you by providing support and identifying resources that can make the journey more manageable. They will meet with you in the first few days you’re with Agrace and can assist both the patient and family/caregivers.

During your hospice experience, concerns and needs may arise for which patients and caregivers do not have answers; here are common examples:

- Needing to reflect on one’s life—having someone to talk to.
- Reviewing achievements, regrets and goals yet to be accomplished.
- Desiring to reconnect with family and friends.
- Managing increased dependence on others.
- Fearing the unknown: illness and dying.
- Managing financial resources, now and in the future.
- Planning for the future—care of spouse, dependents, pets.
- Planning for funerals (see page 54-56).

How social workers provide support:

- Provide a listening ear and supportive counseling, as needed.
- Assess grief and spiritual needs of the patient and family.
- Facilitate family meetings to identify patient and family goals.
- Coordinate activities to assist the patient in reaching his/her goals or wishes.
- Facilitate difficult conversations about concerns of the patient or family.
- When the patient resides in a long-term care facility, social workers assist with communication between all the caregivers (family, facility staff, etc.) and the patient.
- Assist with completing advance directives such as the Power of Attorney for Healthcare.
- Assist with completing applications for medical or financial assistance.
- Assist with locating additional care through community programs, personal caregiver agencies or facility placement.
- Assist with finding community resources such as home-delivered meals, emergency-call systems, transportation, durable medical equipment, etc.
- Make referrals to community counseling resources when indicated.
- Assist with funeral planning, brain/tissue donation and autopsy requests.
Volunteer Support

Agrace volunteers are a part of the team that cares for patients and supports their families. Each volunteer completes an extensive screening process, orientation and training. Agrace volunteers can be a great resource for comfort and assistance. These compassionate people choose to help in a variety of ways:

**Companionship:** Volunteers’ companionship can include playing cards and games, chatting over a cup of coffee, reading books, going for walks or wheelchair rides, or watching a movie. The possibilities are endless!

**Transportation:** Volunteers can assist with transportation needs, including running a variety of errands as well as driving patients to and from medical appointments.

**Light housekeeping and light meal preparation:** Volunteers are able to help with light housekeeping tasks, such as doing a load of laundry, sweeping and dusting. Volunteers can also assist with light snack preparation, such as heating up a bowl of soup or making a favorite sandwich.

**Caregiver relief:** Volunteers can stay with patients for a few hours, allowing caregivers time to do things they need to do and to care for themselves.

**Vigil:** Vigil volunteers provide a constant, caring presence to patients who are nearing the end of life. The presence of a vigil volunteer allows family members to rest, knowing their loved one is not alone.

**Life review:** Volunteers work closely with patients and families to create a lasting keepsake which captures the life story of the patient. Each life review can be personalized by creating oral recordings, selecting meaningful music, gathering family photos or writing a collection of stories.

**Vet-to-Vet:** Volunteers who are veterans share their time to lift the spirits of other veterans. They are a warm “welcome home,” a willing listener who can relate to military culture and a caring presence who knows what it’s like to serve.

If you would like to find out more about how Agrace volunteers can help, please ask any member of your care team. Volunteer coordinators will work closely with you to match your specific needs with a volunteer. Please note that volunteers do not give hands-on care (the care that is usually provided by a nurse or nursing assistant).
Grief and Spiritual Support

Patients and families experience many different kinds of losses in the final months of life, and the expertise of your spiritual & grief counselor can help support, guide, comfort and encourage you. Your counselor is available to provide pre-death and post-death (family) grief and spiritual support.

Common grief concerns and reactions:

Family members often ask “Why would I need grief support when the person I’m caring for is still alive?” Grief starts long before a loved one dies. There is grief in each loss, whether it is the inability of the cared-for person to come to the dinner table, memory loss and confusion, or the loss of independence. The toll that caregiving takes on the family is another reason for grief support.

When we think about death approaching or experience the death of someone close to us, it is natural that we respond with grief. Grief can be very painful. It can seem overwhelming and sometimes frightening. Many people worry about whether they are grieving in the “right” way and wonder if their feelings are normal. It is important to understand that grief is unique and individual. There is no right way—or wrong way—to grieve. Grief lasts longer than most people expect, and we often need support beyond what family or friends can provide. If you are worried about your reactions, please ask to speak to an Agrace spiritual & grief counselor. More detailed educational materials are available, including information about grief reactions and spiritual discussion opportunities. If you are comfortable using the Internet, please visit agrace.org/griefsupport.

Spiritual opportunities:

Living and dying is considered a spiritual experience by many people. Toward the end of life, opportunities for spiritual exploration, affirmation and healing may surface. There may also be religious needs for sacraments and rituals. Spiritual awareness and religious needs may be different for the patient, the family or friends. Honoring all of the possibilities may enrich the experience for everyone. Here are some ways family members and friends can support a patient’s spirituality:

- Listen to and respect the identified goals.
- Reflect on the meaning and purpose of life.
- Nourish spirituality and spiritual or religious practices.
- Affirm the patient’s accomplishments in life and his or her legacy.
- Creatively honor and ritualize memories.
- Respect the mystery and sacredness of living and dying.
- Address any fears of dying.
- Identify anger at God, a higher power, self or others.
- Explore feelings of guilt, shame, regret, emptiness and loss of direction.
- Explore unresolved relationships and issues.
- Identify feelings of abandonment by God, a higher power, family or friends.
- Address questions surrounding the meaning of suffering and pain.
- Support the process of offering and receiving forgiveness.
- Acknowledge dreams, nightmares, post-traumatic stress (for example, war veterans).

Continued on next page
Agrace HospiceCare's grief and spiritual support is available to you through a variety of services and programs. Please ask your spiritual & grief counselor for information about any of these opportunities that you would find helpful for yourself or other family members:

- One-on-one grief and spiritual support
- Support groups for adults and children
- Education and outreach
- Memorial events

**Spiritual care resources:**

  New York: Free Press.
- **Callanan, Maggie**, *Final Journeys: A Practical Guide for Bringing Care and Comfort at the End of Life.*
  New York: Bantam.
  New York: Bantam.
- **Dancing Heart, Maria**, *The Last Adventure of Life: Sacred Resources for Living and Dying from a Hospice Counsellor.*
  Scotland: Findhorn Press.
- **Kubler-Ross, Elisabeth**, *On Death and Dying.*
  New York: Touchstone.
- **Schoenbeck, Susan**, *The Final Entrance: Journeys Beyond Life.*
  Madison, WI: Prairie Oak Press.
- **Smith, Doug, and Marilu Pittman**, *The Tao of Dying.*
  Vero Beach, FL: Caring Publishing.

**Respite Care**

Caring for someone at the end of life is hard work on many levels, and all caregivers can benefit from taking an occasional break. Sometimes it is very hard to structure time away as a caregiver, but Agrace’s respite care offers this opportunity.

Whether you need time to catch up on sleep, to get out of town for a short vacation, to attend an important work seminar or to simply take a few days to refresh your strength and energy, a respite can be the answer. Respite care is one of the Medicare-covered levels of hospice care. For up to five nights, Agrace patients who live at home (not in a care facility) can come for a brief stay at Agrace in Madison or Janesville, or one of our contracted facilities.

The Four Levels of Hospice Care on page 4 in the Welcome section of this handbook has more details about respite care. **If you want or need a respite from caregiving, please discuss this with your Agrace care team**, who will help make the necessary arrangements. **Respite care requires coordination between care providers, so advance planning is helpful.**
What to Say and Do When Time Is Short

As the end of life nears, people often think about what they want to ask, say or do—while they still can. The suggestions below can help you have meaningful conversations and celebrations when time is short and convey practical information to surviving family. Some suggestions are for the person who is dying, while others are for their family/caregivers.

What to Say


“Goodbye.” If it seems appropriate, give the person permission to die. People who are dying often need to know their loved ones will be OK after they are gone. Tell them you will miss them, but you will be OK.

What to Do

Spend time with those who are important to you. Gather friends and family around you (or connect via Skype or FaceTime). Move up the timing of family celebrations, if desired.

Reminisce about favorite memories and life stories from the past. Talk about favorite music, hobbies, vacations, life lessons, what has brought the most joy to life. This can naturally lead into feelings and thoughts about leaving this life.

Make time for spiritual concerns. If desired, ask for a visit from a spiritual support person, counselor or religious leader. Explore any worries or questions that are on your mind.

Share practical information, such as passwords to access online accounts, where to find important documents, and keys/combinations to lock boxes or safes. Create a list of key contacts, such as your attorney and financial agents; give it to the person who will handle contacting them.

What to Ask

• How can I make you more comfortable right now?
• Is there anything you’d like to say to family/friends that you haven’t already said?
• Are there any messages you’d like me to write down to give to others?
• Is there anything else you want to do before you die?
• Do you have any regrets? Are there any relationships you want to mend?
• Are there any old friends you want to contact now, or that I should notify after you die?
• Do you have any personal items you would like to give to a friend or family member?
• When it is your time to die, is there anything that we can do to make it easier for you?
• Do you want to be alone, or with someone?
• Do you have any requests or preferences for your funeral?
• How can I honor you?
• How would you like to be remembered?
Planning a Funeral

Planning a funeral while you are grieving the loss of a loved one can be difficult. Agrace social workers will offer help with this process by asking about final wishes, choice of funeral home, special requests and cultural traditions. Because there are many options, and costs for these options vary greatly, it helps to understand the basics of funeral planning before you make choices. The information below may help.

There are several ways to celebrate a life: a traditional funeral service, a memorial service, a home funeral, direct burial/cremation and green burial. When a person dies, several legal forms must be completed by a funeral director. In Wisconsin, a family member or designee can fill the role of a funeral director; typically, this is done when a family prefers a home funeral and green burial (see page 56).

If you plan to work with a funeral home or cremation service, Agrace can help you contact them. Funeral directors provide a variety of support services beyond the required paperwork. They will walk you through the planning process by asking about the person to be honored, as well as addressing some of your emotional, spiritual and financial needs. They should help you make arrangements that are manageable within your budget. Ask questions and take the time you need to ensure you and your family understand your options and are comfortable with your choices.

Questions to consider when planning a funeral or memorial gathering:

- What type of disposition of the body is preferred: cremation, in-ground burial, above-ground entombment in a mausoleum?
- Should the body be present for a gathering?
- What type of service or gathering is appropriate: religious, military, secular, visitation only?
- What cultural or faith traditions were important to the deceased?
- How do you want them to be remembered?
- Whom do you wish to include in the gathering?
- What location would be most appropriate or convenient?

A professional funeral director will coordinate details such as:
- writing and publishing an obituary,
- assisting with Social Security and military/veterans’ benefits,
- contacting vendors typically needed (clergy, musicians, cemetery, florist), and
- filing and securing the death certificate from the county register of deeds (needed for transferring titles to personal property, claiming life insurance benefits, and closing investment, retirement savings and bank accounts).

Cost Concerns: Upon request, funeral directors must provide a price list of all goods and services they provide. For low-income residents of Wisconsin, financial assistance for funerals is available through the state’s Department of Human Services, if certain criteria are met. If you need this assistance, ask your Agrace social worker, or the staff of your funeral home about these programs.
Common Funeral Options

**Embalming** is used to temporarily preserve a body while keeping a lifelike appearance. It is not required by any funeral home, for burial or for cremation. However, depending upon the service choices that are made by the family, embalming may be desired or required.

**Viewing of the body** (having an “open casket”) may help reinforce the reality of the death and provides an opportunity to say goodbye.

**A visitation** is a social gathering where friends and family can offer sympathy in person and be present to support you following a death. It also allows you to face mourners on your terms at your chosen time and place, rather than seeing them at unexpectedly at the grocery store or at work. A visitation can include memory-sharing and a eulogy, as well as a display of pictures and personal items that reflect the life of your loved one.

**Cremation** is an alternative to interment/interment of an intact body. If you choose cremation, you can also have a visitation, a viewing, and a memorial service or funeral. After cremation, the remains may be buried, scattered or divided into portions, depending upon your faith tradition and wishes. For cremation to legally take place in Wisconsin, 48 hours must elapse from the time of death. Authorization forms must be completed by the next of kin before cremation, and a death certificate must be filed. It usually takes more than 48 hours for these requirements to be met. A casket is not required for cremation, but funeral homes and crematories usually require a rigid container of a material such as heavy cardboard to ensure safety and dignity when moving the body.

**A funeral service or ceremony** offers a structured format to celebrate the life of your loved one and reinforce your faith beliefs. It provides the comfort of familiar traditions and the opportunity to create new and meaningful rituals.

**A burial (casket or urn)** provides family and friends a permanent site to visit and reflect in a loved one’s place of rest.

**A reception** allows for storytelling and celebrating a life in a less-structured atmosphere. Often, food is served. Your funeral director may know of local restaurants or halls that will accommodate a funeral reception.

**Cemetery:** Burial of cremated remains in a cemetery is not required by law, but it may be desired if it is consistent with one’s faith tradition. In Wisconsin, burial vaults and urn vaults are not required by law, but most local cemeteries require outer burial containers for caskets, and some require that an urn is either made of a nondegradable material or is buried inside an urn vault. Many cemeteries have rules about burying several cremated remains in the same plot and about the format of grave markers. Ask your funeral director or cemetery administrator for the rules of your cemetery before making these choices.
**Home and “green” funerals:** Any funeral choice—burial, cremation, procession, printing or body-preparation—has some environmental impact, but all may be made “greener.” It is possible to respect your personal and faith traditions while still being friendly to the earth. Green options include burial in a casket made of renewable resources or in a shroud, formaldehyde-free embalming and cremation in renewable-resource containers.

Home funerals and green burials are legal throughout the United States. Home funerals are ones in which care for the deceased and services are held at home, or in a prepared space after the death. A home funeral allows family and friends to participate in most, if not all, after-death rituals. Some funeral homes will assist with non-traditional or environmentally friendly funeral and burial choices, but you may prefer to do your own research to decide how to proceed. These lists contain resources for more information on these choices and many other aspects of funeral planning:

**Websites**
- [homefuneralalliance.org](http://homefuneralalliance.org) – National Home Funeral Alliance: supports home funeral education, home-funeral-friendly funeral directors and funeral guides lists by state
- [funerals.org](http://funerals.org) – Funeral Consumers Alliance
- [funeraled.arts.org](http://funeraled.arts.org) – Funeral Ethics Organization
- [finalpassages.org](http://finalpassages.org) – Final Passages: home funeral and green burial education
- [naturalend.com](http://naturalend.com) – The Natural End: connecting families with green burial and home funeral friendly funeral directors, cemeteries and service providers
- [nedalliance.org](http://nedalliance.org) – National End-of-life Doula Alliance, supporting end-of-life doulas and the families they serve

**Books**
- “Planning Guide and Workbook for Home Funeral Families” by Lee Webster, Donna Belk
- “Undertaken with Love” by Holly Stevens and Donna Belk
- “Caring for the Dead: Your Final Act of Love” by Lisa Carlson
- “Final Rights: Reclaiming the American Way of Death” by Lisa Carlson, Joshua Slocum
- “Home Funeral Ceremonies: A primer to honor the dying and the dead with reverence, light-heartedness and grace” by Donna Belk, Kateyanne Unnullisi
- “Caring for Your Own Dead” by Lisa Carlson
- “The Natural Death Handbook” by Josefine Speyer, Stephanie Weinrich

Please remember that guidelines, options and laws regarding funerals and burial will change over time. A professional funeral director can provide the most current information needed to make choices that work for you and your family.

*Agrace HospiceCare thanks Cress Funeral Services and Gunderson Funeral Home for their expertise in developing portions of this information.*
Suggested books:

**Caregiving: The Spiritual Journey of Love, Loss and Renewal**
Author: Beth Witrogen McLeod ISBN #: 0471392170

**When Love Gets Tough: The Nursing Home Decision**
Author: Doug Manning ISBN #: 1892785005

**The Dying Time: Practical Wisdom for the Dying & Their Caregivers**
Authors: Joan Furman and David McNabb ISBN #: 0609800035

**A Caregiver's Survival Guide: How to Stay Healthy When Your Loved One is Sick**
Author: Kay Marshall Strom ISBN #: 0830822305

**May I Walk You Home? Courage and Comfort for Caregivers of the Very Ill**
Authors: Joyce Hutchison and Joyce Rupp ISBN #: 159471214X

**Caregivers and Personal Assistants: How to Find, Hire and Manage the People Who Help You (Or Your Loved One!**
Author: Alfred H. Degraff ISBN #: 0962110612

**The Gifts of Caregiving: Stories of Hardship, Hope and Healing**
Author: Connie Goldman ISBN #: 1577491173

**Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care and the Patient with a Life-Threatening Illness**
Author: Hank Dunn ISBN #: 1928560032

**Handbook for Mortals: Guidance for People Facing Serious Illness**
Authors: Joanne Lynn, Joan Harrold and The Center to Improve Care of the Dying ISBN #: 0195146018

**The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Other Dementias, and Memory Loss**
Authors: Nancy L. Mace and Peter V. Rabins ISBN #: 0446618764

**Learning to Speak Alzheimer’s: A Groundbreaking Approach for Everyone Dealing with the Disease**
Authors: Joanne Koenig Coste and Robert Butler ISBN #: 0618485171

**Always on Call: When Illness Turns Families into Caregivers**
Author: Carol Levine ISBN #: 0826514618

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**Coping with Your Difficult Older Parent: A Guide for Stressed-Out Children**
Authors: Grace Lebow, Barbara Kane and Irwin Lebow ISBN #: 038079750X

**The Fearless Caregiver: How to Get the Best Care for Your Loved One and Still Have a Life of Your Own**
Author: Gary Barg ISBN #: 1931868565

**Making the Moments Count: Leisure Activities for Caregiving Relationships**
Author: Joanne Ardolf Decker ISBN #: 0801857007

**The Needs of the Dying: A Guide for Bringing Hope, Comfort, and Love to Life’s Final Chapter**
Author: David Kessler ISBN #: 0061137596 (Revised Jan. 2007)

**Self-Care for Caregivers: A Twelve Step Approach**
Authors: Pat Samples, Diane Larsen and Marvin Larsen ISBN #: 1568385609

**When a Loved One Falls Ill: How to be an Effective Advocate**
Authors: Gerri Monaghan and Brian Monaghan ISBN #: 9780761165071

**Walking on Eggshells: Caring for a Critically Ill Loved One**
Author: Amy Sales ISBN#: 9780882823805

**Videos for caregivers:**

- **The Gift of Healing Presence: Encouraging Thoughts for Busy Caregivers**
  Willow Green Productions

- **The Grit & Grace of Being a Caregiver: Maintaining Your Balance as You Care for Others**
  Willow Green Productions

- **Caregiver Wellness Healing Arts Communications**

- **VideoCaregiving** – www.videocaregiving.org A visual education center for family caregivers includes videos on caregiver and Alzheimer’s.
Books for grieving adults:

- **Dennis, Dixie.** Living, Dying, Grieving.
- **Bonanno, George.** The Other Side of Sadness: What the New Science of Bereavement Tells Us About Life after Loss.
- **Hickman, Martha.** Healing After Loss.
- **Wright, Norman.** Recovering from Losses in Life.
- **Salmansohn, Karen.** The Bounce Back Book: How to Thrive in the Face of Adversity, Setbacks and Losses.
- **Levine, Stephen.** Unattended Sorrow: Recovering from Loss and Reviving the Heart.
- **Smith, Harold Ivan.** ABC’s of Healthy Grieving: A Companion for Everyday Coping.
- **Cole Jr., Allan Hugh.** Good Mourning: Getting Through Your Grief.
- **Fuller, Susan L.** How to Survive Your Grief When Someone You Love Has Died.
- **De Vries, Robert C. and Zonnebelt-Smeenge, Susan J.** Traveling Through Grief: Learning to Live Again after the Death of a Loved One.

For a more complete list of suggested books on grief for adults, visit [www.agrace.org/griefsupport/resources.html](http://www.agrace.org/griefsupport/resources.html) or ask your Agrace team.
Resources for grieving children:

Preschool through elementary school:

- **Brown, Margaret Wise.** The Dead Bird. Reading, Massachusetts: Addison-Wesley, 1958. Extremely simple text and pictures for very young readers. Straightforward story line about finding a wild bird that is dead, touching it, burying it, and mourning it (“until they forgot”). An early classic.


- **Viorst, Judith.** The Tenth Good Thing About Barney. New York, New York: Atheneum, 1971. Barney, the boy’s cat, dies, is buried and is mourned. How to write a eulogy? Barney was brave and smart and funny and clean. He was cuddly and handsome, and he only once ate a bird. It was sweet to hear him purr in my ear, and sometimes he slept on my belly and kept it warm. But that’s only nine good things. Are cats in heaven? The 10th good thing is learned in the garden: Barney is in the ground and he’s helping the flowers to grow.

Middle school and high school:

- **Coerr, Eleanor.** Sadako and the Thousand Cranes. New York, New York: Bantam Dell Publishing Group, 1977. Based on a true story, Sadako is a survivor of Hiroshima who develops leukemia. Her courage becomes legendary as she strives to make 1,000 origami cranes. Although she makes only 644, her classmates finish the rest and bury them with her.


Younger voices speak for themselves about dying and grief:

- **Krementz, Jill.** How It Feels When A Parent Dies. New York, New York: Knopf, 1981. In short essays, 18 children and adolescents (7 – 16 years old) describe their reactions to a parent’s death. Each essay is accompanied by a photograph of its author.

All ages:


Giving Back to Agrace

Family members often express interest in helping to support Agrace after their hospice experience, either by volunteering their time and talent or by making a donation. We are honored to have this support. If either of these opportunities interests you, here is more information that will be helpful.

Volunteering with Agrace

Agrace’s trained volunteers are available to help by providing companionship to patients and support to their family members during the hospice experience. Each year, about 1,000 community volunteers donate more than 80,000 hours to support Agrace’s mission—by either working directly with patients or by helping in our offices, gardens, café and thrift stores.

If volunteering with Agrace appeals to you, we welcome your interest. However, family members of our patients must wait a year after the death before they begin to volunteer with Agrace. Details about volunteering are available at agrace.org/volunteer, or call us at (608) 327-7163.

Agrace Foundation—Making a Financial Gift

Agrace provides compassionate, nonprofit care to any patient who needs it, regardless of whether they can pay. To do so, we rely on gifts from community donors. Donations also allow Agrace to grant special end-of-life wishes, provide free grief support to our patients and their families, offer needed breaks for family caregivers, and much more. Charitable donations help us support the needs of our patients and their families throughout Agrace’s service area. Anytime you have questions about donating to Agrace, call (608) 327-7180.

Suggesting memorial donations to Agrace in an obituary: To invite memorial donations to Agrace, include the words below in the obituary: “Memorials suggested to Agrace HospiceCare: 5395 E. Cheryl Parkway, Madison, WI 53711 or agrace.org/donate.”

Direct donations: To make a donation to Agrace by check, mail your check to Agrace at 5395 E. Cheryl Parkway, Madison. To donate with your credit card, please visit agrace.org/donate or call (800) 553-4289.

If you are making a gift to Agrace in memory of a loved one, or with proceeds of an inherited estate, please record the name of the person whose memory is being honored on the memo line of your check.

Thrift store donations: Agrace operates four thrift store locations in southern Wisconsin that resell quality, donated merchandise at thrifty prices. The stores are located on Madison’s east and west sides, and in Janesville. Donations of clothing & accessories, furniture, books and home goods are accepted, during store hours. For more information, visit agracethriftstore.org or call (608) 327-7180.
How Donations Help

Tax-deductible donations to Agrace—of any amount—help fund these essential programs:

**Care for All:** Each year, dozens of our neighbors who cannot afford hospice or palliative care services receive them at no cost through Agrace’s Care for All program. Those we serve include some of our most vulnerable community members—children and young adults with no insurance, seniors without caregivers, and people who lack safe housing or have special needs.

**Respite care:** Providing end-of-life care for a family member or friend can leave caregivers fatigued and stressed. To give them a break of up to five days, Agrace offers respite care for hospice patients. Community gifts supplement insurance reimbursements, which cover less than 35 percent of the total cost of respite care.

**Clinical education & training:** It takes a special commitment to work with patients who are seriously ill or dying. Community donations allow Agrace to fund staff educational opportunities and professional development programs, which increase staff competence and retention.

**Wish Program:** The Wish Program helps our hospice patients achieve their end-of-life goals. A wish can be something a patient could not attain during his/her life, something he/she cannot afford or simply a final desire. Agrace has granted more than 130 patient wishes since 2010.

**Grief (bereavement) services:** Every year, more than 2,300 adults and children get support from Agrace’s grief services to help them cope with the death of a loved one. Although hospices are required to provide grief support, it is not covered by Medicare, Medicaid or private insurance. Community donations enable us to offer specialized grief support that is open to everyone in our service area, even if their loved one did not have hospice care.
As Death Approaches

Although it may be difficult for you to decide to read this section, it includes information that will help you and your loved ones through the last hours before death. We’ve included a step-by-step list of how Agrace will support family members with the common actions that must be taken in the hours and days following the death.
As Death Approaches

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Talking About Death and Understanding Death Anxiety

Having a life-limiting condition brings an awareness that life has entered its final stages. It is often difficult to come to terms with the reality of one’s eventual death. It’s natural for a person to experience a variety of feelings and fears related to the dying process and death itself.

Many hospice patients experience “death anxiety.” It can be expressed with anger, withdrawal and confusion or demanding behavior. Sometimes death anxiety is expressed by restlessness and agitation, crying, a need to talk, picking at clothes/bed linens, trying to leave/get out of bed or insomnia. Sometimes the anxiety can turn into preoccupation with bowels/schedules/routines, etc. Spiritual and emotional struggles are a natural part of this experience.

Anxiety is a common part of the dying process. Though anxiety may make caregivers and others uncomfortable, usually what the dying person needs is the acceptance and willingness of families/caregivers to allow the person to express his or her anxiety. It is not always easy to talk to a person about his or her death, but the following suggestions may help you:

- **Be sensitive** to what the experience is like for the dying person. Every person brings their whole life experience and perceptions to dying. This experience is unique to each person and may be different from how others see it.
- **Listen** with openness and acceptance to what the person wants to share. People will reveal themselves at their own pace.
- **Offer to assist** the dying person as they think through how they want to say goodbye to loved ones. Some ideas are selecting special items to give away, writing a letter, making an audio or video recording or even helping with special funeral planning. An Agrace volunteer may be able to help record memories or assist with the writing.

Please see page 53, “What to say and do when time is short,” for other topics you may want to discuss at this time.
Changes You May Observe in the Last Hours

You may observe some of the following signs in the patient as death nears. They are part of the body’s natural process of dying.

Food and fluids:

It is natural and common for people to lose their desire to eat and drink as their condition declines. They may take only sips of liquids or small bites of food that can be swallowed easily. At some point, they may lose the ability to swallow well and may not take in anything at all.

As the body shuts down, food and fluids are no longer needed. Eating and drinking when not hungry or thirsty can make a dying person more uncomfortable because their body has trouble handling food and fluids.

So how is it possible that a dying person who is not eating or drinking can be comfortable? Healthy people become very thirsty if they are without water on a hot day, as their body’s sodium level drops quickly. However, in people who are near death, dehydration that comes from gradually eating and drinking less seems to have a natural anesthetic (numbing) effect, which can lead to a peaceful, comfortable death. *

Even though your loved one is not hungry or thirsty, they may feel discomfort from having a dry mouth. Using mouth swabs and moisturizers for the lips can help bring relief.

Please see page 11 in this handbook for suggestions and more information.

Changes in bladder and bowel function:

The patient’s urine output normally decreases and may become darker in color. This is due to the decrease in fluid intake as well as a decrease in circulation through the kidneys.

Loss of bladder and bowel control may occur as the patient declines. A urinary catheter or protective undergarment may be necessary to prevent skin breakdown and keep the patient comfortable.

Fatigue and sleep:

Weakness and fatigue increase as death nears. The patient may need help with simple tasks such as taking a sip of water or turning in bed. They may sleep most of the day.

Agrace staff can help the patient with everyday needs such as bathing and hygiene. We will offer suggestions for conserving energy so time can be spent focusing on whatever the patient enjoys. We strive to provide care that allows the patient to be as awake and as comfortable as possible.

Changes in breathing:

The patient may demonstrate various breathing patterns. Although these patterns might be distressing to you, they rarely cause discomfort for the patient. Breathing may be slow and even at times, and irregular and shallow at other times. Breaths may be separated by long pauses. These pauses are called “periods of apnea” and may last from seconds to more than a minute. As death nears, periods of apnea may lengthen. A patient may experience periods of apnea for several days before death.

Respirations may also become very rapid at times. Again, these patterns might be distressing to you, but they rarely cause discomfort for the patient. If you question the patient’s comfort at any time, please call your Agrace staff immediately.

Many patients experience an irregular pattern of breathing minutes before death. It is often followed by a short period of very shallow “gasping” breaths, and then breathing ceases. This, too, is expected and not uncomfortable for the patient.

Respiratory congestion/loud breathing:

Some people develop loud, rattling breathing due to their body’s inability to process fluids. Saliva that can no longer be swallowed builds up in the throat, causing the patient’s breathing to become louder and moist sounding. Although the noise may sound distressing, the patient generally does not feel any distress or have difficulty breathing.

If the congestion is significant, the nursing staff may use medications to reduce the production of saliva. Suctioning has limited benefits and may worsen the congestion. Repositioning the patient can dislodge the secretions in the throat and ease congestion and is often the most effective way to help.

Temperature and color changes:

Changes in circulation of blood may cause some noticeable changes in the patient’s body. Hands and feet may become cooler to the touch and may sometimes become darker or paler in color. The skin may appear blotchy and purplish on the arms and legs. This discoloration, called “mottling,” is the result of diminished circulation. Progressive mottling can be a sign that death is near. Patients are not usually aware of these changes and rarely experience discomfort from them.

Some patients may develop a fever as they near death. Medication is not always effective in reducing the temperature, though nursing staff may administer medications at times. Most patients do not appear uncomfortable as a result of fever. Cool compresses can increase comfort.
**Pain:**

Pain management is an important part of end-of-life care. Pain can almost always be managed, and the patient can be kept comfortable through the dying process. Medications can be used to keep the patient comfortable without too many side effects and without excessive sedation.

**Disorientation:**

Because of changes in the body’s chemistry, the patient may appear confused about what time it is, or where he or she is. The patient may not recognize close and familiar people. Providing calm reassurance in response to the patient’s questions or statements is helpful.

**Consciousness:**

Some patients may become unresponsive for hours or even days before death. Others may remain clear and alert up to the last few moments. Generally patients experience a gradual decrease in their level of consciousness as death approaches.

As a patient becomes less responsive, opportunities for meaningful communication may also decrease. It is important to understand, however, that the patient continues to hear and have a level of awareness even if they are unable to respond. You should always assume the patient hears everything you are saying. We encourage you to talk to the patient as clearly and directly as if he or she were awake and alert.

**Restlessness:**

Some patients experience a period of restlessness as death approaches. Restlessness may be caused by physical, emotional or spiritual factors. You may observe the patient picking at their clothes or bedding, reaching into the air or moving about in bed. Providing a calm and reassuring environment may be helpful.

**Symbolic language:**

Sometimes patients will use words and phrases that initially may lead the family to believe the patient is confused. This language can sometimes be very meaningful to both the patient and family, and symbolic of the life they led and experiences they are having.

Patients may talk about events in their past as they process their lives. They may use language that describes the need to move, travel or go to another place, or they may talk about a specific time that they will die. They may speak to someone who is no longer alive or express a need for reconciliation. A supportive presence is encouraged during this time, and we suggest you pay attention to what is said, as it can often be very meaningful. Listen attentively and sensitively and acknowledge the experiences.

**Withdrawal:**

Patients often become less interactive and more withdrawn from family and friends as death draws near. This may be due in part to physical factors but may also reflect the patient’s need to process the situation internally. Withdrawal can be one of the more difficult aspects of the dying process for family and friends. A loving, supportive presence may be all the patient needs or wants at this time.
A Note to Family & Friends

There are few things about death and dying that are predictable—we don’t know when it will happen or how it will happen; we don’t know who will be with us or how we will feel. Agrace is always available to assist you during this time.

Agrace’s staff will do their best to identify when a patient is approaching death. We inform and contact families when changes occur to allow for the family to be present if they desire. Please understand that there are times that patients die without showing the typical signs.

Grief Support for Bereaved Family

Within a week after the death, your Agrace social worker will call to check on you. Your Agrace spiritual & grief counselor will also call, in 4 to 6 weeks, to offer support that’s based on your needs. Our grief support will continue for a year after the death, and may include mailings, phone check-ins, one-on-one support and participation in grief support groups.

Please know you can turn to Agrace for help if you’re struggling with grief at any time. Your counselor is available Monday through Friday from 8 a.m. to 5 p.m. Grief support is also provided on weekends by on-call hospice professionals. Please call (800) 553-4289 to reach the on-call staff.
Care at the Time of Death

When death occurs at home:

Please call Agrace if you think the patient is in the dying process or has died. You should call us no matter what time of the day or night. **Do not call 911.**

Immediately after the death, you may feel “numb” and may have trouble concentrating. Survivors often ask, “What do I do now?” Your Agrace team is available to assist and support you.

If you want to take some time for family to gather before calling Agrace, you are welcome to do so. There is no hurry. Help is always as close as your telephone. We will come as soon as you ask us to, but you can spend time alone first, if you want. We will respect your final moments with the patient, either alone or with our staff present.

Once you call Agrace, a nurse will come. If you want to have a social worker, spiritual & grief counselor, clergy member or a spiritual-care person present, the nurse will help you contact them. Please tell our staff if there are rituals you would like observed at this time.

Your Agrace team will take care of the following:

- The nurse will pronounce the death. He/she will check for the absence of a pulse, heartbeat, respiration and blood pressure to determine the time of death. The coroner will be notified, if necessary.
- The nurse will remove tubes, such as catheters.
- The Agrace team will bathe and dress your loved one. We will ask whether you would like to help. Participate only if you are comfortable doing so.
- If you are working with a funeral home, your team will call the funeral home when you are ready, if help is needed.
- Your team will also ask you if there is any special clothing you would like your loved one dressed in. The clothing may be given to the funeral director at this time, or it can be taken to the funeral home later.
- If no funeral or memorial service is planned, your team may ask you if you would like a bedside service.
- Your Agrace counselor can assist with funeral or memorial service planning.
- Your nurse will call to have the medical equipment, such as a bed or wheelchair, removed when you would like.

- After the death, there are often phone calls to make to family and friends. Your team may offer to make the phone calls or assist you with the phone calls.
- **Your nurse may assist you with disposing of any unused medications that are “controlled substances.”** This important safeguard is done according to Agrace’s Medication Disposal Policy to make sure that medications are not taken by someone other than the person for whom the medication was prescribed. If you have questions about this practice, please see page 34 of this handbook for details.
- When the funeral home arrives, you may choose to escort your loved one to the vehicle. Your team may also escort your loved one or go with you to the vehicle if you would like.
- When the funeral home staff has gone, your team may stay with you for a period of time. Please tell them when you are ready for them to leave.
- Your team will contact the doctor and other team members to let them know about the death.
When death occurs at the Agrace Inpatient Unit:

If you think the patient has died, notify a staff member. They will assess the patient for vital signs and pronounce the death. The coroner will be notified, if necessary.

The Agrace staff will assist you in many of the same ways noted on page 68. One important difference is that when it is time, staff will work with you to determine your wishes for the procession of the patient’s body out of the building. If you choose to be present when the patient’s body is transported, there will be a procession and Agrace staff will be honored to join. If you choose not to be present when the patient’s body is moved, our staff will escort the body.

When death occurs at a skilled nursing facility, assisted living facility or community-based residential facility:

If you think the patient has died, inform a nurse or other facility staff member. The facility staff will call Agrace, and an Agrace nurse will make a visit to confirm that the patient has died. The coroner will be notified, if necessary. If you wish, you may call family members, friends and other important people. If you wish to have an Agrace social worker, a clergy member or a spiritual-care person present, we will assist you in contacting them. Please notify the Agrace staff if there are rituals you would like observed at this time.

You should be comfortable taking whatever time you need with your loved one. We are dedicated to helping you and your family, and want to respect your final moments with the patient, either alone or with our staff present. When you are ready, we will call the funeral home of your choice and support you with assistance in funeral planning.

Why might Agrace call the coroner?

The Agrace nurse may call the county medical examiner following the death. Please do not be alarmed; reasons for this call may include:

- it is required by county law for all deaths,
- the patient had an injury during their time on Agrace services, or
- the patient sustained a life-altering injury before they started hospice care, such as a car accident or other injury that permanently altered their physical health.

During this call, the medical examiner will ask the nurse for details of the patient’s medical history. Although this information should be in their medical record, you may need to help clarify some details for the medical examiner.
After-death Notifications

After the death of your loved one, there may be calls to make. Some agencies, organizations and personal services may need to know the date of your loved one’s death. In most cases, the funeral home will provide death certificates, as well as information about those organizations and agencies that need to be notified as soon as possible.

Some of the following entities may need notification calls:

<table>
<thead>
<tr>
<th>Type of organization</th>
<th>Phone number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance companies: medical insurance, life insurance, disability insurance, etc.</td>
<td></td>
</tr>
<tr>
<td>Social Security</td>
<td></td>
</tr>
<tr>
<td>Pension plans</td>
<td></td>
</tr>
<tr>
<td>Veterans Administration</td>
<td></td>
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<tr>
<td>Credit card companies</td>
<td></td>
</tr>
<tr>
<td>Creditors</td>
<td></td>
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<tr>
<td>Attorney</td>
<td></td>
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<tr>
<td>Executor of estate</td>
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<tr>
<td>Accountant</td>
<td></td>
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<tr>
<td>Religious community (church, synagogue, etc.)</td>
<td></td>
</tr>
<tr>
<td>Employer/former employer</td>
<td></td>
</tr>
<tr>
<td>Clubs, fraternal organizations, professional groups</td>
<td></td>
</tr>
<tr>
<td>Bank(s)</td>
<td></td>
</tr>
<tr>
<td>Investment companies</td>
<td></td>
</tr>
<tr>
<td>Mortgage companies</td>
<td></td>
</tr>
<tr>
<td>Government offices, including the Internal Revenue Service</td>
<td></td>
</tr>
<tr>
<td>Landlord</td>
<td></td>
</tr>
<tr>
<td>Pharmacy (for automatic refills)</td>
<td></td>
</tr>
<tr>
<td>Other (use spaces below)</td>
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</tbody>
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Advance Directives, Forms & Policies

Agrace HospiceCare
What Are Advance Medical Directives?

An advance medical directive is a written document that allows you to plan and direct the types of health care you may receive in the event you become unable to express your wishes.

Advance Medical Directive Policy

Agrace HospiceCare provides hospice and palliative (comfort) care to terminally ill patients and their families, in accordance with each individual patient’s goals and wishes.

Agrace recognizes that everyone has a right to make decisions related to his or her own medical treatment, including the right to accept or refuse medical care and the right to create advance medical directives.

Agrace provides patients and families with information and state forms for the following directives:

- **Power of Attorney for Healthcare**: A power of attorney for healthcare allows you to assign other individuals to make healthcare decisions on your behalf if you are unable to do so.
- **Living Will**: A living will expresses your preferences about life-sustaining procedures and feeding tubes in the event that you are in a terminal condition or in a persistent vegetative state.
- **Code Status**: Your code status directs what attempts are made to save your life in case your heart stops or your breathing stops. Regardless of your code status, we will provide aggressive pain and symptom management measures to ensure your comfort.
  - **Do not resuscitate (DNR)**: If you choose do-not-resuscitate (DNR) status, you will be kept comfortable and have a natural death without medical actions to attempt to restart your heart or your breathing.
  - **Resuscitate**: If you choose resuscitate status, aggressive medical actions may be taken to restart your heart or your breathing. These medical actions may include IVs, medications, CPR (cardiopulmonary resuscitation), breathing tubes or electricity through your heart.

Agrace does not discriminate against an individual patient based on whether or not he or she has executed advance medical directives.

You can request a copy of our complete Advance Medical Directives policy from any Agrace staff member.
Emergency Operations

At Agrace, we understand the importance of providing consistent, uninterrupted services for our patients and families. Agrace has a detailed Emergency Operations Plan that outlines an organized process for managing and recovering from a variety of emergencies and natural disasters.

Agrace’s Emergency Operations Plan

Agrace’s emergency operations plan includes policies and procedures for ensuring appropriate and timely responses in the event of a natural disaster or another emergency affecting Agrace or the community. In these types of situations, you can count on Agrace to:

- anticipate your needs and ensure patients/families have enough supplies and medications before severe weather strikes,
- stay in contact by calling patients/families and contacting local emergency management regarding any potential patient safety issues, and
- be there, making every effort to ensure essential visits for patient care are completed.

Your Emergency Operations Plan

Agrace encourages all patients/families to prepare for potential emergencies. Take time today to think about your needs and make an emergency plan that fits those needs.

Make Your Plan

1. List your personal support network. Make a list of the people who could help you if there is an emergency—family, friends. Then ask them to be part of your support network. Make sure one of them has a key to your home and knows where you keep your emergency supplies. If you use a wheelchair, oxygen or other medical equipment, show friends how to use these devices so they can move you, if necessary.

2. Make a communication plan. Your support network may not be together when disaster strikes, so plan how you will contact one another and what you will do in different situations.

3. Plan for evacuation. Have a plan for evacuating (leaving your home or local area). Local authorities may not be able to provide information immediately on what is happening and what you should do. However, if you are told to evacuate, do so immediately. Ahead of time, choose several places you could go, in different directions from your home. If you need medical transport or cannot evacuate by yourself, make arrangements in advance.

4. Consider staying put. It may simply be best to stay where you are. Consider what you would do to “shelter in place” alone or with members of your support network.

5. Contact your local Emergency Information Management Office. Some keep registries of people who would need assistance in an emergency. If you add your name to a registry, be sure you understand what you can expect. A registry is never a substitute for being prepared personally.

For immediate help:

If you need emergency responders to help you in the case of a household fire, severe weather or other emergency, call 911.
Assemble Your Supplies

Assemble a kit of supplies that could help you get through a brief emergency. Below are some suggestions from FEMA, the Federal Emergency Management Agency, of what you could include in your kit.

**Basic provisions:**
- Water: one gallon per person per day, for at least three days, for drinking and sanitation
- Food: at least a three-day supply of non-perishable food; can opener for food, if needed
- Battery-powered or hand crank radio and a NOAA Weather Radio with tone alert, and extra batteries for both
- Flashlight and extra batteries
- First aid kit
- Whistle to signal for help
- Dust mask to help filter contaminated air
- Plastic sheeting and duct tape to “shelter in place”
- Moist towelettes, garbage bags and plastic ties for personal sanitation
- Wrench or pliers to turn off utilities
- Pet food and extra water for your pet
- If possible, extra oxygen, insulin, catheters or other medical supplies you regularly use

**You may also want to add these items:**
- Prescription medications
- Medical prescriptions and doctor orders
- Medical alert tags or bracelets or written descriptions of your disability and support needs, in case you are unable to describe the situation in an emergency
- Extra eyeglasses and hearing aids if you have them; extra batteries for hearing aids
- Battery charger for motorized wheelchairs or other battery-operated medical or assistive technology devices
- Personal care/hygiene items, such as a toothbrush and toothpaste, tissues, wash cloth/towel, comb, deodorant
- Copies of important documents:
  - medical insurance cards, Medicare/Medicaid cards
  - physician contact information, a list of your allergies and health history
  - the style and serial numbers of the support devices you use
  - family records, wills, deeds, Social Security numbers
  - charge and bank account information
  - tax records

Learn more about creating your own emergency operations plan at [www.ready.gov](http://www.ready.gov), or ask your Agrace social worker for help.