



# Serenity Hospice and Home Patient Handbook and Caregiver Training Guide



A Perfect Combination of Expert  
Professional Care and Loving  
Compassion

Serenity Hospice & Home 815-732-2499



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## About Serenity Hospice

Dear Caregiver,

We at Serenity Hospice and Home believe it to be a privilege that you have asked us to help you care for your loved one. We will promote an environment that will allow the patient to live life fully by honoring his or her wishes. Together we can provide comfort on this final journey.

Because we know there are so many questions, so much to do and so much to learn, it is our hope that this book will assist you in providing care. This training guide will give you information and insight to help you understand and perform your caregiver duties.

Serenity Hospice and Home serves many patients, with diverse problems from different backgrounds and locations. Some patients we serve for months and others only a few days. This book was prepared for all those we care for, because they all deserve the best care we can offer.

This book has been designed as an overview. Please remember:

- More information is available.
- Any information that is unclear will be reviewed.
- No question or concern is too small.
- Feel free to contact the hospice team members at anytime.
- Nurses are available 24 hours a day, 7 days a week.

You have already done so much by surrounding your loved one with love and compassion. By sitting, listening, holding their hand, you have given a gift to them: the gift of your presence.

Hospice care is focused on each person's values, beliefs, and wishes; not the disease that has made them a patient.

May comfort & peace be with you,

*The Staff of Serenity Hospice and Home*



## About Serenity Hospice

### Bill of Rights for Family Members of Those With a Serious Illness

- It is my right to look after my own needs. Only when I take care of myself am I able to give the best care and attention to the patient. Even though my own needs may not seem as great as the patient's, I have to look out for myself too.
- It is my right to enjoy my own health. I need not feel guilty about this. It is not my fault that my loved one has this illness.
- It is my right to build up my own network of support and get help for myself even though others in the family choose not to.
- It is my right to choose whom I will and will not talk to about my loved one's illness. I do not wish to hurt anyone's feelings by not sharing everything at all times, but when I am ready to share my feelings, I will.
- It is my right to take some "time off" from caring for the patient without feeling disloyal. I believe it is okay for me to see a movie, go shopping, eat out, or enjoy some other diversion. It gives me "emotional energy" to keep going.
- It is my right to ask for outside help from friends, other family members, and professionals if I cannot manage all the responsibilities of caring for the patient at home myself.
- It is my right to disagree with my loved one who is ill because we are still "real" people, and if he or she tries to use the illness as a weapon, I have the right to reject that and do only what can be expected of me.
- It is my right to be told the truth about the illness and what is going on. If I am a child, I need to be told in words that I can understand.
- It is my right to refuse to make promises I know I "can't keep" to the sick person, for if I do, I will only feel guilty at some later date.
- It is my right to maintain hope and to maintain as much normalcy in my life as possible. I must be able to continue living as positively and normally as possible to enhance the quality of the life of my loved one who has the illness.

From Make Today Count, Inc.



## About Serenity Hospice


### Serenity Hospice and Home Mission Statement

*Believing in the dignity of life,  
Serenity Hospice and Home  
offers care to the terminally ill  
and their families.*

*This encompasses physical, spiritual  
and emotional needs of the family unit  
with emphasis on the desires  
of the patient and family.*

*Serenity Hospice and Home  
believes that living continues  
until the moment of death and  
our focus is on promoting  
optimal living through  
this final journey of life.*

*If at any time you believe Serenity Hospice and Home  
is not meeting its mission, please call the  
Executive Director,  
Lynn Knodle, at 815-732-2499*



## About Serenity Hospice

### **Hospice is:**

- A special way of caring for people who are seriously ill, with the emphasis on comfort (palliative) care and symptom control rather than on curative treatments.
- A philosophy of care for patients and families who are facing life-limiting illnesses, providing support and care in the last phase of an incurable disease.
- Hospice neither hastens nor postpones death. Hospice exists in the hope and belief that through appropriate care and the promotion of a caring community sensitive to their needs, patients and their families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them.

### **Serenity Hospice & Home Is:**

- A not-for-profit, free standing agency established in 1984.
- A Medicare/Medicaid certified agency.
- Licensed by the Illinois Department of Public Health.
- Accredited by The Joint Commission.
- A member of national and state Hospice & Palliative Care Organizations.
- An agency that serves the counties of Boone, Carroll, DeKalb, Lee, Ogle, Stephenson, Whiteside, Winnebago, and the towns of Walnut and Ohio in Bureau County.
- A team of caring professionals, focusing on relieving the symptoms of the disease and assisting the family in coping.

## About Serenity Hospice

### The Hospice Care Team

In order to meet the needs of patients and their family members, Serenity Hospice & Home maintains a team of professionals, trained in various disciplines, to focus on the physical, spiritual, and emotional needs of the patient. Patients and their caregivers are part of the team and are always invited to our plan of care meetings.

### Medical Director

The Medical Director is an Illinois licensed physician responsible for overseeing the patient's Hospice care. The Medical Director reviews each patient's Plan of Care to make sure all needs are being met in the best possible way, and makes periodic home visits to provide care. Our Medical Director works with your personal physician to assure that the physical aspects of your care are closely monitored and attended so that the best possible comfort care can be achieved.

### Registered Nurses


All Hospice nursing services are based on patient need and performed under a "Plan of Care" for that patient. All Serenity Hospice & Home nurses are licensed professionals specifically trained to do Hospice nursing. Many of the nurses are also Board Certified in Hospice & Palliative Care. A hospice nurse is on call 24 hours a day, seven days a week to assist with any questions or needs. For more information regarding a nursing visit, please see the "Preparing for a Visit" section on pages 20-21.

### Certified Nurse Assistants

A certified nursing assistant (CNA) can visit on a regular schedule if you choose. The CNA can provide personal hygiene care, such as bathing, washing hair, brushing teeth, giving back rubs, providing skin care, and changing bed linens as well as light housekeeping tasks. CNA's are supervised by Registered Nurses.

### Physical Therapists

Specialized physical therapies are sometimes needed. We also offer massage and other complementary therapies for our patients. The schedules will vary for those who will be coming into your home. Please feel free to discuss convenient times with staff.





## About Serenity Hospice

### The Hospice Care Team Cont...

#### Social Workers

Our social workers offer emotional support, counseling, and coordination of community resources and support services, as well as helping with final arrangements. A hospice social worker is assigned to each patient and family for a psychological and social assessment. Where indicated, a proper referral is made to the appropriate agency. The social worker documents the findings in the patient chart and makes follow-up visits as indicated. When appropriate, patient/family concerns are brought to the Interdisciplinary Team. Examples of items social workers can assist families with are as follows:

- Assisting with caregiver options when there is no primary caregiver, or the burden of care is too much for a caregiver.
- Assisting with funeral arrangements.
- Assisting Veterans to receive entitled benefits.

#### Bereavement Companions

Bereavement Companions assist in preparing patients and families for this difficult time and providing support for survivors. They facilitate all the hospice bereavement services, including the monthly support group meetings for survivors and mailings to families and loved ones. Companions work with the patient and family before and following the death. Bereavement Companions are a community resource for anyone experiencing grief, whether or not the loss was a Serenity Hospice and Home patient.

#### Chaplain Services

Spiritual care needs are assessed by our Chaplain, who will visit, or coordinate visits with other clergy, according to the wishes of the patient and family.

#### Volunteers

Opportunities for specialized care may be provided by trained Volunteers. Volunteers do many things for patients and their families such as, light housework, cooking, running errands, and providing general companionship. Volunteers receive 16 hours of instruction and attend frequent in-service seminars.

## Patient Rights and Responsibilities

### All patients have the right to:


- Be fully informed in advance about service/care to be provided, including the disciplines that furnish care and the frequency of visits as well as any modifications to the service/care plan.
- Have one's property and person treated with respect, consideration, and recognition of patient dignity and individuality.
- Be able to identify visiting staff members through proper identification.
- Be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property.
- Voice grievances/complaints regarding treatment or care, lack of respect of property without restraint, interference, coercion, discrimination, or reprisal by or from hospice staff and administration.
  - ◇ Illinois Central Complaint Registry Hotline: 800-252-4343
  - ◇ TTY for Hearing Impaired Only: 800-547-0466
  - ◇ IL Dept. of Public Health: <http://www.dph.illinois.gov/topics-services/health-care-regulation/complaints>
  - ◇ The Joint Commission: [https://www.jointcommission.org/report\\_a\\_complaint.aspx](https://www.jointcommission.org/report_a_complaint.aspx).
- Be informed of any financial benefits when referred to an organization.
- Receive information about the scope of services the organization will provide and specific limitations on those services.
- Exercise rights as a patient of hospice.
- Obtain information concerning my diagnosis, treatment, and prognosis in terms that I understand.
- Receive information necessary to give informed consent to Hospice treatment, understanding that Hospice care is not curative in purpose, but is designated to alleviate pain, relieve symptoms, and offer support to caregivers.
- Receive care under the direction of my personal physician and/or Hospice medical director by staff and volunteers who are qualified.

## Patient Rights and Responsibilities

- Have my values, preferences, and way of life respected and incorporated into my plan of care. Serenity Hospice & Home shall not impose the dictates of any value or belief system on me or my family.
- Participate in development and revisions of the plan of care and to have my caregivers involved in the planning and provision of care.
- Have every consideration of privacy, security, and confidentiality of information with regard to medical, personal, and family matters.
- Refuse treatment to the extent permitted by law and to be informed of the medical consequences of such refusal.
- To revoke consent for hospice care.
- Be involved in resolving conflicts about care or service.
- Be free from restraint or seclusion.
- Be served without regard to race, color, national origin, gender, handicap, age, disease, sexual preference or religion.
- Have communication needs met.
- Be informed over changes in charges not covered by Medicare/insurance.
- Have reports of pain believed and responded to quickly.
- Receive information about pain and pain relief measures.
- Have a concerned staff committed to pain prevention and management.
- Receive effective pain management.
- Make informed decisions about proposed and ongoing care.
- Formulate advance directives.
- Be notified of the potential benefits, risks, and effects of the care or services provided.

## Patient Rights and Responsibilities

**All patients have the responsibility to:**

- Provide a safe environment for the provision of care for the hospice team.
  - Provide complete and accurate information regarding illness and treatment to the hospice team.
  - Participate in and adhere to the hospice plan of care.
  - Report any concerns about his/her understanding of the course of treatment or his/her ability to comply with instructions.
  - Follow instructions he/she is given for performing a procedure or using a piece of equipment.
  - Notify Serenity Hospice & Home when a piece of rental equipment is no longer needed.
  - Notify Serenity Hospice & Home if he/she will not be home for a previously scheduled visit.
  - Notify Serenity Hospice & Home when there are unexpected changes in the patient's condition.
  - Ask your nurse what to expect regarding pain and pain management.
  - Discuss pain relief options with your nurse.
  - Work with your nurse to develop a pain management plan.
  - Ask for pain relief when pain first begins.
  - Help your nurse assess your pain and to tell the nurse if your pain is not relieved or if you have any worries you have about taking pain medication.
  - Express any concerns about the ability to follow proposed care plan or course of treatment.
  - Verbalize understanding and acceptance of consequences when refusing to follow the plan of care, services, or treatment.
- 

## Electronic Documentation

Our goal as your hospice care team is to ensure that we are giving our patients quality care. When members of the health care team come for a visit, you may notice them using a laptop computer, iPad, or other electronic devices. At Serenity Hospice our health care team charts in an electronic health record which immediately updates the patient's electronic chart. This allows all other health care team members to have up to date information at all times.

When using the electronic documentation method, members of the health care team must log into a secure website by entering their user name and password. This ensures that all personal healthcare information is secure. All members of the Serenity health care team follow the HIPAA regulations.

If at any time you have questions or concerns about electronic documentation, please ask and we would be happy to discuss this more.



## Who Pays for Hospice?

Payment options for hospice services include, but are not limited to, Medicare, Medicaid, and private health insurance.

### Medicare Hospice Benefit

The Medicare Hospice Benefit provides comprehensive coverage for hospice care. Medicare beneficiaries who have coverage under Medicare Part A and meet eligibility for hospice care can access the Medicare benefit.


- The Medicare Hospice Benefit reimburses Serenity Hospice and Home at a daily rate, or per diem, for all of the services provided.
- Medicare Part A will be used to cover services related to the life-limiting illness during the time the patient uses the Medicare Hospice Benefit. The patient still has access to services under Medicare that are not related to the terminal illness.
- All Medicare paperwork and billing pertaining to the life-limiting illness is handled by Serenity Hospice and Home.

### Medicare Part D (Medications)

Medications for symptom control or pain relief are covered by the Hospice Medicare Benefit. Any medications currently covered under your Medicare Part D benefit unrelated to your terminal illness will be reviewed with the hospice physician, hospice team and your Medicare Part D provider to determine coverage.

### Medicare HMO Coverage

If an individual is enrolled in a Medicare-approved HMO, electing hospice is simple.

- The Medicare HMO transfers coverage to Medicare Part A for hospice benefits.
  - Under a Medicare HMO plan, an individual has freedom of choice in selecting the hospice provider, even if it is outside the HMO provider network.
- 

## Who Pays for Hospice?

### Medicaid Hospice Benefit

Medicaid is a state-funded program that provides medical coverage for persons who have limited financial means and who meet eligibility requirements for hospice care.

- The Medicaid Hospice Benefit reimburses Serenity Hospice and Home at a daily rate, or per diem, for all of the services provided.
- All Medicaid paperwork and billing pertaining to the life-limiting illness is handled by hospice.
- Hospice staff will verify coverage and assist individuals in applying for Medicaid.
- Spend-down amounts must be satisfied in order to access maximum coverage under the Medicaid Hospice Benefit.

### Private Health Insurance Coverage

Hospice benefits vary widely among insurance plans. Serenity Hospice and Home will verify and negotiate benefits for people with commercial or private health insurance.

- Coverage will be determined at the time of admission to hospice and the allowable benefits will be explained.
- In most situations, Serenity Hospice is able to negotiate a daily rate that provides coverage for hospice services. Under the terms of the anti-kick back laws, insurance policy, and federal law, we are legally obligated to collect patient responsibility, co-insurance, co-payment, or deductible. If you have any issues or concerns with your insurance or any charges you may receive, we will be more than happy to assist you.

### Coverage for Services Unrelated to Hospice Care

There may be occasions when the patient requires medical services unrelated to the life-limiting illness that are not covered by the hospice benefit. Insurance coverage for these services will be based on the type of service and the health insurance policy of the patient. Please consult with Serenity Hospice and Home for further explanation prior to seeking outside services.

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## Who Pays for Hospice?

### Coverage for the Uninsured

Serenity Hospice and Home is a non-profit organization committed to serving the needs of its community. Financial Assistance is available for hospice services to patients and families who meet criteria defined in the Serenity Hospice Financial Assistance Policy.

### Discontinuation of Hospice Services

The patient can choose at any time to discontinue hospice care. On occasion, individuals may choose to receive active treatment or alternative medical benefits instead of hospice care. With proper notification, this transition can be easily accomplished for the patient. Medicare, Medicaid, and most private insurance plans allow for hospice benefits to be reactivated at a later date.





## Levels of Hospice Care

| Level of Care  | Definition   | Location   | Length of Care  | Example  |
|--|--|--|---|--|
| <b>Routine home care</b><br><br><u>Reimbursement</u><br>Per diem—meaning a set daily rate that covers nursing, meds and equip          | Hospice care provided by Hospice staff wherever the patient calls home. Scheduled visits from Hospice team members and on-call provided 24/7 | Patient's home<br>Sr. apartment<br>Nursing Home<br>Adult living facility             | No time limit when certified eligible<br>2 Certification periods of 90 days and then every 60 days thereafter | Availability of willing and able primary caregiver<br><br>The terminal illness can be managed by caregiver(s)  |
| <b>Continuous home care</b><br><br><u>Reimbursement</u><br>Set hourly rate   | Indicators are for patient/family crisis requiring intense and continuous nursing care provided by RN or CNA                                 | Patient's home,<br>Sr. apartment,<br>Nursing Home or<br>Adult living facility        | 8 or more hours in a 24 hour period   | Emergency type situation of uncontrolled symptoms or exacerbation of disease process. Care provided by nurse and nursing assistant.  |
| <b>Respite care</b><br><br><u>Reimbursement</u><br>Set rate includes room & board cost   | Provides time for caregiver rest and to be relieved of duties for a temporary period of time   | Inpatient bed in Serenity Home or contracted bed in hospital or skilled nursing home | 5 consecutive days during a covered period.   | Caregiver themselves becomes ill or would benefit from a rest period of the day-to-day duties of giving care   |
| <b>General inpatient care</b><br><br><u>Reimbursement</u><br>Set rate includes coverage for higher level of care and room & board cost | Care that may require procedures necessary for pain control, symptom management that cannot feasibly be provided in the home setting         | Inpatient bed in Serenity Home or contracted bed in hospital or skilled nursing home | Short term<br><br>Usually a few days  | Uncontrolled pain, Intractable nausea, Respiratory distress, Severe skin wounds, Psych/Soc problems, Symptoms not manageable in other settings or beyond caregiver ability |
| <b>Residential care</b><br><br><u>Reimbursement</u><br>Private payment for room & board  | Available to current hospice patients when around the clock care is needed. Offers supportive environment                                    | Serenity Hospice Home  | Weeks to months enables patients to stay in SH even when GIP or respite eligibility is not met                | When other locations of care do not meet the care needs of patient   |


## Levels of Hospice Care

**Routine Care** is end-of-life care provided in the patient's home or place of residence (assisted living, nursing facility, etc.). The hospice service is most often paid by Medicare, Medicaid, or most private insurance companies. If the patient lives in a nursing facility, the responsible party for Room and Board payments does not change.

**Respite Care** is care available to Hospice patients providing time for caregivers to rest and for relief of duties for a temporary period of time. This care is provided at Serenity Home and is paid for by Medicare, Medicaid, and most private insurance.

**General Inpatient Care** is care for pain and/or symptom management that cannot feasibly be provided in the patient's home setting. This care is provided at Serenity Home and paid for by Medicare, Medicaid, and most private insurance.

**Routine Care with Private Payment of Room and Board** is available to patients who wish to receive Routine Care in Serenity Home. This is end-of-life care provided in the Serenity Home when General Inpatient criteria are not met. The patient and family elect to pay the Residential Room and Board rate of \$225 per day, beginning at midnight each day.



## **Levels of Hospice Care**

### **Day Out Program**

Caregiving is a difficult task. It often leaves little time for anything else. The job of caring for a loved one can frequently be compared to a marathon and not a sprint. Caregivers must pace themselves. They must take a break and, at times, attend to business or errands.

To help facilitate this, Serenity Hospice & Home offers a Day Out Program.

This program is designed to enable the caregivers of hospice patients time to have a "day out." Patients may come and spend between 2 and 8 hours of a single day at the Serenity Home. While at Serenity Home, patients will have the benefit of nursing and CNA supervision.

Please contact Social Services at 815-732-2499 for more information.



## Preparing for a Visit


### Visits

Visits will be made by the members of the Hospice Team which may include a physician, nurses, certified nursing assistants, social workers, chaplains, trained volunteers, bereavement companions, and support staff.

The Hospice nurse will make regularly scheduled visits to assess the patient based on the their needs and condition. Services performed by the nurses may include:

- **Training** for caregivers on basic care to make the patient comfortable.
- **Training** for caregivers on personal care.
- **Training** for symptom management (i.e. shortness of breath, anxiety, pain management).
- Vital signs.
- Listen to heart and lungs.
- Look at skin condition.
- Review medications.
- Refill prescriptions.

The Hospice nurse is on-call and can make visits 24 hours a day, seven days a week, including evenings, weekends, and holidays.



## Preparing for a Visit

### Four Ways to Prepare for A Visit from The Hospice Staff

Please  
Do Not Smoke  
During The Visit



Second-hand smoke is hazardous.  
We want to smell fresh for the next  
patient we will be visiting.

Please  
Keep any naughty dogs  
secure in another room  
During The Visit



Barking dogs make it hard to talk.  
Biting dogs are hard on us.

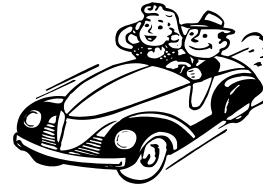
Please  
Have Liquid Hand Soap



And Paper Towels

This will help control germs  
for you, our next patient  
and ourselves.

Please  
Call 732-2499  
If you are not  
going to be home



for a scheduled visit

We appreciate your help  
in managing our time.

## When to Call Hospice

The hospice office is open **Monday through Friday from 8:00am to 4:30pm**. At all other times the answering service will take your call and notify the on-call nurse. That nurse will return your call within 10 minutes.

**CALL SERENITY HOSPICE & HOME**  
**815-732-2499**  
**Please DO NOT Call 911**

Hospitalization and ambulance transportation without the consent and knowledge of Serenity Hospice and Home will be the financial responsibility of the patient/family and not that of Serenity Hospice and Home.



## When to Call Hospice

Please call Serenity at 815-732-2499 with any questions and concerns. We are available 24 hours a day, seven days a week to take care of any issues or problems that may arise. Remember, no concern is too small. The hospice staff needs to know what is happening to provide the best comfort for the patient, to work more efficiently with the physician and ease the stress of the caregiver. Good communication allows us to offer the best quality of life possible for all involved.

The hospice nurse can assist if the patient is having:

- Increased pain.
- Any bleeding.
- Increased restlessness.
- Any injury.
- Problems breathing.
- Slurred speech.
- A change in mental alertness.
- Unusual sweating.
- Nausea or vomiting.
- Inability to urinate.
- Constipation or diarrhea.
- Problems with equipment.
- A change in food / fluid intake.
- Medication questions.

On the rare occasion that a return call from a nurse is not received within the time frame of 10 minutes, please call and ask that the nurse be paged again.

If at anytime you call 815-732-2499 and do not get an answer or there is a fast busy signal, please call the **hospice answering service directly at 1-800-654-9209. In the unlikely event that the call center is experiencing a phone outage, please call the emergency cell at 815-677-4660.**


## **Safety and Equipment**

### **Medications**

Hospice supplies the appropriate drugs to control pain, relieve nausea, promote rest, ease heavy breathing, and minimize other distressing problems. The medication hospice provides is delivered directly to you. Filling prescriptions at the pharmacy is limited to medication not provided by hospice. Vitamins and previously used medications, not related to the terminal illness, are not part of the hospice program. Serenity Hospice & Home works with a pharmacy specializing in the care of hospice patients.

### **Equipment**

To promote a safe and comfortable environment, oxygen, walkers, wheelchairs, electrical beds, air mattresses, commodes and other supplies are leased from a vendor as part of the hospice benefit and delivered to the home. The nursing staff will bring sheets, bed pads and other supplies. For any questions about supplies, please ask your nurse.





## Safety and Equipment

Keeping hands clean is one of the most important things we can do to stop the spread of germs and stay healthy.

### When?

- Before, during, and after preparing food.
- Before eating food.
- Before and after caring for someone who is sick.
- Before and after treating a cut or wound.
- After using the toilet.
- After changing diapers or cleaning up a child who has used the toilet.
- After blowing your nose, coughing, or sneezing.
- After touching an animal, animal feed, or animal waste.
- After handling pet food or pet treats.
- After touching garbage.

### How?

**Wet** your hands with clean, running water (warm or cold), turn off the tap, and apply soap.

**Lather** your hands by rubbing them together with the soap. Be sure to lather the backs of your hands, between your fingers, and under your nails.

**Scrub** your hands for at least 20 seconds. Need a timer? Hum the “Happy Birthday” song from beginning to end twice.

**Rinse** hands well under clean, running water.

**Dry** hands using a clean towel or air dry them.

*For more details on handwashing,  
visit CDC’s Handwashing Website @  
[www.cdc.gov/handwashing](http://www.cdc.gov/handwashing)*

## Safety and Equipment

### Fall Prevention Guidelines

The risk of falling, and problems related to falls, have serious implications to the quality of life for the patient. *Please review the following information carefully; we believe by increasing your awareness of fall prevention, you will feel more competent in offering a safe plan of care.*

#### The risk of falls increases when:

- A previous fall has occurred in the last six months.
- A patient does not recognize his/her own limitations.
- Muscle strength is decreased.
- Assistive devices are used incorrectly.
- The medical condition changes.
- Environmental hazards are present.
- Certain medications are administered.

Patients receiving hospice care may have multiple risk factors which make it all the more important to have a safe plan of care in place.

It is always important to talk to hospice team members about any safety concerns you have. A safety re-assessment will be completed and changes in the plan of care can be made. Assistive devices and monitoring systems are available as needed.

#### The Serenity Hospice and Home nurse will:

- Complete a fall risk screening tool.
- Check for safety hazards in the home.
- Identify medications that increase fall risk.
- Provide safety recommendations and education.

#### The caregiver should:

- Share information with Serenity Hospice and Home staff.
- Reduce hazards in the home (see checklist on the next page).
- Record medication administration times and effects.
- Have an increased awareness to safety precautions.
- Promote proper use of assistive devices.

## **Safety and Equipment**

### **Fall Prevention Guidelines Cont...**

Taking a proactive approach will help prevent falls. Please look around your home to ensure that a safe environment is being provided.

- ☐ Adequate lights in hallways, bedrooms, and bathrooms.
- ☐ Remove rugs or small rugs need to have non-skid backing.
- ☐ Traffic areas are free of clutter and electrical cords.
- ☐ Stairways are in good repair, have hand rails and are free of objects.
- ☐ Chairs are sturdy and secure (arms aid when rising).
- ☐ Bathroom grab bars (towel bars are not strong enough to be grab bars).
- ☐ Raised toilet seat (in a highly visible color).
- ☐ Patient wears proper fitting footwear or non-skid socks.
- ☐ Maintain a clean environment.
- ☐ Have frequently used items in an easy to reach position.
- ☐ Have canes and walkers next to patient and encourage them to use as instructed.
- ☐ Pets should not be under foot.

### **Be aware of things that contribute to falls:**

- Alcohol use.
- Vision and hearing deficits.
- Low blood pressure readings.
- Feeling weak and/or dizzy.
- Rising quickly after eating or sleeping.
- Effects from medications.

**Please also note that there may come a time when it is not safe for the patient to be alone.**



## Safety and Equipment

### Fall Prevention Guidelines Cont...

This chart shows the time frame during which the caregiver should monitor the patient for drowsiness and dizziness following the administration of medication. The patient should be observed closely and caution exercised during these time frames.

| Medication | Effects Begin | Effects May Last |
|------------|---------------|------------------|
| Morphine   | 15-30 minutes | 30-90 minutes    |
| Ativan     | 30 minutes    | 1-6 hours        |
| Haldol     | 20-30 minutes | 2-6 hours        |

*All slips, trips, and falls need to be reported to the hospice nurse at 815-732-2499*

## **Safety and Equipment**

### **Disaster Guidelines**

#### **Power Failure**

1. Sometimes telephones continue to function – report a power failure by telephone, if possible (1-800-334-7661, in Rochelle 815-562-4155).
2. Locate a flashlight.
3. If the patient is using oxygen locate the back up emergency tank and start using it.
4. Use candles only if patient is not using oxygen.
5. Notify the Hospice office (815-732-2499) of problems. We will assist wherever possible.
6. Only when the patient is safe, go to a neighbor's house to call the Hospice office or report a problem, if necessary.

#### **Tornado Threat**

1. Keep tuned to radio or television for weather updates.
2. Stay away from windows.
3. If the patient is agitated or problems occur, notify the Hospice office at (815-732-2499).

#### **Tornado Reported Within County**

1. If a basement is available, go to the basement. Sit as far away from windows as possible, against inside walls to protect against airborne objects, glass, etc.
2. If there is no basement, go to any inside room or wall, away from glass, sit under a table, etc., and cover the patient and self for protection against airborne objects.
3. If the patient is bed bound, push the bed against the wall farthest from the window. Pull blinds, shades, or drapes on all windows in room and cover the patient with a blanket to protect him/her from flying debris.

## Fire

1. Know where any fire extinguishers are located in the home.
2. Have a fire escape plan; leave the house or apartment quickly with the patient.
3. Call (911) to report the fire after leaving the area of the fire. Provide name and address and the location of the patient if bed bound. Do not hang up the phone until you are sure the Fire Department understands the location.
4. Keep the patient comfortable.
5. If the patient is bed bound, carefully slide the patient off the bed using the bed sheet. Pull the sheet from same end of patient's head to safety. Ensure the patient does not slide off the sheet. If you are unable to slide the patient totally clear of smoke or fire area, place a wet towel over the patient's face.
6. Call the Hospice office at (815-732-2499). We will respond and assist as needed.



## Caring for the Hospice Patient

### A Peaceful Environment

- The environment that surrounds a patient should be one that allows the patient to see some of his favorite objects: the garden, the farm fields, the river, the bird feeder, the TV, etc.
- Having photographs of family, friends, vacations spots, greeting cards, artwork from children and other memorabilia will be meaningful to the patient.
- The lighting around a patient can make them uncomfortable. Prolonged bright lights can cause headaches. Is the patient a person who enjoyed the sunshine coming in the window or did they have the blinds tilted to shade the light? A night light may help a confused patient at night.
- Certain colors can affect the mood: peaches, pinks, beiges are soothing and red, yellow and orange can increase anxiety.
- Allowing patients to maintain their independence is important; this can be done using remote control devices for the TV, radio, ceiling fan and having their electric bed control within their reach.
- Aromatherapy essential oils provide soothing scents. For relaxing use lavender, chamomile, rose, sandalwood and eucalyptus. To increase alertness use clary, sage, neroli, and rosemary. Ask the patient if the fragrance of flowers is welcome.
- The companionship of a beloved pet can be very important to a dying person. The time together is more important than any concern about germs.
- The sense of hearing remains very strong even when the patient is comatose. Music can be comforting. Visiting and conversation should always include the patient. Avoid talking over the patient and be careful not to confuse or exhaust the patient.
- Be sensitive to annoying sounds such as, ringing phones, barking dogs, beepers and loud voices.

If you practice a few of these ideas, the environment of your loved one will be enhanced.

## Caring for the Hospice Patient

### Helpful Hints for Caregivers

- Take a look around your home through the eyes of the patient. What are you able to see? What are you able to hear? Is there plenty of light? Are there any cold drafts?
- Touching, talking and listening are important tools in caring for your loved one.
- To keep items within reach for the patient; place a small lazy Susan on the over bed table.
- Portable patient call systems are available from Hospice; baby monitors and wireless door bells can be very helpful when you need to be away from the patient.
- Gold Bond powder is good to soothe irritated skin.
- An easy way to crush pills is to place the pill in a plastic bag and use pliers to pinch the pill. **NEVER** crush a medication until you have talked to the nurse or pharmacist because some medications will lose their potency if crushed. **(Do Not Crush MS Contin or Oxycontin tablets, they are time release medications)**.
- Cleanliness is always important; a 1:10 bleach solution (one part bleach to ten parts water) can be used to disinfect toilets, linens, tubs, commode. Bleach should be used with caution.
- The smell of urine can be controlled with a solution of water and vinegar to rinse bedpans and urinals.
- To promote regular bowel movements, add fiber to the diet. Good sources of fiber are bran cereal, prunes, and prune juice.
- Emptying bedpans can be a distasteful task, but you do not want to show any negative feelings to the patient, so breathe through your mouth so the smell will not go into your nose.
- Foley catheters can be used to manage patients who cannot control their urine. Ask your Hospice nurse for more information about this.



## Caring for the Hospice Patient

### Helpful Hints for Caregivers Cont...

- It is helpful to have things written down. Consider keeping a journal, log or notes.
- Hot or cold applications may provide comfort to the patient; the applications can be applied for 20 –30 minutes, but never longer than one hour. Remember to place a cloth over the application. It should never touch the patient's skin directly. If you are interested in trying hot or cold application ask your Hospice nurse for a corn bag.
- Keep the patient involved with life. Provide current magazines and newspapers, turn on the TV, work with hobbies, do some light household paperwork.
- Keep a sense of humor.
- Never run out of medications. Make sure all medications are refilled before the weekend. Your Hospice nurse can help with this.
- Rest when the patient rests.
- It is a good idea to have paper towels available; they can be used in place of bath towels and washcloths when cleaning up messes. Paper towels can stop the spread of infections.
- Check the bony parts of the patient's body frequently and apply lotion. A cotton sock, with the toe cut out and a shoulder pad sewn inside is great for heel and elbow protectors.
- Offer fluids frequently; give with a straw as tolerated. You can dip the straw into the liquid and hold the end with your finger to get small amounts into the patient's mouth. Jell-O is considered a liquid and sometimes fruit nectars go down well. Sipping on Gatorade will help replace fluids. Carnation Instant Breakfast is a good supplement.
- Small frequent meals seem to be tolerated better than a big meal. Offer whatever foods are tolerated and appeals to the patient (custard and cookies may be all they want).
- Provide a restless patient with a backrub, music, reading, TV, change in position, or a snack. Assess for need of pain medication.

## Caring for the Hospice Patient

### Helpful Hints for Caregivers Cont...

- To avoid strain on your back, remember to adjust the height of the bed when working with the patient.
- Designate a place for medical supplies to be stored such as a card table, bookshelf or the top of dresser. It is handy to have everything you may need in one place and covered with a clean towel.
- Medications should not be left out where others / children would have access to them.
- For dry skin, you can add mineral or baby oil to the bath water.
- Do not talk “around” the patient, include them in the conversation.
- Remember to get out or find some quiet place to be alone; you do need some time for yourself.
- Use your Hospice Volunteer.



## Caring for the Hospice Patient

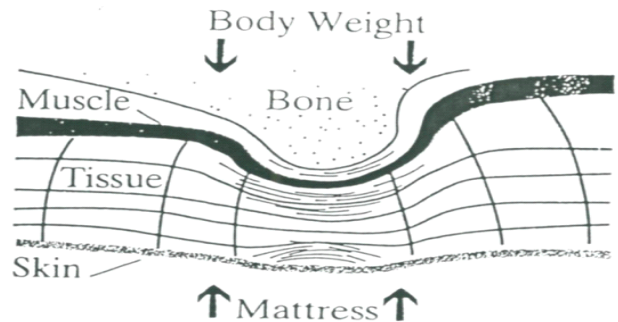
### A Guide for Skin Care

- Inspect:** Inspect the patient's skin daily. A mirror can be used to look at hard-to-see areas. Pay special attention to pressure points (see next page). The goal is to find and correct problems before pressure ulcers form.
- Bath:** Soiled skin should be cleaned as soon as it is soiled. A daily bath is not required but may be preferred by the patient. Bathe with warm water (not hot water). Use mild soap to prevent dry skin, baby oil can be added to the water. Apply lubricating lotions or creams to keep skin soft and intact.
- Control Moisture:** Use pads or diapers to draw urine away from the patient's skin. Barrier creams and ointments will help protect the skin from moisture. A Foley catheter can also be inserted to help keep the patient dry.
- Positioning:** When moving the patient, avoid rubbing the patient's skin on the sheets. A lift pad or sheet can be used to help move the patient in bed. The patient's position should be changed every few hours when in bed or in a chair. Report to the hospice nurse if changing position causes pain or the patient refuses to turn; remember providing comfort is the most important factor. Use pillows and foam wedges to keep bony parts from direct contact with the bed or chair and from touching each other. Keep bed sheets tight to prevent wrinkles. The hospice staff can train you on ways to properly position someone in bed. The hospice nurse may suggest a special mattress to help reduce pressure.
- Avoid:** Avoid massaging skin over bony parts of the body. Massaging may squeeze and damage the tissue under the skin. Avoid the use of donut-shaped (ring) cushions as they will reduce the blood flow. Avoid having the patient lie directly on the hip bone when lying on their side. Avoid having the patient sit in a wheelchair for long periods of time.
- Treatment:** Even with the best care, skin breakdown may occur. If this happens, the hospice nurse will help you care for pressure sores. There are special dressings and treatments that can be used.

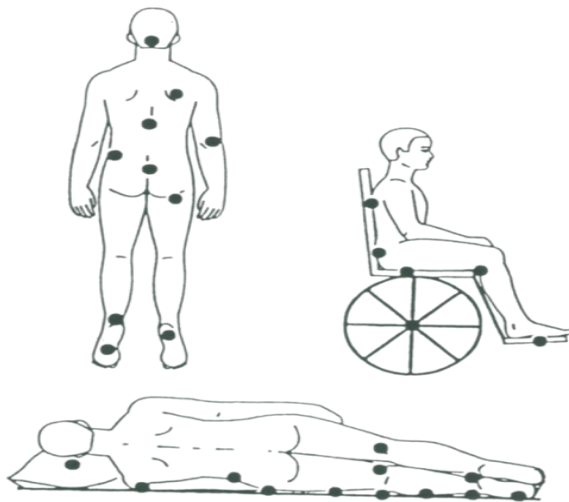
## Caring for the Hospice Patient

### A Guide for Skin Care

**Skin problems:** Bed sores, pressure sores and decubitus ulcers are injuries that occur from unrelieved pressure that damages the skin and underlying tissue. Unrelieved pressure on the skin squeezes tiny blood vessels which supply the skin with nutrients and oxygen.



Risk areas:



**Risk factors:** Being confined to bed or a chair; being unable to move; loss of control of bowels and/or bladder; poor nutrition; and lowered mental awareness.

**Risk Areas:** Hip bone, tail bone, heels, ankles, shoulder blades, spine and back of head.

Pressure sores can develop where bone causes greater force on the skin and tissue and squeezes them against the surface of the mattress or chair. Patients who are unable to move by themselves cannot relieve this

pressure on their skin.

**Warning Signs:** Watch for signs of early skin breakdown that can lead to pressure sores:

- Discoloration of skin (bright pink to redness).
- Increased warmth to area.
- Area is firm to touch.
- Blister or loss of skin.
- Cracked skin.

*Call the hospice nurse at 815-732-2499 if you see any of these warning signs of a pressure sore.*

## **Caring for the Hospice Patient**

### **A Guide for Mouth Care**

- Good oral hygiene will help provide comfort to the patient.
- It is also important that good oral hygiene be provided to comatose patients. They often breathe only through their mouths, which causes dryness and cracking.
- Cleanse the mouth using sponges dipped in warm water.
- The patient should have their head elevated to prevent choking. Be careful not to make the patient gag.
- You can also wash the mouth with a damp wash cloth wrapped around your index finger.
- Apply Carmex<sup>®</sup>, lip balm, KY Jelly<sup>®</sup>, or Oral Gel to dry lips several times each day.
- Be careful using strong mouthwash products. Due to the alcohol content, the mouth will dry out even more.
- If the patient is unconscious remove dentures.

### **Decrease in Appetite:**

- A decrease in appetite is natural because the body functions are slowing down and the body has a sense of what it needs. Because of the social connection we have with food, this can be hard for family members to understand. The person is not “starving.” The body can no longer process food so the person is no longer interested in eating. When a patient at this stage eats it can make them very uncomfortable and cause them physical distress.

## Caring for the Hospice Patient

### A Guide to Nutritional Care

Your loved one may have some problems eating; food and fluids should always be offered, but never forced on the patient. As the patient gets weaker and sleeps more, check carefully that the patient can swallow without choking. There may be days that the patient eats nothing. Food can be offered however forcing a patient to eat so “they can get stronger” or “keep up their strength” should be avoided. All food and fluids should be stopped when the person can no longer swallow.

#### Eating Problems

#### Suggestions

##### Loss of Appetite:

Identify the time of day when the patient’s appetite is best and offer food at that time. Offer several small meals vs. large meals. Encourage a few bites / sips each hour. Cold foods can be more appealing to a patient than warm foods.

##### Nausea & Vomiting:

Offer dry foods like crackers or toast. Avoid fluids before and after eating. Serve foods that have little aroma. Offer clear liquids.

##### Sore Mouth or Throat:

Offer easy-to-swallow foods such as, soup, liquid meals, and popsicles. Provide a straw for beverages. Avoid cigarettes or alcohol. Mash, blend, strain, or puree food, or try baby food. Serve foods cold or at room temperature. Encourage the patient to rinse their mouth after eating using one cup of water and one teaspoon of baking soda.

##### Dry Mouth:

Offer soft foods and add gravy, salad dressings, broth, sour cream, or mayonnaise. Offer liquids with meals. Offer ice cubes, frozen tonic, water, and juices. Frequent mouth care with moistened swabs can help when patient is unable to tolerate food or fluids.

## Caring for the Hospice Patient

### A Guide to Pain Management

**Pain Control:** Pain treatments work differently for different people. It is important that you keep your doctor and Hospice nurses informed about the patient's pain level and how they are responding to the medications and treatments prescribed.

Information that should be shared with the nurse at the initial nurse visit:

- Any allergies to medication.
- Pain medications previously taken.
- Which medications that have helped in the past.
- Any non-medication treatments that help relieve pain such as heat or massage.
- Any fears or concerns you or the patient have regarding the use of medications.

**Pain Medications:** There are many medications available to treat pain. Certain medications work better to relieve different types of pain. A combination of medications may be needed for the most effective relief.

|                          |  |
|--------------------------|--|
| <u>For Mild Pain</u>     | Non-opioid Medications: Tylenol, Aspirin, Ibuprofen. |
| <u>For Moderate Pain</u> | Non-opioid and Opioid Medications in Combination.    |
| <u>For Severe Pain</u>   | Opioids: Morphine, Oxycodone, Dilaudid, Duragesic.   |

Combinations of other drugs refers to the use of antidepressants, anticonvulsants, and steroids in the treatment of pain. It does not mean that the patient is depressed or is going to have convulsions, but these types of drugs have been found to be very helpful in the treatment of tingling or burning sensations related to nerve pain.





## Caring for the Hospice Patient

### A Guide to Coping with Anxiety and Sadness

Anxiety is a common symptom in patients nearing death. Regardless of the cause, anxiety should be identified and managed promptly.

#### Recognizing Anxiety

Anxiety has cognitive, emotional, behavioral, and physical manifestations ranging from mild to severe. Reactions to anxiety can vary. Some may be able to verbalize what they are feeling and other may not. Many of the physical manifestations of anxiety are similar to those caused by the underlying illnesses and treatments. It's important to know what anxiety looks like so you can easily recognize it when it happens.

- Mild anxiety: The patient may be irritable or mildly upset. They might be short-tempered or easily annoyed. They may experience insomnia or difficulty resting.
- Moderate anxiety: The patient may be restless, visibly upset, and have increasing irritability. They may be tearful and express feelings of worry or uneasiness. They may have an increased heart rate, fast breathing, or complain of nausea.
- Severe anxiety/panic: The patient may not be able to focus, even when clear directions are given. The patient may be crying uncontrollably, appear greatly agitated, and even yell and scream. The patient may even have vomiting, chest pain, sweating, dry mouth, or trembling.

#### Treatment

If your loved one is beginning to show signs of anxiety, the first thing you should do is try to calm him down. Sometimes simple distraction could be enough to reduce anxiety level and keep them calm. Breathing techniques, a warm compress, or allowing the patient to discuss their feelings of anxiety or sadness may also help.

If the patient's anxiety or sadness persists, **call the hospice team at 9815-732-2499 and report to the nurse** that they are showing signs of anxiety. The hospice nurse will give you specific instructions and may send a nurse out to evaluate the situation. There are medications to treat anxiety. The hospice nurse may give you instructions to start one of the medications.

Our hospice team of volunteers, chaplains, bereavement coordinator, social workers, comfort aide, nurses, and physicians can help your loved one if they experience these symptoms.



## **Caring for the Hospice Patient**

### **Anxiety and Sadness cont...**

Sadness is the normal, emotional response to a loss. Each person grieves in his or her own way. There is no right way to express sadness. While grief is often associated with the death of a loved one, it may also be experienced at the time of other losses such as the loss of function due to illness, loss of a pet, loss through divorce, loss of future dreams or role changes, and many other changes in life or health.


### **Tips for Helping Your Loved One with Sadness and Grief:**

- Help your loved one maintain a realistic sense of hope, even in the midst of dying. Reframe hope by helping the patient hope for a good night's rest, for better pain control today, or for the chance to see grandchildren one more time.
- Remember that your caring presence is more important than "saying the right thing" and listening may be more comforting to a patient than trying to make conversation.
- As death approaches, a patient may withdraw from everything outside of him/herself in an attempt to cope with the many changes that are occurring. Withdrawal can be part of the natural dying process. Help family and friends understand that process is expected and normal.

### **Tips for Helping You Through the Healing Process**

- Give yourself permission to grieve loss and change
- Get plenty of rest, exercise and eat a healthy diet
- Try to have at least one close person with whom you share your feelings and receive support
- Consider keeping a journal to write down your feelings
- Don't push yourself to make changes in your life too quickly
- Reminiscing and putting together a memory book provide an active way to heal
- Get information about the normal grief process
- Attend a community grief support group by contacting our bereavement team

If you or your loved one are struggling with sadness and grief, call the hospice team at 815-732-2499 to discuss your concerns so we can help you during this process.



## Caring for the Hospice Patient

### A Guide to Pain Management Cont...

**Taking Pain Medications:** Most pain medications are taken by mouth (orally) in the form of tablets or liquid. If it is hard for the patient to swallow, there are other ways to take medications. With rectal suppositories, the medicine dissolves in the rectum and is absorbed by the body. Patches are filled with medicine and can be placed on the skin where they will be absorbed through the skin over a period of many hours. Transdermal gels are prepared by a compounding pharmacist and can be rubbed onto the skin to be absorbed directly into the blood stream without needing to be digested. The subcutaneous injection is medicine that is placed under the skin using a small needle. With intravenous injections, the medicine is placed directly into the vein through a needle. Injectable medications are used infrequently in Hospice care.

**Nondrug Treatments of Pain:** The patient may want to try other treatments along with medications to provide even more pain relief. Biofeedback, breathing and relaxation, imagery, massage, music therapy, hot or cold packs and rest are few examples of treatments that may help.

**Pain Management:** To help pain medicine work best the medications should be taken as ordered by the doctor to keep the pain under control. Do not skip a dose of medication or wait for the pain to get worse before providing medication. The goal is to prevent the pain. Once the patient feels the pain, it is harder to get it under control. There are many different medicines and treatments that can be used. If one medicine does not work, there is another one that can be tried. Talk with the doctor or Hospice nurse. They will work with you to find the pain medicine that will help provide the most relief.

## Caring for the Hospice Patient

### A Guide to Pain Management Cont...

Pain can affect a patient in many ways. It can prevent them from being active, sleeping well, enjoying family and friends and from eating. Pain can also make them feel afraid or depressed. With treatment, most pain can be lessened or controlled. When there is less pain, your loved one will probably feel more active and interested in doing things he or she enjoys.

If the patient is feeling pain, you need to tell the doctors and Hospice nurses right away. Getting help for the patient's pain early can make pain treatment more effective.

#### Have the Patient Describe Their Pain:

- Clearly describing pain will help in choosing the best treatment.
- Different kinds of pain require different kinds of treatment.
- Does pain interfere with the patient's activity, mood, sleep, appetite, or emotions?
- What **kind** of pain is the patient having? There are many different kinds of pain. Ask the patient to think of words that describe what the pain feels like such as, **aching, stabbing, burning, tingling, shooting, nagging, pressing, crushing, pinching, cramping, or squeezing.**
- How **much** pain is the patient having? Describe by using Pain Rating Scale below:

#### Pain Rating Scale

Please select the number that best describes your pain

0      1      2      3      4      5      6      7      8      9      10



## Caring for the Hospice Patient

### Facts About Morphine for Hospice Patients

Many people have concerns and fears about taking morphine and morphine-like medications. This could be because of misconceptions and/or lack of information. Serenity Hospice and Home nurses, physicians, and pharmacists have received extensive training in how these medications work to relieve pain. The staff is very willing to answer all of the questions you may have about these drugs. Patients should never suffer in pain, or discount the need to take pain medication, because of unanswered questions or fear to use the medications ordered.

### The Benefits of Morphine You Need to Know:

- Morphine is proven to be very effective controlling pain and shortness of breath.
- Morphine is available in many forms - tablets, liquids, IV, and others.
- Morphine is cost-effective - your hospice benefit will pay for it.
- Morphine is well tolerated, associated side effects can be controlled.
- Addiction is very rare, less than 1% of patients develop addiction.
- No limit to the doses so it can safely be increased as needed.
- Anxiety will lessen when pain is controlled with scheduled and breakthrough doses.

### Misconceptions & Truths about Morphine

*Misconception: Morphine is given only when death is near.*

**Truth:** It is not the stage of the illness, but the intensity of pain or shortness of breath that indicate use.

*Misconception: People who take morphine will become so sedated they cannot function.*

**Truth:** Sleepiness is a common side effect when first starting Morphine, but in few days their bodies adapt.

*Misconception: Morphine will cause death to happen more quickly.*

**Truth:** Morphine will help provide comfort. It does not hasten death.

*Misconception: Taking Morphine will cause respiratory depression.*

**Truth:** When starting Morphine the dose is low and increased gradually. Morphine is the drug of choice for breathing distress in cardiac and lung diseases.

## Caring for the Hospice Patient

### Information on the Side Effects of Pain Medication

The possible side effects of Morphine and Morphine-like medications include:

- **Nausea**: Occasionally, nausea with or without vomiting occurs when the medication is first started. The nausea should pass in 2-3 days as the patient's body adapts to the effects of the medications. Medications can be ordered to relieve the nausea.
- **Constipation**: Commonly occurs when pain medication is taken routinely. Laxatives and/or stool softeners should be used on a daily basis. Your nurse will provide instructions regarding the use of laxatives.
- **Drowsiness**: Initially may cause drowsy feeling or even sleeping more. Usually, this side effect clears in 2-3 days as the body adapts to the medication. Also the initial increase in sleep may simply be due to decreased pain and the ability to sleep. It is recommended that caregivers should be prepared to offer increased supervision and assistance as needed until the drowsiness subsides.

**When to call the nurse:** (At 815-732-2499, 24 hours a day, 365 days a year)


- No bowel movement for 3 days.
- Drowsiness, hard to arouse, drifts off to sleep during conversation.
- Nausea that affects intake of food and fluids.
- Questions about amount and/or times of medication administration.
- Pain is present, current medications are ineffective.

Please tell the nurse or doctor if the patient is having difficulty with medications. There are medications to help with side effects. Not all medications work for each patient. The doctor and nurses have experience with finding the right medications for your loved one.

**Contact your nurse or doctor immediately if the patient experiences:**

- Uncommon side effects including urinary retention, mental or mood changes, fast/slow or irregular heartbeat, seizures, confusion, severe dizziness or headache.
- Allergic reaction to medicine is unlikely, but would include rash, hives, itching, swelling of mouth, and sudden chest pain.

References: One Point Patient Care Pharmacy. 2014, Ferrell, Coyle. Oxford Textbook of Palliative Nursing, Second Edition. Oxford Press



## Caring for the Hospice Patient

### Facts About Haldol for Hospice Patients

Many people have concerns and fears about using the medication called Haldol/Haloperidol. You may have heard stories about someone in a hospital or nursing home that was “snowed” or “zonked” when they were given this medication. These stories lack medical information and details. Patients may have experienced undesirable side effects due to high doses of Haldol that were given for long periods of time.

Additionally, while the internet is a wonderful tool that makes looking up information on uses and side effects of any medication very easy, it frequently provides only general information that should not be applied to individual patient needs.

The physicians, pharmacists and nurses who provide care for Serenity Hospice and Home patients have received extensive training in how this medication works to alleviate symptoms and promote comfort. Our staff is very willing to answer any questions you may have about the use of Haldol for your loved one. Some of the facts about Haldol/Haloperidol include:

- Approved by the FDA in 1967.
- Classified as a “typical” antipsychotic agent used to treat certain mental conditions.
- On the World Health Organization Model List of Essential Medicines.
- Provides beneficial effects for treating hallucinations, delusions, fear, and agitation.
- Works by blocking dopamine neurotransmission, stabilizing cerebral function.
- Recommended as first-line treatment for delirium at end-of-life.

### Guidelines For Administering Haldol:

- The lowest dose possible will be ordered by the physician.
- The medication will be given for the least amount of time.
- Haldol is available in liquid form for ease of administration.
- Follow the prescription directions carefully. If you are unable to give the medication as ordered, please call the hospice nurse at 815-732-2499 to explain the situation.
- Alcohol should not be used while taking this medication.

## Caring for the Hospice Patient

### Information on the Side Effects of Haldol

- Constipation, diarrhea, dizziness, dry mouth, headache, loss of appetite, restlessness, stomach upset, or trouble sleeping. Tell the nurse if patient is having any difficulties.
- An allergic reaction is unlikely, but seek immediate medical attention for rash, hives, itching, difficulty breathing, tightness in the chest, or swelling of face, lips, or tongue.
- **Contact the nurse immediately** if the patient experiences; blurred vision, chest pain, decreased or difficult urination, difficulty speaking or swallowing, unusual sweating, fainting, fast irregular heartbeat, or rigid or stiff muscles.

We understand the behaviors associated with delirium can be distressing for family and caregivers to observe. Serenity Hospice and Home team members are available to offer support. Visits from social workers, chaplains, grief companions, and volunteers can be arranged to give you education and to comfort you during this difficult time.



***Haldol can improve the quality of life for patients at end of life***

#### References:

Ferrell, Betty R. and Nessa Coyle eds. *Oxford Textbook of Palliative Nursing*, Second Edition. Oxford Press  
Casarett, David, and Inouye, Sharon. *Delirium at the End of Life*, Annals of Internal Medicine, Volume 137  
Gordon, *Delirium*, Journal of Palliative Medicine, Volume 10  
Weissman, D.E. et.al. *Management of Terminal Delirium*, Medical College of Wisconsin, Inc.

## Caring for the Hospice Patient

### Medication Compliance (including controlled medications)

Taking medications properly can make a difference in the way a person feels. The physician has ordered the medications as part of a plan to provide comfort.

Regardless of the medication, the following points should be followed for safe and effective medication usage:

- **Read Labels Carefully.** Observe how much and how often.
- **Follow Directions.** Observe whether medication should be taken before meals, after meals, or with food.
- **Know About Medications.** Know what side effects can occur and report them to your Doctor.
- **Keep A Record.** Keep a simple list of medications and the times given. This is especially important if more than one person is involved in giving medications.
- **Discard Old Or Unused Medication.** Incorrect or outdated meds can be dangerous.
- **Store Medications In A Safe Place.** Store medications out of reach of children or visitors.
- **Do Not Take Over-The-Counter Medications.** Over-the-counter medications should be approved by your Doctor.
- **Do Not Share Your Medications.** Your Doctor has ordered medications for **the patient's** health problems.





## Symptom Management

### Understanding Delirium

The following are symptoms that may occur as the patient's disease progresses. Not all patients will experience these symptoms. For those that do, the symptoms may increase at end-of-life.

- Delirium is a disturbance of attention, perception, thinking, and awareness that occurs in more than three-fourths of people at the end of life.
- Common causes of delirium include: lack of oxygen, fever, infection, electrolyte imbalance, decrease function of kidneys/liver, and medication withdrawal.
- Signs and symptoms of delirium may have rapid onset and include: unintentional excessive motor activity; altered level of consciousness; lack of orientation to person, place or time; paranoia; disorganized thinking; hallucinations; and irritability.


### Non-Medication Care Approaches For Delirium Include:

- Keep eyeglasses, hearing aids, and dentures in use during the day when possible.
- Keep calendar, clock, familiar objects, family pictures clearly visible.
- Encourage pleasant activities during the day (e.g. conversation, singing, etc.).
- Encourage a sleep routine, use nightlight, warm milk, soft blanket and avoid disturbances.
- Avoid stimulating activities, TV, loud noises, too many visitors.
- Offer a calm approach by sitting with patient to support and reassure them.

### Changes in Elimination

Loss of control of the bladder and bowels can occur sometimes as the muscles begin to relax. Urine output diminishes and the color of the urine will become dark. This is a normal response as the circulation to the kidneys decreases.

### Comfort measures you can provide:

- Incontinence can cause embarrassment, so keeping the person clean and dry while preserving their dignity is important.
  - Disposable briefs and under pads may help solve the problem.
  - The nurse can place a catheter tube in the bladder to collect the urine.
- 

## Symptom Management

### Constipation Management

Constipation is the infrequent and or difficult passage of hard stool, which causes pain and discomfort. It is caused by too little fluid or not enough movement in the bowel. Many prescription medications can cause constipation. Bowel function is also affected by activity and diet. For example, regular doses of narcotic type, pain relieving medication frequently cause constipation. The medication regimen should also include use of a laxative to avoid constipation.

#### Signs of constipation:

- No regular Bowel Movement in 3 days.
- Small, hard bowel movements.
- Stomachache or cramps.
- Feeling of fullness, puffy belly.
- Passing excess amounts of gas.
- Leaking of watery stool when bowels have not moved regularly.

#### Ways to prevent constipation:

- If patient is able: increase diet to include high fiber foods such as, bran cereal, fresh fruits and vegetables, dates, apricots, and prunes.
- Increase fluid intake. Encourage a cup of hot liquid in the morning.
- Increase activity level as you can. Even exercises in bed are helpful.
- Have a regular time for an undisturbed visit to the bathroom. 30 minutes after a meal is suggested. Encourage the patient to never ignore the urge to have a movement. Give them a few minutes on the toilet. Instruct them to try to relax and to not strain.

## Symptom Management

### Treatments for constipation:

- The overall goal is to have a bowel movement every 3 days.
- If at any time the dosage of pain medication is increased, the dose of laxatives may need to be increased. The nurse will help with this.
- The recommended laxative contains Senna concentrate and docusate sodium (Colace), which is a natural vegetable laxative plus a softener. The tablets generally produce a bowel movement within 6-12 hours.
- The recommended dosage:
  - 1) Take 2 laxative tablets at bedtime.
  - 2) If no BM by morning, take 2 more laxative tablets after breakfast.
  - 3) If no BM by evening, take 3 laxative tablets at bedtime.
  - 4) If no BM by the second morning, CALL the Hospice Nurse .

### Nausea and Vomiting Management

Nausea is an unpleasant sensation and vomiting is the sudden forceful expulsion of stomach contents through the mouth. These symptoms may occur due to side effects of medications (especially pain medications), an obstruction and alteration of the digestive track, side effects of radiation, etc.

### Ways to Prevent Nausea and Vomiting:

- Avoid foods that are hard to digest.
- If the smell of hot food makes the patient feel ill, try cool or cold meals.
- Have the patient eat several small meals each day instead of three large ones.
- Position the patient with his/her head higher than his/her feet.
- If the patient feels nauseated when waking in the morning, give them some plain crackers.
- Have the patient drink more water.

## Symptom Management

### Shortness of Breath Management

For a patient who is ill, the process of breathing can become difficult at times. This is often referred to as “shortness of breath” or “air hunger.” Breathing difficulty can create a decrease in the oxygen level in the body.

#### Signs of Shortness of Breath may include:

- A restless or anxious feeling.
- A faster breathing rate.

#### Treatment for Shortness of Breath:

- Be calm and reassuring.
- Raise the head of the bed or place more pillows behind the back and head.
- Have the patient sit up and lean forward. This position will help the lungs fill more easily.

### Changes in Respirations

Respirations will change from a normal 12-20 times a minute. They may increase to 40 breaths or decrease to six breaths a minute. The breathing pattern often changes from shallow to panting-like. Periods of long pauses (10-30 seconds) between breathes may occur. This is called apnea. Another change in the breathing is called Cheyne-Stokes respiration. This refers to an abnormal pattern characterized by alternating periods of apnea and deep, rapid breathing.

This kind of breathing is not uncomfortable for the person, but it is a response to the body's weakening condition.

#### Comfort measures you can provide include:

- Elevating the head of the bed.
- Turning the person on their side.
- Having a fan on, gently moving air.
- Talking with nurse/doctor about using oxygen.
- Speaking gently offering reassurance.

## **Symptom Management**

### **Changes in Behavior**

#### **Confusion and Disorientation**

The person near end of life may seem confused about the time of day, place, and even the identity of people around them. The person may report seeing things or people that are not visible to you (a hallucination).

When these symptoms are present, you may wonder if the person is taking too much or not enough medication. Generally, these symptoms are part of dying as the body's metabolism slows down.


#### **Comfort measures you can provide include:**

- Report this change in condition to the nurse/doctor. They will assess the medications being used.
- Identify yourself by name before you speak to the person.
- Provide reassurance by remaining with the person.
- Limiting visitors may decrease the level of confusion.

#### **Restlessness and Agitation**

The person may become restless, such as pulling at bed linens or clothing, or engaging in other repetitive movements. This often happens due to the decrease in oxygen to the brain. Sometimes restlessness or agitation can be a symptom of physical discomfort or pain. Unresolved emotional or spiritual concerns can also be a contributing factor.

#### **Comfort measures you can provide include:**

- Report this to nurse/doctor, they will assess for underlying pain.
  - The social worker and/or chaplain can provide assistance.
  - Minimize distractions such as, loud noises, TV, and ringing phones.
  - Use soft music and low lighting.
  - Have someone sit with the person.
  - Use a baby monitor while out of the room.
- 

## Symptom Management

### Comfort Care Therapies

**Comfort Corn Bag** Therapeutic applications of heat and cold can offer relief from pain and promote comfort. Each comfort bag is filled with roasted corn that can be heated or chilled.

**Good Memories Bring Comfort** Using the Journal in a Jar, as a reminiscing technique, helps bring back thoughts of happy times. The jar contains slips of paper with memory provoking questions on them.



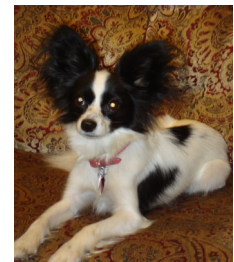
**Made for Comfort** Handmade items, including lap robes, prayer shawls, peace totes, and pocket bags bring comfort. Fidget aprons and activity boxes can comfort patients with dementia.

**Music for Comfort** Serenity Hospice and Home has several musical volunteers who are very willing to share their talents with our patients.



**Comfort Visits** Certified nursing assistants make comfort visits and include extras such as, nail polishing, reading, walks, and more.

**Pet Therapy** Pets have a far-reaching impact on a patient's physical, emotional, and psychosocial well-being. The activity of petting provides comfort and helps relieve stress.



**Creating Memories** A gathering of your family and loved ones brings comfort. We have a photographer available to take family pictures.

**Comfort Foods** Favorite meals can be prepared by volunteers, or our special "Petal Pushers" fund can be used to buy a meal from the patient's favorite restaurant.



**Massage** Massage may help relieve stress, backaches, fatigue, and restlessness.

**Aromatherapy** Aromatic, natural essential oils may offer a sense of well-being.

**Spa bath** Patients staying at Serenity Home may receive a relaxing bath in our whirlpool.

**Talk to any Serenity Hospice and Home team member about scheduling the Comfort Care Therapy of your choice.**

## Hospice Care in the Nursing Home

### How Hospice Can Help in the Nursing Home

Hospice care is provided in nursing homes, assisted living, and other care facilities to enhance the quality of life for patients. Hospice brings expertise in end of life care and assists the facility staff in meeting the specialized needs of the patient and their family. Through the collaborative efforts of both organizations, the best care will be achieved for the patient.

### Increased Services to Patients

- Hospice Certified Nurse's Aides provide additional individualized personal care.
- Hospice volunteers are specially trained to help support the patient with companionship visits.
- Hospice Registered Nurses are on call 24 hours a day, 7 days a week, 365 days a year to provide assessments and interventions related to patient condition.
- Hospice chaplains are available for spiritual visits.
- The Medicare hospice benefit will pay for medications used for palliative/comfort care of the disease.
- A hospice nurse performs regular assessments of the patient and provides symptom and pain management options.
- The Hospice Medical Director is Board Certified as a Hospice Medical Director and many of the nurses and certified nurse's aides are certified in Hospice and Palliative Care, giving them extra education in pain and symptom management.

### Support for the Family

- Hospice will work with family members to meet end-of-life care needs.
- Hospice will communicate with family members to define the quality of life the patient wishes.
- Hospice will prepare family for impending death and educate them about the changes that will occur in a patient's condition as death nears.
- A hospice social worker can assist family in the making of funeral arrangements.
- Hospice will provide bereavement support to the survivors.

## Hospice Care in the Nursing Home

### Support Nursing Home Staff

- Hospice staff will share their expertise on palliative/comfort care measures related to end-of-life issues.
- Hospice staff will provide educational materials on current pain management practices.
- Hospice staff will communicate with the Hospice physician to obtain orders for needed medications and treatments that will provide comfort to the dying patient.
- Hospice staff will offer support to Nursing Home caregivers when they experience feelings of loss and grief.





## Hospice Care in the Serenity Home

### About the Serenity Home

Serenity Hospice and Home is a comprehensive hospice offering the full complement of professional staff to meet the needs of patients and their families. Serenity Hospice and Home has been providing care for the terminally ill in their homes, nursing homes, or residential facilities since 1984. Our constant goal is to serve patients with the highest quality hospice care available. Serenity Hospice and Home strives to improve and expand the services it provides to the community.

In 2009, Serenity Home opened its doors allowing Serenity Hospice and Home to offer another level of care. Serenity Home is a unique place of caring and a special level of service for patients and their families. The 8-bed inpatient facility offers a home-like environment, while providing Hospice's comfort-oriented care and services, including: expert pain and symptom management, 24 hour nursing care, assistance with tasks of daily living, friendly visits from volunteers, spiritual and psychosocial counseling for patients and their loved ones, and bereavement care and support groups for surviving family members. Serenity Home was designed to be family-friendly with special spaces designed for the family to remain close to their loved one during this final journey. Additional areas were designed to accommodate extended families, including a family room, children's playroom, and a family kitchen/dining area for gatherings and celebrations.

### Criteria for Admission to Hospice Care in the Serenity Home:

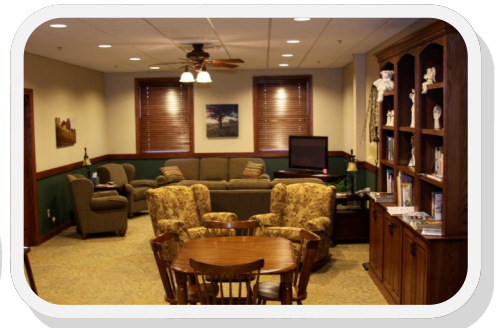
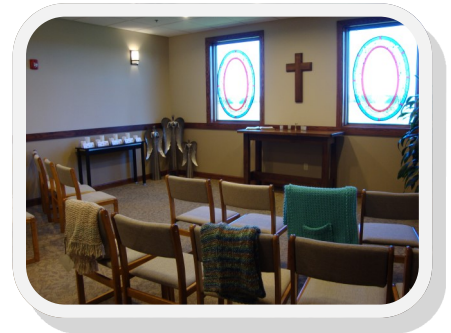
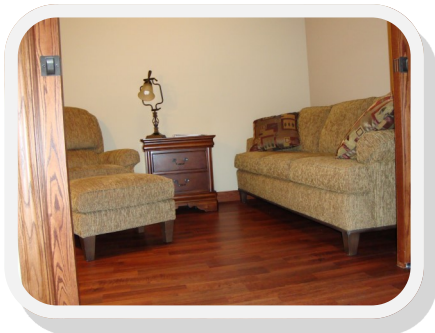
- Diagnosed with a life-limiting prognosis by a physician.
- Goal of care is comfort, rather than cure.
- Complex pain or symptoms requiring professional management (General Inpatient).
- Caregiver needs time to rest or meet other obligations (Respite).



## Hospice Care in the Serenity Home

### Serenity Home Services and Amenities

- Hospice nurses providing 24-hour care.
- On staff Medical Director.
- Physical, emotional, and spiritual support for patient and family.
- Family friendly: in-suite sleeping area, a family kitchen and dining area, children's play room, and a family room.
- Private rooms with access to private patios.
- Open visiting hours.
- Meals prepared according to patient's wishes.
- Quiet chapel for reflection and meditation.
- Hospice volunteers available to provide those important "little extras."



## Preparing for Death

*Just as each person's life is unique, so is their death.*

Because of this it is difficult to give hard facts about what will actually happen at each person's death. As a caregiver, you may wonder about the changes that will occur. The members of the Hospice team can help you prepare for them. Usually, during the weeks to days prior to death, the person's condition declines. This decline may be difficult for you, but the person is usually unconcerned about these changes. Some people exhibit some of these changes and then for some unexplained reason their condition may improve a little. These roller-coaster changes can be emotionally and physically exhausting for the caregivers.

Dying cannot be rushed. The person will continue to live until the body has physically shutdown. As the body begins to deteriorate, a person simultaneously works through emotional and spiritual issues. This is the normal and natural way a person prepares to die.

The following information is only an outline that death is approaching. Please talk with members of the hospice team and use them as a resource to explain what is happening to your loved one. Gathering information will help increase your confidence level and prepare you for the changes that will be occurring with your loved one.

## Preparing for Death

### Typical end-of-life signs may include:


#### One to Two Months:

- Withdrawal from activities and people.
- Less talking.
- Less eating and drinking.
- Sleeping more.

#### One to Two Weeks:

- Disorientation and confusion.
- Use of symbolic language “I want to go home”.
- Changes in blood pressure and pulse.
- Changes in color.
- Irregular breathing.
- Little or no intake.

#### Days to Hours:

- Sleeping most of the time, to unresponsiveness/coma.
  - Discoloration of skin.
  - Long pauses between breaths.
  - Weak blood pressure and pulse.
  - Unable to swallow.
  - Mouth and eyelids no longer close completely.
- 

## Preparing for Death

### Changes in Awareness

The following symptoms may occur at different times for patients, but most occur when death is imminent.

### Withdrawal

It is common for people to begin to withdraw from friends, family, and the world around them. This process may begin weeks before the death. They need to release themselves from their attachments. The body is shutting down, and emotional and spiritual work is being done. This is the natural way a person prepares to die.


#### **Comfort measures you can provide:**

- Follow the person's lead.
- This is not a time to attempt to change the person.
- Be sensitive.
- Offer love and support.

### Surge of Energy

A sudden surge of unexplained energy may be seen. The person may have been in bed and not eating for days, and then they might sit up in the chair and ask to eat. This short-lived event should not be seen as the patient getting better. The rally is a final experience in this life.

#### **Comfort measures you can provide:**

- Enjoy this time for what it is.
  - Use the time to reminisce, say goodbye.
  - Enjoy the time together.
  - Offer full acceptance and support.
- 

## Preparing for Death

### Changes in Body Temperature and Color

#### Coolness & Mottling

The person's hands, arms, legs, and feet may become increasingly cool to the touch. You may also notice a change in the color of the skin; hands and feet may become purplish and knees and elbows may become blotchy (mottled).

The person may appear pale, grayish blue around the lips and under the nail beds. The backside of the person's body may become darker and the skin mottled. This is a normal indication that circulation of blood is decreasing to the body's extremities.

#### Comfort measures you can provide:

- Offer a warm blanket, but not an electric blanket.
- Offer a gentle massage with warm lotion to hands and feet.

#### Fever & Flushing

As the body becomes weaker, so does the temperature control center. This may cause the person to have a fever. The person may throw covers off because they are feeling warm even if the room feels cool.

#### Comfort measures you can provide:

- Change gown and sheet if the person is perspiring.
- Consider opening a window or using a fan.
- Talk with nurse/doctor about Tylenol medication for high fevers.
- Gently wipe with cool moist cloth.

## Preparing for Death

### Noisy breathing

Loud breathing from secretions commonly occurs during the dying process. The noise is from saliva pooling in the back of throat when swallowing slows or stops, or when mucous builds up in the lungs. During breathing, air travels over the secretions, causing a loud snoring or gurgling noise.

It is very important to understand that this type of secretions happen in people who are no longer alert or awake, so they are usually not aware of or bothered by them or the sound of their breathing. It can be uncomfortable for family and friends to hear though. Unfortunately, medications do not work very well in drying up the secretions. Instead, they might make the mucous thicker and cause the mouth and lips to be very dry. The Nurse and the Doctor will help determine if the use of medications to help with the secretions will be helpful. Comfort measures such as gently turning and regularly repositioning your loved one may help and won't harm them.


Changes in breathing and congestion have a tendency to come and go. One minute these symptoms may be present, the next minute it may be clear.

### Comfort measures you can provide:

- Suctioning is avoided because it may only increase the secretions and cause discomfort.
- Gently turn person's head from side to side to allow gravity to drain secretions.
- Gently wipe mouth with a cool moist cloth.



## When Death Occurs

1. Call Serenity when you notice changes in the physical condition of your loved one. The nurse will come to assist you with any care needed.
  2. **At the time of death, the first thing you should do is call Serenity at 815-732-2499.** The nurse will come to your home as soon as possible. You may wish to call other family members or the nurse can help you do this.
  3. When the hospice nurse arrives, they will call the coroner's office and the doctor.
  4. Your loved one can stay in the home until everyone is ready for the funeral home to come. The nurse will place the call to the funeral home for you.
  5. The hospice nurse will prepare your loved one's body by bathing and removing any tubes.
  6. The hospice nurse will stay with you and your loved one until the funeral home comes.
  7. The hospice nurse will gather supplies and small equipment that was brought to your home (to get it out of the way and so you don't have to be concerned about returning it). The nurse will call the equipment company and arrange for them to pick up any large equipment.
  8. Please refer to the next page for directions for proper disposal of medications.
  9. The hospice nurse will provide you with information on our Bereavement program. The program consists of supportive correspondence and educational materials, sent out at intervals during the first thirteen months of bereavement. In addition, we provide support groups. The purpose of these groups is to find meaning in life, kinship, friendship, and understanding. These groups are free and open to anyone who has suffered a loss.
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## **When a Death Occurs**

### **Medication Disposal Information**

Serenity Hospice & Home offers the following information for the safe and secure disposal of prescription medications.

The DEA (Drug Enforcement Administration) released a new rule effective on October 9, 2014. The new regulation expands the public's options to safely and responsibly dispose of unused or unwanted medications. The goal of this rule is to offer options for collecting and destroying drugs in a secure, convenient and responsible manner.

The DEA suggests the following three methods for disposal:

1. Drug take-back programs (events held by community groups).
2. Mail-back programs (sponsored by manufacturers, distributors and/or pharmacies).
3. Collection receptacles for drug disposal (local law enforcement and pharmacies).

If these three methods of disposal are not readily available to you and you would like to dispose of the drugs yourself the Hospice staff would be glad to assist you.

Families should use the following guidelines for drug disposal from the ONDCP (Office of National Drug Control Policy) issued October 2009:

- Take unused, unneeded, or expired drugs out of their original containers.
- Scratch off personal information and make label unreadable.
- Place the medications in a non-descript container (plastic or aluminum).
- Add a small amount of hot water to partially dissolve the medications.
- Mix the liquefied drugs with an undesirable substance, like coffee grounds or kitty litter. This unsightly mixture discourages anyone from using the drugs.
- Seal the container to prevent leaks and breakage.
- Place container in sealable plastic bag.
- Place this package in a trash bag.

## When Death Occurs

### Medication Disposal Information Local Agency Contacts

|   |                                      |  |              |
|---|--------------------------------------|--|--------------|
| Byron Police Dept.<br>232 W 2nd Street<br>Byron IL 61010                  | 815-234-5000<br>(8:00am-4:00pm, M-F) | Oregon Police Dept.<br>115 N 3rd Street<br>Oregon IL 61061           | 815-732-2162 |
| Carroll County Sheriff Dept.<br>301 N Main Street<br>Mt. Carroll IL 61053 | 815-244-2634                         | Polo Police Dept.<br>116 S Franklin Ave<br>Polo IL 61064             | 815-946-2444 |
| Dixon Police Dept.<br>220 S Hennepin Avenue<br>Dixon IL 61021             | 815-288-4411                         | Rochelle Police Dept.<br>416 N 6th Street<br>Rochelle IL 61068       | 815-562-2131 |
| Mendota Police Dept.<br>607 8th Avenue<br>Mendota IL 61342                | 815-539-9331                         | Rock River Reclamation Dist.<br>3333 Kishwaukee<br>Rockford IL 61109 | 815-387-7400 |
| Mt. Morris Police Dept.<br>105 W Lincoln Street<br>Mt. Morris IL 61054    | 815-734-4106<br>(8:00am-4:30pm, M-F) | Sterling Police Dept.<br>212 3rd Avenue<br>Sterling IL 61081         | 815-632-6640 |
| Ogle County Correctional Center<br>107 S 5th Street<br>Oregon IL 61061    | 815-732-2135                         | Whiteside County Sheriff<br>400 N Cherry Street<br>Morrison IL 61270 | 815-772-4044 |

**The DEA hopes that the supply of unused drugs in the home will decrease, thereby reducing the risk of diversion or harm.**

## Bereavement Companionship

### Saying Good-bye

#### “From Your Hands to God’s Arms”

There comes a time to say good-bye. Letting go is one of the most powerful expressions of faith and the greatest parting gift you can offer your dying loved one. The words uttered allow you to give up control (and many hours of caregiving), trusting instead in God’s love. Your words also offer your loved one the comfort of knowing you trust in God so that he or she can draw strength from your faith and assurance.

Saying good-bye can be painful, but the pain is intensified if the process is entered with the illusion that moments after saying good-bye, your loved one will immediately die. Sometimes, the words first spoken do invite a relaxation response, but the final breath may be hours or even days later. More often, the act of saying good-bye is repeated in part, in different forms and by different people over and over.

Helping your loved one move from your hands to God’s arms might include the following:

- **Touch** your loved one in a way that is comforting to them (hold hands, rub their head, snuggle, etc.) Let your physical presence be part of what nurtures a place of trust.
- **Tell** your loved one you love them. If they are unable to respond, then answer for them (and I believe you love me too.)
- **Tell** them that you feel God’s love in the place where you are. Let them know your trust is now with God.
- **Forgive** your loved one of any past estrangement/behavior/words. If they are unable to respond then answer for them (and I believe you forgive me too.)
- **Give** your loved one permission to let go. Again assure them you trust the move from your loving hands into God’s loving arms.

Remember you will likely repeat these acts in different forms many times. Hearing the words over and over creates a foundation of trust so your loved one can feel secure in letting go.

## **Bereavement Companionship**

### **Bereavement Program**

- The Serenity Hospice and Home Bereavement Program supports families and friends after the death of a loved one. Support is provided by phone and mail contact; in person meetings; printed resources; and social networking groups.
- A wide variety of support groups are available. These groups meet at different times and in different locations, to accommodate the needs of many. You will receive a list of these groups in the mail.
- The Serenity Shed is a full functioning workshop that provides a creative environment that supports healing in the grieving process.
- Serenity Hospice and Home's Grief Companions are located at The Shed at 131 N. 3rd Street, Oregon, IL. They are available from 8:00 a.m. to 4:30 p.m. M-F, and other hours by appointment. They will be calling you within the four weeks after the patient's death but feel free to call them anytime with your questions or concerns.

**Serenity Hospice and Home's Bereavement Program is funded in part by grants from the United Way of Ogle County and the 708 Mental Health Board**




## **Bereavement Companionship**

Grieving is a series of painful experiences into which one enters and lives for a period of time after the loss of a loved one. It may produce feelings of fear, anger, regret, guilt, loneliness, a sense of uselessness, helplessness, the inability to focus and occasionally a desire to die.

There is no right or wrong way to grieve. Each person grieves in his or her own way. The crucial issue is to acknowledge that everyone has a right and a need to grieve. Our Grief Companions work with patients, families, and loved ones before and following a death. The Grief Companion facilitates all hospice bereavement services, including the monthly support groups and regular mailings to families and loved ones of the deceased.

Hospice offers support groups for those dealing with the loss of a loved one. The purpose of these groups is to find renewed meaning in life, kinship, friendship, and understanding. Sharing and listening helps group members work through the grieving process. You need not be a Hospice family to participate in the groups. These groups are free and open to ALL who have lost someone they love.



## Bereavement Companionship

### Monthly Support Groups

**Coffee and Conversation** is intended for those who would like to attend a support group, but do not wish to drive at night. It meets the first Saturday of each month from 9:30 a.m. – 10:30 a.m. at the Immanuel Lutheran Church, 1013 Franklin Grove Road in Dixon, IL.

At **Movie and Discussion Night** a thoughtfully selected movie is viewed and a discussion is held on how the movie relates to grief and healing. Participants are free to bring a drink and snack. Movie Night is held on the 1st Monday of the month at the Serenity Shed from 5:30 p.m.-7:30 p.m. Seating is limited, so please call our office at 815-732-2499 to reserve your spot.

**Healing Hearts** offers support, understanding, compassion and hope to bereaved parents, grandparents, or siblings. It meets the second Sunday of each month from 5:00 p.m. - 6:00 p.m. at the Serenity Shed, 131 N 3rd Street in Oregon, IL.

The **First Steps** program offers fellowship, sharing, support and friendship for people who have experienced the death of a loved one. It meets the 2nd Thursday of the month at 11:30 a.m. in a comfortable atmosphere over lunch in a local restaurant. Each person is responsible for the cost of his/her own meal. The restaurant varies so please call for location. Reservations may be made by calling the office at 815-732-2499 by 12:00 p.m. on the Wednesday prior to the meeting.

The **C.A.F.E.** group is intended for those who would like to attend a support group, but do not wish to drive at night. The group meets the 2nd Friday of every month from 9:00 a.m. – 10:00 a.m. Please call the Hospice office at 815-732-2499 by 4:00 p.m. the day before. If no one calls, this group will not meet.

**The Breakfast Club** helps you start your day out right by sharing the most important meal of the day with others who have survived the death of a loved one. The Breakfast Club meets the 2nd Friday of every month from 9:00 a.m. – 10:00 a.m. Please call the Hospice office at 815-732-2499 by 4:00 p.m. the day before. If no one calls, this group will not meet.

The **H.U.G.S. (Helping Understand Grief for Survivors)** program is designed to support those who have lost a loved one to death or those who have delayed their grief and need to begin dealing with it. It meets the 3rd Thursday of the month at The Shed from 5:30 p.m. – 7:00 p.m. Please call our office at 815-732-2499 to RSVP. If no one calls, this group will not meet.

## **FAQs**

**Who pays for care at the Serenity Home?** Medicare, Medicaid and most private insurance companies cover General Inpatient (GIP) and Respite care as part of their plan requirements. Private payment arrangements are available when services are not covered by other entities.

**Who determines the level of care a patient is eligible for?** Medicare, Medicaid, and private insurance companies have determined the standard criteria for the various levels of care. Serenity Hospice & Home must follow these guidelines. It is the role of the Interdisciplinary Team, made up of nurses, physicians, social worker, and other team members to assess the patient's overall condition and determine which of these levels of care match the patient's condition and needs. A patient's condition is evaluated daily in the Serenity Home and the patient and/or family is notified about any change in level of care.

**How long can a patient stay at Serenity Home?** Medicare and Medicaid pay for Respite care up to 5 days in a covered period and for General Inpatient care for the duration of time that a patient meets the established criteria, based on the patient's care needs. Private insurances provide different coverages, generally based on patient condition and subject to preauthorization. When the GIP level of care is no longer appropriate, care may be continued in the Serenity Home, if desired, through private payment of the room and board. In this case Medicare pays for Routine care as they would if the patient was in their home or a nursing facility. There is no limit to the number of days a person can stay at Serenity Home under private payment of room and board as long as the criteria for Hospice admission is met.

**Who makes referrals?** Anyone can make a referral. Physicians and Social Workers refer a large percentage of patients to hospice. Relatives and friends often refer a loved one. Sometimes the patient will call for himself or herself. Once the initial contact is made, a member of our staff will speak to the patient's physician or case manager to see if the patient meets the criteria for admission to hospice.

## FAQs

**Who provides care at the Serenity Home?** The Serenity Home is staffed by Registered Nurses and Nurse's Aides to provide care to patients. The full complement of Hospice support staff members, such as Chaplain, Bereavement Coordinator, Social Worker, etc. are available to provide other services as indicated. Serenity Hospice & Home's physician visits patients to assess any care needs they may have and will coordinate care with the patient's personal physician if so desired. A patient's personal physician is welcome to follow their care while in Serenity Home.

**Are there set visiting hours?** The Serenity Home is open 24 hours a day. Family and friends are welcome to visit at any time the patient and family wish. Children are always welcome.

**Can I tour the facility?** We welcome the opportunity to show the facility and services we offer. If you have a group, please call ahead so that we may have staff available for the tour and to answer any questions.

**Is Serenity Home a nursing home?** No. Serenity Home is a unique environment of care for people on the final journey of life. You must be a Serenity Hospice & Home Hospice patient to receive care in Serenity Home.





## Veteran Recognition

### **Proudly Serving Those Who Served Us**

WE HONOR VETERANS

America's Veterans have done everything asked of them in their mission to serve our country and we believe it is never too late to give them a hero's welcome home. That is why Serenity Hospice & Home is taking part in the **We Honor Veterans** program, which is administered by the Veteran's Administration. Serenity Hospice and Home has achieved the highest ranking (Level 4) due to the many ways we assist and honor our Veteran patients. We are prepared to meet the specific challenges that Veterans and their families may face at end of life. We have embraced our mission to serve America's Veterans. It is our way of saying thank you for the sacrifices they have made in serving us.

### **At Serenity Hospice and Home we offer the following services for our Veterans:**

- Specialized, compassionate care for the unique needs of Veterans.
- A Veteran to Veteran volunteer program.
- Emotional and spiritual support to veterans and their families.
- Information regarding access to resources and VA benefits.
- Unique remembrance opportunities and personalized ceremonies to honor our Veterans.

America's Veterans and their loved ones have unique needs. Veterans frequently carry experiences from their military service that may present unique challenges at the end of life. These needs are influenced by:

- Combat or non-combat experience.
- The war in which they served.
- Their branch of service and rank.
- If they were a Prisoner of War (POW).

Serenity Hospice and Home is committed to meeting the unique needs of Veterans at the end of life, and providing expert professional hospice care to every terminally ill Veteran. We understand that a Veteran's view of their service, whether positive or negative, greatly impacts how they view their disease, especially if it is directly related to their service.



## Veteran Recognition

### Veteran Pinning Ceremony

As one of our services to Veterans, Serenity Hospice conducts a Pinning Ceremony for each of our Veteran patients. The ceremony honors the Veteran and their service to America. The Pinning Ceremony is a special time for family to gather and honor the unique sacrifices and bravery of their Veteran.

The service is held where the Veteran lives; whether it is Serenity Hospice Home, their own home, or a residential facility such as a nursing home.

Contact Serenity's Social Workers, at 815-732-2499 to schedule a time for your Veteran's Pinning Ceremony.

### Veteran's Benefits

As a We Honor Veterans Partner, Serenity also helps Veterans and their families to:

- Enroll and access VA benefits.
- Be recognized for their service with special ceremonies.
- Replace lost medals and awards.
- Receive extra support from other Veterans.

### Veteran Memorial Stone

Each Veteran served by Serenity Hospice and Home has the opportunity to be honored in Serenity's Memorial Gardens with an engraved stone, free of charge to families. If you are interested in an engraved memorial stone and have not received a form, please contact our Bereavement Services at 815-732-2499.

*Thank You For  
Your Service*



## Resources

### Glossary of Medical Terms:

Health Care Professionals sometimes use confusing technical terms, so this glossary was prepared to help you understand words that may be used when you are discussing the care of your loved one.

**Acute** = Sharp, severe. Acute conditions usually have rapid onset and last a short time.

**Airway** = The passage through which air enters the body to the lungs.

**Airway Obstruction** = Blockage of airway.

**Analgesic** = A medicine that relieves pain.

**Anorexia** = Loss of appetite.

**Aphasia** = Loss of verbal expression or comprehension.

**Ascites** = Abnormal accumulation of fluid in the abdominal cavity.

**Atrophy** = Shrinking or wasting away of a body part.

**Axillary** = Pertaining to the armpit.

**Bed sore** = An ulcer of the skin and underlying tissue produced by prolonged pressure.

**Blood Pressure** = The force of the circulating blood pulsing against the walls of vessels.

**Cannula** = A tube inserted into the body for infusion or drainage of fluids.

**Catheter** = A tube inserted into the body for moving or injecting fluids.

**Chronic** = Long and drawn out or frequently occurring, slow, progressive course.

**Comatose** = A state of unconsciousness caused by illness, person can not be aroused.

**Constipation** = Infrequent passage of dry, hard, stool.

**Contracture** = Permanent shortening of muscles.

**Convulsion** = An involuntary, usually violent movement or spasms of the muscles.

**Decubitus Ulcer** = An ulcer of the skin and underlying tissue.

**Dehydrated** = Insufficient fluid in the body.

## Resources

**Distention** = Swelling of the abdomen.

**Diuretic** = An agent that increases the production of urine.

**Edema** = Excessive accumulation of fluid in tissues.

**Fecal Impaction** = A mass of hardened stool in the rectum.

**Flatus** = Gas in the stomach or intestine.

**Foley Catheter** = A tube inserted into the bladder.

**Guided Imagery** = The use of mental image to create a distraction to relieve pain.

**Hospice Team** = Physicians, nurses, social workers, aides, volunteers, pastors, and others who will be supporting the patient and family.

**Hematoma** = A collection of blood in a tissue due to broken blood vessel.

**Hemorrhage** = Copious bleeding, either internally or externally.

**Hydration** = The act of providing the body with adequate fluids.

**Hypotension** = Abnormally low blood pressure.

**Hypoxia** = Lack of oxygen.

**Incontinence** = Inability to control urine.

**Jaundice** = A condition that gives the skin a yellow tinge.

**Laxative** = An agent that promotes bowel evacuation.


**Lethargy** = A condition of weakness and slowness.

**Malignancy** = An abnormal growth of tissue, progressive and invasive.

**Mucous Membrane** = Lining of passages and body cavities.

**Mucous** = A sticky substance secreted, that moistens and protects.

**Narcotic** = A powerful drug that relieves pain.



## Resources

**Necrosis** = Tissue or bone death usually caused by lack of blood.

**Non-Productive Cough** = Cough without producing secretions.

**Patent** = Open, accessible.

**Peristalsis** = A wavelike movement in the intestines to move contents along.

**Petechiae** = Pinpoint purplish-red dots on the skin.

**Pressure Sore** = An ulcer of the skin and underlying tissue from prolonged pressure.

**Productive Cough** = A cough in which mucus is raised.

**Prognosis** = Prediction of the course or end of a disease.

**Pulmonary** = Concerning the lungs.

**Respiratory Distress** = Labored breathing.

**Secretion** = The product of a gland, such as saliva.

**Sedative** = An agent that calms or tranquilizes.

**Skin Breakdown** = A condition in which the skin's integrity is compromised.

**Sputum** = Saliva, mucous.

**Subcutaneous Injection** = A shot into the tissue just beneath the skin but not into the muscle.

**Sublingual** = Under the tongue.

**Suppository** = A cone shaped medication that melts when inserted into the rectum.

**Topical** = Applied to the skin.

**Turgor** = Elasticity of the skin.

**Ulcer** = An open lesion on the skin or mucous membrane.

**Unresponsive** = A condition in which a patient does not react to stimuli.

**Urinary Retention** = Inability to pass urine.

**Vital signs** = Measurements of respiration, pulse, blood pressure and temperature.

## Resources

### **Lending library in the Serenity Home:**

Books are available on:   Coping  
                                  Children and Grief Issues  
                                  Caregiving  
                                  Making Informed Decisions  
                                  Helping Older Adults.

For help obtaining a book or video call the Serenity Hospice and Home office at 815-732-2499. The office staff will be glad to help you, we lend books out free of charge.

### **Internet sites**

**Serenity Hospice and Home:** <http://serenityhospiceandhome.org/>

**National Hospice & Palliative Care Organization:** [www.nhpco.org](http://www.nhpco.org)

**Caring Connection:** [www.caringinfo.org](http://www.caringinfo.org)

**Hospice Net:** [www.hospicenet.org](http://www.hospicenet.org)

**Hospice Foundation of America:** [www.hospicefoundation.org](http://www.hospicefoundation.org)



## Resources

### HIPAA Notice of Patient Privacy

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

We may use your health information for purposes of providing you treatment, obtaining payment for your care and conducting health care operations. We are required by law to guard against unnecessary disclosure and maintain the privacy of your protected health information (PHI). We are also required to abide by the terms of this Notice.

We reserve the right to make changes to the terms of this Notice and any changes will apply to PHI that is already in our possession.

#### A. WE ARE PERMITTED UNDER FEDERAL LAW TO MAKE THE FOLLOWING USES OR DISCLOSURES OF YOUR PHI WITHOUT YOUR AUTHORIZATION:

**To You.** We may disclose your PHI to you or to your appointed representative.

**Treatment.** We may use PHI to provide you with medical treatment. For example, we may disclose your PHI to doctors, nurses, pharmacists, clergy, suppliers of medical equipment, medical or nursing students, volunteers, other health care providers or personnel who are involved in taking care of you.

**Payment.** We may use and disclose PHI to bill and collect payment for the treatment and services you receive from us. For example, we may be required by your health insurer for reimbursement to provide information regarding your health care status and may need to explain your need for hospice care and services we will provide for you.

**Health Care Operations.** We may use and disclose PHI in the course of performing activities called “health care operations.” For example, we may use your PHI to perform business management and general administrative activities of Serenity Hospice & Home, including managing our activities related to complying with the HIPAA Privacy Rule.

**Appointment Reminders: Treatment Alternatives.** We may use and disclose PHI to remind you of an appointment, or to tell you about possible treatment options or alternatives that may be of interest to you.

**Required By Law.** We may use and disclose PHI as required by Federal, State or local law as long as any disclosure complies with the law and is limited to the requirements of the law.

**Public Health Activities.** We may use or disclose PHI to public health authorities or other persons authorized to carry out certain activities related to public health, such as to report disease, injury, birth or death, or to report child abuse or neglect, or to notify a person who may have been exposed to a communicable disease in order to control the spread of the disease.

**Abuse, Neglect or Domestic Violence.** We may disclose PHI in certain cases to proper government authorities if we reasonably believe a patient is a victim of abuse, neglect or domestic violence.

**Health Oversight Activities.** We may disclose PHI to a health oversight agencies in connection with audits, criminal or civil investigations, inspections, licensure or disciplinary action and other activities it undertakes to monitor the health care system, government health care programs and compliance with certain laws.

## Resources

### HIPAA Notice of Patient Privacy Cont...

**Lawsuits and Other Legal Proceedings.** We may use or disclose PHI when required by a court or administrative tribunal.

**Law Enforcement.** Under certain conditions, we may disclose PHI to law enforcement officials for the purpose of reporting or investigating criminal activity.

**Coroners, Medical Examiners, Funeral Directors.** Under certain conditions, we may disclose PHI to a coroner, medical examiner or to funeral directors consistent with applicable laws.

**Organ and Tissue Donation.** Under certain circumstances, we may use or disclose PHI in order to facilitate an organ, eye or tissue donation and transplantation.

**Research.** We may, under very select circumstances, use and disclose your PHI for research purposes. Before any disclosure of PHI for such research purposes, the project will be subject to an extensive approval process.

**In the Event of a Serious Threat to Health or Safety.** We may use or disclose PHI about you, consistent with applicable law and ethical standards of conduct, when necessary to prevent a threat to your health or safety or to the public.

**Specialized Government Functions.** We are permitted to disclose PHI for certain military and veteran activities, for national security and intelligence activities, protective services for the President and others, medical suitability determinations and inmates and law enforcement custody.

**Disclosure Required by HIPAA Privacy Rule.** We are required to disclose PHI to the Secretary of the United States Department of Health and Human Services when requested by the Secretary to review our compliance with the HIPAA Privacy Rule.

**Worker's Compensation.** We may disclose PHI as authorized by worker's compensation laws or other similar programs that provide benefits for work-related injuries or illness.

**Business Associates.** We may disclose PHI to individuals or entities that perform services for us if we obtain written assurances that they will safeguard the information.

**Marketing and Fundraising.** We may use and disclose PHI for marketing and fundraising purposes in certain limited circumstances. You may opt out by notifying our office at 815-732-2499.

**Individuals Involved in Your Care or Payment.** We may disclose PHI about you to people involved in your care or payment for your care if we have your verbal agreement, or if you have the opportunity to object but do not. If you are not present or you are unable to consent or object, we may exercise professional judgment in determining whether the use or disclosure of PHI is in your best interests.

ALL OTHER USES AND DISCLOSURES OF PHI ABOUT YOU THAT ARE NOT MENTIONED ABOVE, MAY ONLY BE MADE WITH YOUR WRITTEN AUTHORIZATION.

B. UNDER THE HIPAA PRIVACY RULE, YOU HAVE THE FOLLOWING RIGHTS REGARDING YOUR PHI:

**Right to Request Restrictions.** You or your appointed representative have the right to request additional restrictions on certain uses and disclosures of your PHI. You or your appointed representative have the right to request a limit on disclosures of your PHI to someone who is involved in your care or the payment of your care. You have the right to restrict disclosure of PHI to a health plan with respect to treatment for which you have paid fully out of pocket. However, we are not required to agree to your request.



## Resources

### HIPAA Notice of Patient Privacy Cont...

**Right to Receive Confidential Communications.** You or your appointed representative have the right to receive communications regarding PHI in a reasonable manner or location. For example, you may request to receive communications regarding PHI with you privately with no other family members present. You or your appointed representative must make your request in writing to our Compliance (Privacy) Officer. We will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.

**Right to Inspect and Copy.** You or your appointed representative have the right to inspect and receive a copy of PHI. You or your appointed representative must make your request in writing to our Compliance (Privacy) Officer. We may charge a reasonable fee for copying and assembling costs associated with your written request.

**Right to Request Amendment.** If you feel that your PHI is incorrect or incomplete, you or your appointed representative have the right to request that we amend it by submitting your request in writing to our Compliance (Privacy) Officer. We may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your PHI was not created by Serenity Hospice and Home, if the PHI you wish to amend is not part of the health information you or your appointed representative are permitted to inspect or copy, or if, in the opinion of Serenity Hospice & Home, the records containing your PHI are accurate and complete.

**Right to Receive an Accounting of Disclosures.** You or your appointed representative have the right to request an "accounting" of certain disclosures that we have made of your PHI by submitting your request in writing to our Compliance (Privacy) Officer. The request should specify the time period for the accounting starting on or after April 14, 2003. Accounting requests may not be made for periods of time in excess of six (6) years. We may charge a reasonable fee associated with your written request.

**Right to be Notified of Breach of PHI.** You or your representative have the right to be notified in the event of a breach of your PHI. Should we discover that your PHI has been breached, you will be notified by U.S. Postal Service mail sent to the address in your records within 60 days of discovery.

**Right to a Paper Copy of This Notice.** You or your appointed representative have a right to a separate paper copy of this Notice at any time even if you or your appointed representative have received this Notice previously. To obtain a paper copy of this Notice, please contact our Compliance (Privacy) Officer.

**Complaints.** If you or your appointed representative believe your privacy rights have been violated, you or your appointed representative may file a complaint with us or the Secretary of the United States Department of Health and Human Services. To file a complaint with our office, please contact our Privacy Officer at the address and number listed below. We will not retaliate or take action against you for filing a complaint. All complaints must be submitted in writing. Serenity Hospice & Home encourages you to express any concerns you or your appointed representative may have regarding the privacy of your information.

**Questions.** If you or your appointed representative have any questions about this Notice, please contact our Compliance (Privacy) Officer at the address and telephone number listed below:

1658 South IL Route 2, P.O. Box 462  
Oregon, IL 61061  
(815) 732-2499  
THIS NOTICE EFFECTIVE APRIL 14, 2003  
Revised SEPTEMBER 23, 2013

Serenity Hospice & Home  
1658 S. Illinois Route 2  
P.O. Box 462  
Oregon, IL 61061

Phone: 815-732-2499 Fax: 815-732-6077

