HOSPICE

Dear Friend:

Thank you for inviting hospice into your life. It is a privilege to serve you. This Caregivers Guide is designed to make it as easy as possible for you to keep important information organized and readily accessible. It can serve as a convenient guide and reference tool as questions arise.

Visiting Nurse Hospice and Ontario-Yates Hospice have supported patients and their families in Monroe, Ontario and Yates counties since the mid-1990s with their mission of care and compassion. We are not-for-profit agencies dedicated to the people we serve. Hospice supports patients and their loved ones throughout this most difficult time, providing professional home care that meets both medical and emotional needs, promoting as full and comfortable a life as possible.

In hospice, our patients and their families always come first. We know that comfort begins by staying in familiar surroundings, being cared for by caregivers who become like family. We provide quality care and compassion to those that need it, including those who may be unable to pay.

Our hospice professionals are experienced in every aspect of hospice care, from guiding the patient's smooth transition from hospital to home. . .to providing comfort care with respect and compassion. . . to supporting family and friends through their bereavement following death.

Hospice emphasizes quality, rather than length, of life. Hospice neither hastens nor postpones death; it affirms life and regards dying as a normal process. The hospice program stresses human values that go beyond the physical needs of the patient. Hospice ensures that patients spend their final days with dignity and in comfort.

Your questions are extremely important to us. Please never hesitate to ask about any aspect of your care. We want to be responsive to your needs and concerns, and we will be available to you around the clock.

Again, thank you for the privilege of caring for you—you are an important member of our hospice family.

Sincerely yours,

Your Hospice Team

Visiting Nurse Hospice
2180 Empire Blvd.
Webster, NY 14580-2098
Phone: 585.787.8315
Fax: 585.787.9726

Ontario-Yates Hospice
756 Pre-Emption Road
Geneva, NY 14456
Phone: 315.789.9821
Fax: 315.789.3427

www.urmhomecare.org

The Hospice Pledge to our Patients and Families

We will treat you and your family members with courtesy and respect.

We will call you before we visit to let you know when we will be coming to see you.

On the first visit we will explain to you the care and services we will be providing.

We will talk with you about all of the prescription and over-the-counter medications you take, and fully answer any questions you have.

As we care for you, we will stay up-to-date on changes in your medications, making sure you understand what they are for, when to take them, and any side effects you may experience while taking the medications.

We will talk to you about your pain, and work to make you comfortable.

We will talk with you about how you can make your home environment safer for you to move around in.

We will stay informed and up-to-date about your home care needs and treatments.

We will explain details about your illness so that you can understand it.

We will listen carefully to what you have to say so that we can meet your needs.

If you contact the hospice office for help or advice, we will get you in touch with the proper person to answer your questions.

We want you to feel good about the care you get from everyone at hospice, and be able to rate us a 10 with every encounter.

Let us know immediately if we are not living up to our pledge.

ICARE: Integrity, Compassion, Accountability, Respect, Excellence

Patient & Family Centered I CARE Plan

We care about you! Please consider completing this information summary to improve our understanding of your needs so we can provide the highest quality person-centered care. This summary will help our healthcare providers consider your personal preferences in addition to clinical care needs. Please ask if you need help completing this form and share this information with your primary caregiver for posting in a central location in your home. Clinical information and goals will be documented by healthcare provider(s) in the plan of care.

Name: ____________________ **Today's Date:** ____________

Address me as: ____________________ **Date of Birth:** ____________
Mr./Mrs./MS, last and/or first name or other Day/Month

Family and/or Care Partner Name: ____________________ **Phone:**
Emergency Contact: ____________________ **Phone:**
Additional Contacts: ____________________

Personal goals and notes: Anything we can do to help make our time together most meaningful

Personal care preferences: Specific likes or dislikes (e.g., music, TV, noise level, lighting etc.)

Communication: Preferences or special needs with communication (e.g., hard of hearing etc.)

Mobility & safety notes: Preferences or special needs related to moving around (e.g., walking)

Nutrition: Dietary needs and preferences (e.g., temperature, texture, flavor, likes or dislikes etc.)

Spirituality: Observances, courtesy requests or other considerations

Social history: General work/life or other information that you'd like the care team to know

Please do not hesitate to ask for assistance from your care provider to complete this form.

Thank you for sharing!

The Hospice Team Members

Hospice services are brought to you by a group of people. . .a team. You, your doctor, and your caregivers are part of this team too. This team decides your plan of care, which is reviewed regularly.

Attending Physician
Participates in the plan of care, works closely with the team and remains the patient's primary physician.

Medical Director
Oversees the hospice plan of care and advises the hospice team. The medical director is a resource of information regarding hospice medical care and reviews each case at regular intervals.

Registered Hospice Nurse
Assesses and manages the plan of care, including pain and symptom management. Makes regular visits, based on patient and family need. Will teach caregivers how to care for a family member and provide comfort care.

Social Worker
Deals with the psychosocial needs of the patient and family facing terminal illness. Available to assist with legal, financial and social resources.

Home Health Aide
Provides personal care and assistance with activities of daily living, feeding, bathing and hands-on care.

Chaplain
Provides support and comfort directly or contacts local clergy at the request of patient/family.

Bereavement Counselor
Provides support during hospice care and up to one year after death. Exact services are based on family need, but can include support groups or private counseling.

Volunteer
Trained to provide respite, emotional support, companionship, and assist with day-to-day activities.

In addition, hospice may provide physical therapists, occupational therapists, speech therapists and dietary services.

Quick Reference

Reaching the hospice team members when you have a need or question is important. Your team members are listed below.

Attending Physician: ______________________________

Hospice Medical Director: ______________________________

Hospice Nurse: ______________________________

Hospice Social Worker: ______________________________

Hospice Chaplain: ______________________________

Hospice Aide Coordinator: ______________________________

Hospice Volunteer Coordinator: ______________________________

Hospice Bereavement Coordinator: ______________________________

The team members are available Monday through Friday, 8:00 am to 4:30 pm. If you have a question or concern after office hours, a hospice nurse is on call and will address your concerns appropriately. Please be assured that a Hospice Administrator is also on call and can assist as needed.

For help when you need it, call our Monroe County office at **585-787-8315** during normal business hours (Monday through Friday, 8:00 am to 4:30 pm) and our on-call service at **585-787-2233** outside of normal business hours. When using the on-call service, request that the operator connect you to the Hospice On-Call Nurse.

For the office that covers Ontario and Yates Counties, call **800-253-4439** at any time.

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Patient Bill of Rights and Responsibilities

Exercise of Rights and Respect for Property and Person

1. The patient has the right:
   a. To exercise his or her rights as a patient of the hospice;
   b. To have his or her property and person treated with respect;
   c. To voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of the hospice; and respect for property by anyone who is furnishing services on behalf of the hospice; and
   d. To not be subjected to discrimination or reprisal for exercising his or her rights.
2. If a patient has been adjudged incompetent under state law by a court of proper jurisdiction, the rights of the patient are exercised by the person appointed pursuant to state law to act on the patient's behalf.
3. If a state court has not adjudged a patient incompetent, any legal representative designated by the patient in accordance with state law may exercise the patient's rights to the extent allowed by state law.
4. Hospice must:
   a. Ensure that all alleged violations involving mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property by anyone furnishing services on behalf of the hospice, are reported immediately by hospice employees and contracted staff to the hospice administrator;
   b. Immediately investigate all alleged violations involving anyone furnishing services on behalf of the hospice and immediately take action to prevent further potential violations while the alleged violation is being verified. Investigations and/or documentation of all alleged violations must be conducted in accordance with established procedures;
   c. Take appropriate corrective action in accordance with state law if the alleged violation is verified by the hospice administration or an outside body having jurisdiction, such as the State Survey Agency or local law enforcement agency; and
   d. Ensure that verified violations are reported to state and local bodies having jurisdiction (including to the State Survey and Certification Agency) within five working days of becoming aware of the violation.

Information and Choices Regarding Care and Services

1. Hospice respects the rights of the patient in making decisions and choices affecting his/her present and future health status. The patient has the right to be informed of all treatment prescribed, when and how services will be provided, and the name and functions of any person and affiliated agency providing care and services.
2. The patient has the right and responsibility to participate in planning care and treatment or changes in care and treatment.
3. The patient has a right to:
   a. Refuse treatment within the confines of the law after being fully informed of and understanding the consequences of such actions.
   b. Information regarding his/her care before the start of service, including 3rd party coverage for services and any changes for services not covered.
   c. Receive a written copy of the Patient Bill of Rights upon admission.
   d. Receive effective pain management and symptom control from the hospice for conditions related to the terminal illness;

e. Choose his or her attending physician;
f. Be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property;
g. Receive information about the services covered under the hospice benefit;
h. Receive information about the scope of services that the hospice will provide and specific limitations on those services.

Charges for Services and Billing Policies

The patient has the right to:

1. Voice grievances and suggest changes in hospice policies and services to any representative of the patient's choice without restraint, interference, coercion, discrimination or reprisal.
2. Be informed of the policies for submitting complaints or suggestions. These are as follows:
    a. The patient is encouraged to discuss problems or suggestions with the caregiver and/or the caregiver's immediate supervisor.
    b. The patient may submit written complaints at any time to the program serving him/her:

(The program serving Monroe County)	(The program serving Ontario and Yates Counties)
Hospice Director Visiting Nurse Service 2180 Empire Boulevard Webster, NY 14580	Hospice Manager Ontario-Yates Hospice 756 Pre-Emption Road Geneva, NY 14456

    c. Complaints or suggestions may also be made over the telephone, Monday through Friday, 8:00 am to 4:30 pm by calling and asking for the Hospice Director.

(The program serving Monroe County)	(The program serving Ontario and Yates Counties)
585-787-8315	800-253-4439

3. If the patient is unable to resolve their complaint with the hospice, the patient may file a complaint with the New York State Department of Health Hotline: 1-800-628-5972. The hotline can be called 24 hours a day, seven days a week.

Patient's Responsibilities

1. Patient and/or family must be willing to accept service and be willing to participate and cooperate in carrying out the plan of care.
2. Patient must be able to self-direct his/her care, be able to summon help in an emergency if unattended, or have a backup plan if not able to self-direct care.
3. Patient and/or family will promptly notify hospice in the event that a visit must be cancelled.
4. Patent and/or family will treat hospice employees with respect and will not discriminate based on race, national origin, marital status, creed, age, sex, disability or sexual orientation.
5. Patient and/or family understand that documents containing confidential information about the patient may be left in the home for use of assigned caregivers. Patient and/or family assumes responsibility for protecting the privacy of such information.
6. Patient and/or family agree to comply with the fee related policies of the agency.
7. Patient is responsible for his/her own actions when prescribed medical treatments or agency instructions are refused.
8. If the patient does not comply with responsibilities, hospice may initiate the discharge process.

A Message From the Foundation

Donating to Hospice

Hospice gives patients and loved ones the opportunity to openly embrace the end of life. Generous community support allows hospice to continue its tradition of providing a team approach to caring for patients and their families. It also allows us to make decisions based on what is best for patients, knowing that a caring community supports the work we do. Hospice is responsible for providing care in a variety of settings, whether in your home or a hospital, nursing home or comfort care home. Gifts to Visiting Nurse Hospice and Ontario-Yates Hospice assist with services that are not covered by insurance, such as bereavement support and specialized care for dying veterans. They also help defray costs for the care of patients who are uninsured or underinsured.

You Make the Difference

Your generous gift, regardless of size, will make a difference in someone's life and in the quality of care available to those that hospice serves. Hospice gives donors the opportunity to remember special individuals with a memorial or tribute gift. A commemorative gift honors a loved one's life and serves to reflect upon the memories that live forever. A gift made in honor of an individual recognizes a person who has had a special impact on your life.

Thank you for helping us provide quality end-of-life care for the patients and families we serve.

For more information, contact:

(Hospice in Monroe County)
Visiting Nurse Foundation
2180 Empire Boulevard
Webster, NY 14580
585-274-4253

(Hospice in Ontario and Yates Counties)
Ontario-Yates Hospice
756 Pre-Emption Road
Geneva, NY 14456
585-274-4301

Visiting Nurse Hospice and Ontario-Yates Hospice, along with other programs (Visiting Nurse Service, Visiting Nurse Signature Care, Meals On Wheels, Visiting Nurse Foundation, Finger Lakes Visiting Nurse Service, and Finger Lakes Home Care) are non-profit charitable organizations and your contributions are tax-deductible.

The Hospice Medicare Program & Other Insurance Coverage

The Medicare Hospice Benefit

Medicare provides a special program for persons needing hospice care. This program covers services, medications, supplies, and equipment needed for the comfort of patients. The services and items provided must be needed to treat the terminal illness. Hospice is a program of care delivered in the patient's place of residence by a Medicare-certified hospice.

Pre-Authorization

All services, medications, supplies, or equipment related to the terminal diagnosis must be pre-authorized by the hospice. Medicare pays the hospice directly at a specified daily rate for all care and supplies provided. Hospice delivers care based on the plan of care related to the patient's terminal diagnosis and is not responsible for care obtained for the patient outside of this plan of care. Remember, these restrictions apply only to the terminal diagnosis and related diagnosis. Unrelated medical problems may be treated in your usual fashion.

Hospice will need to approve any treatments, medications, tests, or emergency room visits in advance. If the patient receives any of the above without approval, hospice is not responsible to cover the cost incurred.

What is a benefit period?

The Medicare Hospice Benefit consists of two 90 day periods followed by an indefinite number of 60 day periods.

At the end of each certification period, the hospice team must agree that the patient is terminal. If the patient is improving or the illness has stabilized, the hospice team will discuss alternatives to hospice care with the patient and family.

Do I keep my own doctor?

Yes, hospice works directly with the patient's doctor.

What happens if I move out of my hospice service area?

A transfer to another Medicare certified hospice would be arranged by your hospice team.

How does the Medicare hospice benefit cover hospitalizations?

If a patient has symptoms that are proving to be difficult to manage at home, a few days in a hospital may be necessary. The need for this care must be assessed by a hospice nurse. The types of problems that may warrant a trip to the hospital are increased pain, acute nausea, vomiting, or shortness of breath. If such a trip out of the home is needed, the hospice nurse or social worker will help you arrange transportation. The Medicare Hospice Benefit requires the pre-authorization of any hospital stay related to the terminal illness, including the emergency room. **Remember, call hospice day or night!**

How can the caregiver get a break?

Short breaks of an hour or two can be arranged with the help of a volunteer. For those willing to pay privately for four hours per week or more, our sister licensed home health agency can provide aide service. If a longer break is necessary, a period of up to five days of care can be arranged by the nurse or social worker at a skilled nursing facility. This break is referred to as a respite.

How does the patient pay for hospice care?

Medicare pays hospice directly for each day hospice is responsible for care. During hospice care, you should not receive a bill for services covered by Medicare. If any questions come up regarding billing, ask your hospice nurse or social worker for help.

What if I no longer want hospice care?

Receiving hospice care is a choice, and the patient and family have the right to change their minds at any time. If you have any questions or concerns about continuing on hospice, please discuss them with your hospice nurse or social worker. If you do choose to discontinue hospice care, you can be referred again at any time.

Medicaid Hospice Benefit

The Medicaid hospice benefit generally provides the same coverage as Medicare. Your Medicaid card will be used to confirm your eligibility for this benefit.

HMO Managed Medicaid Plans

Each HMO may have a different hospice benefit. The hospice nurse or social worker will verify what your plan covers and discuss that with you.

HMO Hospice Benefits

Each HMO has its own hospice benefit plan. The nurse and social worker will verify coverage and discuss that with you. If you have a senior HMO plan such as Blue Choice Senior or Preferred Care Gold, your hospice services will be covered by your Medicare benefit and not by your HMO plan.

In addition to those services provided by your Medicare benefit, the Hospice Foundation, through donations in memory of patients, is able to provide additional services including our Bereavement Support Program, annual Remembrance Ceremonies, and individualized family support.

Hospice Care Locations

Where can you receive hospice care?

- At home
- Nursing Home
- Hospital
- Inpatient hospice
- Respite care
- Comfort care homes

Advent House
1010 Mosley Rd.
Fairport, NY 14450
(585) 223-6112

Aurora House
2495 South Union Street
Spencerport, NY 14559
(585) 617-4863

Benincasa Inc.
3880 Rush-Mendon Rd.
Mendon, NY 14506
(585) 624-8070

Light Hill (Canandaigua Comfort Care Home)
5160 Parrish Street Ext.
Canandaigua, NY 14424
(585) 393-1311

House of John
14 Spring Street
Clifton Springs, NY 14432
(315) 462-5646

Isaiah House
71 Prince St.
Rochester, NY 14605
(585) 232-5221

Journey Home
994 Long Pond Rd.
Rochester, NY 14626
(585) 225-1240

Keuka Comfort Care Home
35 Route 54
Penn Yan, NY 14527
(315) 536-1690

Mount Carmel House
228 Frisbee Hill Road
Hilton, NY 14468
(585) 366-4949

Serenity House
1278 Brace Road
Victor, NY 14564
(585) 924-5840

Shepherd Home
1959 Five Mile Line Rd.
Penfield, NY 14526
(585) 381-0890

Sunset House, Inc.
3746 St. Paul Blvd.
Rochester, NY 14617
(518) 467-3524

Webster Comfort Care Home
700 Holt Rd.
Webster, NY 14580
(585) 872-5290

Personal Affairs

Preparing for the challenge of declining health

When a health crisis occurs, it may be too difficult or too late to let people know what you want. Planning ahead will ease family decision-making because they will know your wishes. Patients and caregivers can prepare by discussing the following topics.

Advanced Directives (See Appendix, page 51)

In a medical crisis, most of us would like to have a say in what happens to us. However, if unconscious, we will not be able to do so. It is a good idea to let everyone know **in advance** what we want done in a medical crisis.

An advanced directive makes it possible for us to inform our families, our doctors, and our hospitals what we want done when we can no longer speak for ourselves. The documents that are available may be confusing, so feel free to discuss them with your nurse or social worker.

MOLST

The Medical Orders for Life-Sustaining Treatment (MOLST) Program is designed to improve the quality of care people receive at the end of life. MOLST is based on communication between the patient or spokesperson and health care professionals to ensure informed medical decision-making.

The MOLST Program:

- Assists health care professionals discuss and develop treatment plans that reflect patient wishes.
- Results in the completion of the MOLST form.
- Helps physicians, nurses, health care facilities and emergency personnel honor patient wishes regarding life-sustaining treatments.

Health Care Proxy (See Appendix, pages 52-59)

The New York Health Care proxy law allows you to appoint someone you trust—for example, a family member or close friend—to decide about treatment if you lose the ability to decide for yourself. You can give the person you select, your "health care agent" as little or as much authority as you want. You can allow your health care agent to decide about all health care or only certain treatments. You may also give your agent instructions that he or she has to follow. Your agent can then make sure that health care professionals follow your wishes and can decide how they apply as your medical condition changes. Hospitals, doctors and other health care providers must follow your agent's decisions as if they were your own.

What decisions can my health care agent make?

Unless you limit your health care agent's authority, your agent will be able to make any treatment decision that you could have made if you were able to decide for yourself. Your agent can agree that you should receive treatment, choose different treatments, and decide what treatments should not be provided in accord with your wishes and interests. If your health care agent is not aware of your wishes about artificial nutrition and hydration (nourishment and water provided by feeding tubes), he or she will not legally be able to make decisions about these measures. Artificial nutritional and hydration are used in many circumstances, and are often used to continue the life of patients who are in a permanent coma. Be sure that once you complete a health care proxy that you give a copy to your health care providers, such as your doctors, as well as to your family and/or friends.

The Living Will (See Appendix, pages 60-61)

The living will is a legal document in which you can indicate what you want to be done (or what you don't want done) in a time of medical crisis—when you are terminally ill, are permanently unconscious or incompetent. The living will gives your caregivers the authority to follow your specific instructions regarding the medical treatment you want under these conditions.

Is a health care proxy the same as a living will?

No. A living will is a document that provides specific instructions about health care treatment. It is generally used to declare wishes to refuse life-sustaining treatment under certain circumstances.

In contrast, the health care proxy allows you to choose someone you trust to make treatment decisions on your behalf. Unlike a living will, a health care proxy does not require that you know in advance all the decisions that may arise. Instead, your health care agent can interpret your wishes as medical circumstances change and can make decisions you could have not known would have to be made.

Durable Power of Attorney

This is a more general legal document. It is more comprehensive and is usually used by one person to grant another the ability to function on their behalf in a specific capacity. For example, a person may grant to another the ability to pay their bills and to handle their finances, if they are too sick to write their name or to go to the bank themselves. As long as the person who grants the Durable Power of Attorney is competent, they stay in control. No one can take over you finances without your permission.

Do Not Resuscitate (DNR) Order (See Appendix, page 63)

Do not resuscitate means that in the event that your heart and breathing stops, you would not receive emergency treatment in the form of cardiopulmonary resuscitation (CPR). The do not resuscitate order must be signed by your physician to be activated. A copy of the signed order will be given to you to keep in your home and hospice will also keep a copy.

Please Note:
A DNR order is required for any transfer or admission from home to an inpatient facility or comfort care home.

Funeral Planning

If you need assistance in planning for your funeral, please let us know. Your hospice nurse or social worker or bereavement coordinator will be able to help you.

Memorial Donations and Endowments

Memorial Donations can be directed to:

(Hospice in Monroe County)
Visiting Nurse Foundation
2180 Empire Boulevard
Webster, NY 14580

(Hospice in Ontario and Yates Counties)
Ontario-Yates Hospice
756 Pre-Emption Road
Geneva, NY 14456

If you would like more information about directing gifts, or setting up a permanent endowment, please call:

(Hospice in Monroe County)
Foundation Director for Monroe County
585-274-4293

(Hospice in Ontario and Yates Counties)
Gift Officer for Ontario and Yates Counties
585-274-4301

Basic Home Safety

Pets

To help us provide you and your family with the best possible care, we ask that you please keep your pets confined when the members of the hospice team visit. Although your pet may be very gentle and loving to you and your family, the hospice nurses, social workers, chaplain, home health aides and volunteers are strangers to your pets. Your pet may not react in a predictable way and may feel that our staff is threatening to you or your family.

Electrical Safety

- Extension cords should be placed away from walkways.
- Replace frayed or broken cords.
- Never overload electrical outlets.
- Keep electrical appliances away from sinks, tub, and shower areas.
- Power bars or outlet adapters are a safe choice.

Fire Safety

- Smoke detectors should be present on each level of the home.
- Change the batteries in your smoke detector every six months.
- Develop a family escape plan.
- Have your furnace, fireplace and woodstove cleaned and inspected every year.
- Clear all pathways, never block an exit.
- Instruct all household members not to smoke in bed. Patients often need supervision for smoking due to increased weakness and sleepiness.
- No smoking or open flames in the home where oxygen is used.
- Keep fire extinguishers within reach.

Kitchen

- Do not use the stove or oven for heat.
- Do not wear loose clothing around the stove.

Bathroom

- Tubs and showers need non-skid mats or strips to avoid falls.
- Install grab bars in showers and tub areas to assist with patient transfers.
- Install a raised toilet seat.
- Always check water temperature before entering tub or shower.
- Consider installing a night light in the bathroom.

Outdoors

- Entrance ways should be well lit and clear of debris, ice, leaves and snow.
- The house numbers need to be clearly visible from the street, day and night.

Weapons

We respect your right to own weapons. We require, however that all weapons and ammunition be out of sight and reach while the hospice caregivers are in your home.

Emergency Preparedness

- Every family should have a Family Emergency Plan. (www.Ready.gov is a great resource)
- If you relocate during an emergency, (shelter, other family members) it is very important that you notify your home care agency of your new location.
- Consider creating a “Go Box” that contains copies of important papers, identification, extra medication, wind up flashlights and radios. This would be taken with you should you have to evacuate.

Infection Control

Protecting the patient and caregivers from infection can be done using some basic rules. The nurse will be glad to review these with you.

- **Wash hands**
  Caregivers hands, as well as the patient's, should be washed, particularly before food preparation and eating.

- **Use liquid soap**
  Be sure to wash between fingers, count to 20 as you scrub, rinse well using warm water, and dry completely. If the sink area has many users, keep a roll of paper towels nearby instead of a cloth towel.

- **Use Gloves**
  Disposable gloves need to be used when the caregiver may be in contact with blood, bowel movements, urine, or other bodily fluids. As soon as the task is done, throw the gloves away and wash hands well.

- **Cleanup patient area**
  Trash that has blood or other body fluids should be placed in a plastic, leakproof bag for regular trash disposal. Clean spills of bodily fluids immediately with a 10% bleach and water solution (one part bleach to 10 parts water). Air out the room when possible.

- **Dispose of needles, syringes, and other sharp objects**
  If the patient uses these items, dispose of them in a hard plastic jug (bleach or detergent bottle). Another option is a metal coffee can with a secure lid that has been reinforced with heavy duty tape. Keep out of reach of children.

- **Visitors**
  If a visitor states that they are not feeling well, encourage them to come back another day when they are feeling better. Household members should be relieved of direct patient care duties if they are not well. If this is not possible, good hand washing, gloves, and a mask that covers the nose and mouth will provide protection.

Remember: The most important infection control measure is to wash your hands.

Caring for a patient in bed

A patient in a bed needs help with the following:

- Keeping clean and dry
- Moving from side to side
- Eating and drinking
- Getting comfortable
- Protecting the skin from breakdown

Useful items to have on hand:

- Moist, disposable wipes
- Adult briefs
- Gloves
- Pads that protect the bed
- Extra sheets
- Extra pillows
- Bedpan/urinal
- Lotion
- Powder
- Serving tray or bed table
- Cups with covers, straws
- A hospital bed is often more comfortable for the patient, as well a great back saver for the caregiver. Ask the hospice nurse to help obtain a bed

Turning a patient from side to side in bed

1. If the patient is in a hospital bed, raise the side rail on the side the patient is going to be turned towards.
2. Move the patient closer to you as you stand at the side of the bed.
3. Move the pillow towards the raised side rail, providing support for the head.
4. Bend the knee that is on top.
5. With your hand on the closest shoulder and hip, turn the patient towards the side rail.
6. Firmly place a pillow behind the back for support.
7. Place another small pillow or folded towels between knees and ankles.
8. Adjust the shoulders, pulling the bottom shoulder slightly out. Add a pillow under the arm.
9. Adjust the head pillow for comfort. Ask if the patient feels comfortable. Put up both side rails, cover the patient for warmth.

Placing a lift sheet

A lift sheet is useful when a patient can no longer help move themselves. It is a flat sheet or extra large bath towel placed under the patient and can move the patient without directly pulling on the patient.

1. With the patient lying on their side, place a lengthwise folded flat sheet along the back from the shoulders to the thighs. Tuck at least half of this under the patient.
2. Put the side rail up on the side you have been working on, move to the other side (put this side rail down) and assist patient to roll over the folds of the lift sheet.
3. Straighten out the sheet, smoothing out the wrinkles. Position the patient as desired.

To lift a patient to the top of a bed

There needs to be two people to accomplish this, one person on each side of the patient. Each person should grab an edge of the lift sheet around the shoulder and an edge by the hips. Use a count of three, lift and move up to the head of the bed.

Changing sheets with a patient in the bed

The side rail opposite the caregiver should be kept up. Turn the patient to that side and move as close to the rail as is comfortable for the patient. Pad the rail with an extra blanket.

1. Working from one side, loosen the bottom sheet and tuck as much as possible under the patient.
2. Attach the top and bottom corners of the clean sheet on the side you are working on.
3. Smooth the clean sheet over to the patient, then fold and tuck the sheet under the patient. It is best if you tuck the clean sheet under the dirty sheet.
4. Put up the side rail and move over to the other side of the bed. Lower that rail.
5. Help the patient roll over the lump of dirty and clean sheets. Pull out the dirty sheet.
6. Pull the clean sheet tight and attach to corners.
7. A lift sheet may also be added to this procedure.
8. Keep the head of the bed as flat as the patient can tolerate.

Putting a patient on the bedpan

1. Put on gloves. Powder the bedpan to decrease friction.
2. With the opposite side bed rail up, roll the patient to that side.
3. Place the bedpan squarely on the buttocks.
4. Roll the patient back over on top of the pan. Check between the legs to make sure the patient is positioned properly.
5. Raise the head of the bed.
6. Put up the other side rail. Stay within calling range or leave a bell nearby.
7. When the patient is done, lower the head of the bed. While holding onto the pan, roll them off the pan. Be careful not to let the pan tip.
8. Help cleanse the patient and pat dry.
9. Dispose of the waste in the toilet, clean out the bedpan.
10. Remove gloves and wash your hands.
11. Always be sure to check the comfort of the patient and make sure the bed rails are up.

Helping the patient move from a bed to a chair

Before starting, remember to bend your knees, keep your back straight, and reach as little as possible. This will help prevent you from injuring your back.

1. Explain to the patient what you are planning to do.
2. Move slowly.
3. Put the head of the bed up and have the patient turn towards the edge of the bed.
4. Swing the patient's legs down to the floor as you bring them to a sitting position. Wait a few moments to allow the patient to adjust to sitting up.
5. Have the chair placed at the head of the bed, facing the foot of the bed.
6. Face the patient and place your right foot between the patient's feet. Keep your back straight, reach under the patient's arms as they place their arms on your shoulder.
7. Hug the patient gently while raising them off the bed, and pivot the patient towards your left (to the chair).
8. Lower the patient to the chair, remember to bend your knees and keep your back straight.
9. Reverse these steps to return the patient to bed.

Assisting the patient from sitting to standing

1. Assist patient in moving to the edge of the bed or chair. Be sure the patient has something on their feet so they do not slip on the floor.
2. Stand directly in front of the sitting patient, with your feet shoulder width apart.
3. Tell the patient to place their hands on your shoulders.
4. Place your hands under the patient's arms. Brace yourself by bending knees and keeping your back straight.
5. Straighten yourself, gently raising the patient. Allow the patient to pull on your shoulders.
6. Do not let go unless you are sure the patient is stable.

Assisting the patient to walk

1. Before walking with the patient, permit them to stand for a few seconds to assess balance and avoid dizziness.
2. Support the patient by placing one arm around their waist or holding their clothes at the waist.
3. If the patient is using oxygen, tubing should be held to the side, away from the feet.
4. Allow the patient to set the pace. Observe the patient for the need to rest.

Helping the patient from the bed to a wheelchair or bedside commode

1. Place the wheelchair or bedside commode next to the bed (the head of the bed, facing the foot of the bed). LOCK THE BRAKES!
2. Refer to the directions for transferring the patient from sitting to standing.
3. Place your right foot in between the patient's feet.

If you are helping the patient get up or walk, and find you can no longer manage the patient, ease them to the floor slowly. Make the patient as comfortable as possible before going to get help.

Fall Prevention

How to create a safer environment, reduce risk of falls and injury

- Address environment hazards such as removing throw rugs, increase lighting, relocate electrical cords and other clutter.
- Implement alarm systems when appropriate, such as personal alarms/monitors, bed sensors, emergency alert pendants or wrist bands, and call bells.
- Consider sleeping in same room and/or close by for closer supervision at night.
- Address use of walkers, canes, wheelchairs, hospital beds, bedside commodes.
- Consider physical therapy or occupational therapy evaluation for instruction on safety techniques and recommendations regarding assistive devices.

Because hospice patients are particularly vulnerable to falling, the hospice team will address risk factors on an ongoing basis, and stress the importance of maintaining a safe environment whenever possible.

Skin Care

Skin care is important during illness. Patients find they must spend more time resting in bed or lying in one spot for a long time. It is best to try and prevent any skin breakdown, which can cause the patient additional discomfort.

There are several basic ideas to keep in mind when caring for the skin.

- Keep the skin clean
- Keep the skin well moisturized
- Relieve pressure by changing the patient's position

How often should the patient be bathed?

Usually 2-3 times a week is enough. Some patients with very dry skin may not need a full bath more than once a week. If the patient is incontinent, then bathing of the private area may be necessary on a daily basis.

What products are best to use?

Soaps with a high fat content, such as Tone or Dove are the best choices. It is important that the patient be rinsed very well. There are "no rinse" products available for skin and hair.

You will also need several wash clothes and towels. If the patient requires a bed bath, you will find that two basins (from past hospital stays or plastic dishpans) will make things easier. Use one for washing and one for rinsing.

Is lotion necessary?

Most patients have dry skin and this will increase the likelihood of a bed sore developing. Applying lotion after the bath and several times each day keeps the skin in better condition. This is also a good time to notice changes in the patient's skin. If you do notice changes, alert the hospice nurse.

How do I give the patient a bedbath?

1. Prepare the room. Check for drafts and consider turning up the heat.
2. Assemble the supplies needed on a table: basins, lotion, washcloths, towels, soap, and clean clothes.
3. Fill basins with warm water, changing frequently to keep it warm. Add a capful of body oil, if desired.
4. Apply very little soap. A little goes a long way.
5. Wash, rinse well, and dry each area before moving on. Remember to keep the patient covered, except for the area being washed.
6. Wash the patient in this order: face, ears, neck, shoulders, upper chest, arms, back and buttocks. Change water and washcloths.
7. Continue with each leg and foot region. Finish with the lower abdomen and private parts. Remember to rinse well.
8. Wash and dry between skin folds and toes.
9. Apply lotion when the bath is complete. Pay special attention to the back, heels, elbows and hip areas.
10. If you see a red spot that does not go away, tell the hospice nurse and try to keep the patient from lying on the area. Do not rub this area.

Mouth Care

Regular mouth care helps the patient feel better. It also prevents mouth sores and infections. A patient's appetite may also be better with a fresh mouth. A patient who is unable to do their own care will need help. If you have any questions regarding mouth care, speak with the hospice nurse.

Regular mouth care

- Clean the mouth and teeth at least two times a day using a "toothette" or soft toothbrush. This needs to be done even if the patient is not eating or drinking. Use a small amount of toothpaste.
- Do not use mouthwashes that contain alcohol. Use hydrogen peroxide only on advice from the nurse.
- Keep the lips moist with small amounts of Vaseline® or other lubricants.
- Check the patient's mouth for red areas or white patches. Ask the patient if there are any sore areas.
- Use the toothbrush gently, moving from the gums down to the teeth. Be careful about how far back the toothbrush is going. If the brush is placed too far back, the patient may gag.
- If the gums bleed easily, use a "toothette" or cloth instead of a toothbrush.

Dentures

- Loss of weight and aging may change how dentures fit.
- Speak with a dentist regarding measures that will help the dentures fit better.
- Ask the patient, and look every day for sore areas. Report any problems to the hospice nurse.
- Dentures may be removed at night, if this is the patient's habit. Clean the mouth and dentures.
- Rinse the mouth and dentures with water after every meal.

Mouth infections

In addition to poor mouth care, some drugs and treatments can cause mouth infections. The patient will have sore areas in the mouth, redness, or white patches on the gums or tongue. The patient may also have bleeding gums or a sore throat. Report any of these concerns to the hospice nurse.

- Avoid spice or highly seasoned food.
- Use a bland diet.
- Limit use of dentures until the infection is gone.
- Avoid foods and liquids that are very hot or very cold.
- Do careful mouth care after meals and at bedtime.

Dry mouth

- Have the patient sip on liquids frequently during waking hours. Use of ice chips or Popsicles may be helpful.
- To stimulate saliva, use sugarless gum or candy, chewable vitamin C, or pineapple chunks.
- Continue to rinse with baking soda mouthwash or non-alcoholic mouthwash like Biotene®. Do not use mouthwash containing alcohol or hydrogen peroxide.
- The hospice nurse may also suggest an artificial saliva product.

Pain and Symptom Management

Our goal is to make sure you are as comfortable as possible while on our hospice program. When any new symptoms arise during your care, we will strive to achieve the best symptom management, as quickly as possible.

Comfort Care Kit

A Comfort Care Kit may be ordered for the hospice patient.

This kit is to help get you the medications you need as soon as you need them. The Comfort Care Kit is a sealed unit (a bag or a box) that you keep in your home. It remains sealed until you are instructed to open it by your hospice nurse. The kit contains starter doses of the most common medications you might need as your condition changes. The Comfort Care Kit is approved by your doctor at the time it is first brought into your home.

Using the Comfort Care Kit allows you and your family to avoid the inconvenience and anxiety of waiting for your doctor to call in a medication, and also avoids an emergency trip to the pharmacy to pick it up. It allows you almost immediate access to important medications at a time when you need them most.

Please ask your hospice nurse about our Comfort Care Kit, and if it is right for you.

Managing Anxiety/Uneasy Feelings

What is Anxiety?

Anxiety is a feeling or deep sense that things are not right. It is OK to experience anxiety sometimes. Anxiety can help people to focus on completing a task or to deal with a stressful situation. But it is not alright for people to have strong, extreme and lasting worry and fear about everyday life. People who have trouble with activities of daily living because of these feelings should ask for help to manage their anxiety.

What are the Symptoms of Anxiety?

- Fear
- Worry
- Sleeplessness, disturbing dreams or nightmares
- Confusion
- Rapid breathing
- Racing heartbeat
- Tension
- Shaking
- Inability to relax or get comfortable
- Sweating
- Problems paying attention or concentrating

What to Report to the Hospice Team?

- Feelings that may be causing anxiety (like a fear of dying or worrying about money)
- Concerns about illness
- Relationship problems with family or friends
- Spiritual concerns
- Signs and symptoms that anxiety is changing or getting worse

What Can be Done to Help Relieve Anxiety?

The hospice team will try to find the cause for your anxiety.
They will talk with you and your primary care provider about treatment options.

Things you can do:

- Activities that have helped your anxiety in the past.
- Write down your thoughts and feelings.
- Treat physical problems, such as pain, that can cause anxiety.
- Try relaxing activities like deep breathing or yoga.
- Play soothing music.
- Keep your surroundings calm.
- Limit visitors

- Massage your arms, back, hands or feet.
- Count backward slowly from 100 to 0.
- Avoid caffeine and alcoholic beverages.
- Exercise.
- Provide reassurance and support.
- Ask for help from family, friends and other members of your care team.
- Live life one minute at a time.
- Use ordered medications as prescribed.

References

Anxiety Disorders Association of America. Tips to Manage Anxiety and Stress. Available at http://www.adaa.org/tips-manage-anxiety-and-stress. Accessed October 10, 2015.

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Reviewed by the HPNA Education Services Committee June 2011.
Reviewed by the HPNA Professional Development Advisory Council October 2015.

Managing Restlessness

What is restlessness?

- An inability to rest, relax or concentrate
- Extreme restlessness is sometimes called agitation
- A condition that occurs in nearly half of all patients during the last 48 hours of life

What are signs of restlessness?

- Muscle twitching
- Moving around without a known reason
- Pulling at sheets, covers or clothing
- Trying to get out of bed for no known reason
- Fidgeting
- Sleeplessness
- Inability to get comfortable
- Grimacing

What to report to the hospice care team?

- Any of the signs or behaviors listed above
- Inability to administer medications by prescribed method
- Things that make the restlessness worse, for example: loud music
- Things that make the restlessness better, for example: soft music
- Concerns that you may have as a caregiver to cope
- Need for spiritual support
- Situations that might be unsafe

What can be done for restlessness?

The team will try to find the reason for the restlessness and talk with you about treatments.

Things you can do:

- Administer prescribed medications as ordered
- Offer frequent reassurance
- Offer relaxation activities, for example: play soothing music
- Keep things calm, for example: decrease numbers of visitors
- Read favorite stories, poems, etc. in a calm voice
- Hold the person's hand, give them a gentle massage
- Keep the person safe, for example: do not leave the person alone while restless and check frequently when calm
- Understand that restlessness may be a sign that the patient is close to death - let other family members know what is happening

Managing Delirium

What is delirium?

- A sudden change in a person's mental status over a period of hours to days
- Mental clouding with less awareness of one's environment
- Confusion about time, place and person

What are the signs and symptoms of delirium?

- Reversal of sleep and awake cycles
- "Sundowning" or confusion that is worse at night
- Mood swings that may change over the course of a day
- Difficulty focusing attention or shifting attention
- Hallucinations or seeing, hearing or feeling things which are not there
- Agitation and irritability
- Drowsiness and sluggishness
- May be restless and anxious

What to report to the hospice team?

- Any of the signs or behaviors listed above
- Changes in food or fluid intake
- Decrease in urine output
- Change in frequency or type of bowel movements
- Depression
- Wandering
- Withdrawal from people or activities
- Any change in medications the team is unaware of

What can be done for delirium?

Delirium is common at the end-of-life. It has many causes. The team will try to find out what is causing the delirium. The team will discuss treatment options with you. As a caregiver you may:

- Keep the patient safe
- Remind the patient who you are when you assist with caregiving. Tell them what you are going to do. For example, "I am going to help you get out of bed now"
- Offering support such as "I am right here with you"
- Try to maintain a routine and structure
- Avoid asking a lot of questions
- Provide a quiet, peaceful setting, without TV and loud noises
- Play the patient's favorite music
- Keep a nightlight on at night
- If starting a new medication, watch for improvement, worsening or side effects and report to healthcare provider

What to report to the hospice team?

- Any signs or symptoms listed above

Not everyone with delirium has all of the signs and symptoms. Any new problem will be evaluated by the hospice team and new ways to manage the symptoms will be discussed.

The nurse can provide additional information about this condition. Report any changes to the nurse so that they can plan interventions for optimal care.

*Other HPNA Teaching Sheets are available at www.HPNA.org

Control of Pain

Some illnesses or treatments may cause pain. The patient may have pain now, or be worried that they will have pain in the future. Fortunately most pain can be relieved.

What is pain?

Pain is what the patient says it is. No two people feel pain in the same way. Hospice will listen to what the patient tells us their pain is, not necessarily what the family reports the pain as. Pain can be sudden, intense, mild, dull, long-term, deep, etc.

What causes pain?

There are many causes of pain: emotional, physical, and spiritual. Most of the pain we treat in hospice comes from a tumor. The tumor presses and sometimes destroys nerves, bones or body organs. Other conditions that cause pain are arthritis, headaches, past injuries, and many other illnesses. Sometimes what appears to be only physical pain may also be emotional or spiritual. Sometimes physical pain is not managed until the emotional and spiritual issues are addressed.

Why does the hospice team work so hard to relieve pain?

When a patient is relieved of pain, many other problems are relieved as well. It is easier to sleep, eat, move, enjoy your family and do normal activities. Relief of pain helps the patient have less feelings of fear, sadness, helplessness, or anger.

How is pain treated in hospice?

Choosing the right treatment for each patient needs takes skill. Your doctor and the hospice nurse will look for the simplest and most effective pain medication. Unfortunately, sometimes finding the right pain medication takes a little time. Your doctor may have to change dosages, frequency of administration, or try a different medication. Be sure to tell your hospice nurse how the patient feels. This information helps them help the patient. There are many different options for administering pain medication that do not require an IV or injection.

Why does the hospice nurse want pain medication taken on a schedule?

The best way to control pain is to stop the pain before it starts; if the patient waits until the pain is severe, the pain medication has less chance to work well. The goal is to prevent pain.

Will the patient become addicted to the pain medication?

NO! The patient has an illness that causes pain. Taking medication to stop this physical pain is a treatment, not a bad habit. Studies show that pain medication used in this way rarely causes addiction. It is important that each patient be supported with the right kind and amount of pain medication.

What are the side effects of pain medication?

All medications can have side effects, but not all people experience them. People react in different ways. The doctor or hospice nurse can help the patient work through any side effects they may have.

- **Sleepiness**

  This happens when the patient begins taking or increasing a pain medication. After two or three days of following a pain treatment plan, this feeling will often pass. The body adjusts to the change. Remember, pain is tiring and with relief of pain, the patient will sleep. Sometimes there is a delicate balance between being able to provide pain relief without causing some sleepiness. Hospice will work with the patient to determine what are acceptable levels of sleepiness versus pain control.

- **Constipation**
  Pain and other medicines often make the patient constipated.

What is constipation?

- Bowel movements occurring less often than your usual pattern
- Hard stool that may be difficult to pass or increased difficulty moving bowels
- Incomplete passage of stool or straining when trying to have a bowel movement

Constipation can be prevented by:

- Taking laxatives or stool softeners as ordered by your healthcare provider especially if taking opioid pain medication; should be taken on a regularly scheduled basis not just as needed
- Drink plenty of fluids, eat fruits and vegetables if able
- Walk or sit upright after meals which helps with digestion
- Patients should still be having bowel movements even if not eating

What to report to Hospice?

- No bowel movement in two days and date of last bowel movement
- Change in the frequency or consistency of bowel movements
- Abdominal symptoms – pain, cramping, tenderness, nausea, vomiting, bloating, distention, reflux, gas, feeling of fullness
- Blood in stools, diarrhea or oozing stools
- Medication changes since last visit

Reference:
http://hpna.advancingexpertcare.org/wp-content/uploads/2015/04/TS03E-Constipation.pdf

- **Nausea**
  When the patient starts a new medication, there may be a day or two of nausea. Call the hospice nurse, who will arrange for some medications to help the patient during these early days. Do not stop taking the pain medication without speaking to the hospice nurse first.

If the patient can no longer swallow, how will the patient get the pain medication?

There are many other types of medicine that your doctor can order. The doctor and the hospice nurse must look at the patient's needs and current situation before deciding on the best choice.

What else can the patient do for pain?

There are several things to help with pain. Medicine is important, but here are a few examples of other ways to help control pain.

- Soaking in a tub of warm water
- Guided imagery
- Touch, light massage
- Ice packs, especially if there is swelling
- Music
- Relaxation with deep breathing
- Distraction

Nutrition: Issues of Not Eating and Drinking

It is normal for the terminally ill patient to eat and drink very little. When someone is ill, eating becomes less important. Food may be unpleasant to smell or taste, and the desire for food is lost. Nausea can also be a common problem. The kindest thing we can do for the patient is not make them feel ashamed for not wanting to eat. Although mealtime can be a special time for many of us, there are more important ways to spend time with the patient in this final stage of life. How much we care can be shown by respecting the choices the patient is making. Frequent oral care, small sips of fluid, ice chips, and ointment on the lips are all ways to show support to the patient at this stage.

Studies have shown that most terminal patients do not benefit from artificial fluids (IV) or foods (TPN). These measures may cause nausea, vomiting, increased congestion, pain and many other problems. Many families express concern that the patient will "starve" if they are not forced to eat and drink. This is a common concern but, in reality, you will not extend the patient's life by forcing them to eat or drink. Often, people feel helpless over this issue. Remember, it is natural for a patient who is dying to stop eating and drinking. Therefore, it is very important to let the patient take the lead; they know their body.

- Do not force the patient to eat.
- Notice which time of day the patient has more energy and make that mealtime. Many patients do well at breakfast, with less appetite as the day goes on.
- Small meals, using smaller dishes will be less overwhelming for the patient.
- Give the patient some choices—a bowl of pudding or ice cream.
- Increase the calories of foods with cream, butter, cheese, powdered milk added to whole milk, and powered, high protein supplements.
- Leave high calorie snacks within reach of the patient.
- Eating can be tiring, have the patient rest before and after each meal.
- Make the eating experience quiet and pleasant. Candles, flowers, soft music, and good conversation all help.
- Use an instant breakfast drink any time of the day; add ice cream and whole milk.
- Add a bedtime snack—hot chocolate and toast.
- Practice good mouth care; a pleasant tasting mouth will improve the taste of the food.
- If the patient's dentures do not fit properly, speak with a dentist for suggestions.
- What sounded unappealing today may sound fine tomorrow.
- Many patients lose their taste for coffee, tea, fried foods and alcohol. Common acceptable foods are pasta, milk products, breads, custards, fruit and soups.
- If nausea is a problem, use small portions, salty (not sweet) dry foods like toast, ginger ale, and clear liquids if the nausea continues.
- If nausea is a problem, talk with the hospice nurse about a medication that will help control the nausea.
- If the patient has mouth sores, use soft food that is neither hot or cold. Stay away from salty foods and liquids containing alcohol.
- DO NOT take it personally if the patient does not what to eat what you have prepared or suggested. Let the patient take the lead.

Nausea and Vomiting

Nausea and vomiting are common problems and may be a result of:

- Treatments
- Medicine
- Constipation
- Illness or infection

The problem can be helped by:

- Taking laxatives as ordered to avoid constipation
- Staying still and getting adequate rest
- Using the anti-nausea medicine as ordered by your healthcare provider
- Avoiding strong odor such as perfumes and deodorizers
- Slowing sipping carbonated drinks that have gone flat or peppermint tea
- Avoid eating and drinking immediately after vomiting
- Once vomiting has stopped, start with ice chips or Popsicles
- Continue clear liquids as tolerated (water, chicken broth, JELL-O) for 24 hours; keep amounts small
- Provide foods as requested by patient in small, frequent amounts
- If nauseous after taking medications, be sure it is being taken correctly and with a lot of fluid; some medication needs to be taken with food.

What to report to Hospice?

- Amount and frequency of nausea
- Description of vomited fluid (bright red, dark brown, green)
- Altered mental status
- Abdominal pain and bloating relieved by vomiting
- Medication changes since last visit

Reference:

https://hospiceofthevalleys.org/wp-content/uploads/2014/05/PT17E-Nausea-Vomiting.pdf

Fluid Retention

Patients often have fluid buildup in their legs, ankles, feet and hands, as well as other places. This is called edema. The doctor or nurse who is familiar with the patient's case may be able to give you more information.

Here are three common causes of edema:

- The heart is weaker
- There is less protein in the diet
- There is less moving around

There are several things you do to help relieve the fluid buildup:

- Elevate the area affected above the heart if possible, and if not, elevate as high as possible.
- Avoid tight clothing, belts, rings, socks or shoes.
- It may be helpful to avoid salt. Check foods for high salt content.
- The doctor may order a diuretic, or "water pill". If so, make sure the patient takes it.
- Have patient move around if able.
- If the patient is unable to get out of bed, have the hospice nurse show each caregiver how to do exercises with the patient.

Shortness of Breath

When a patient has trouble breathing, it can be frightening for the patient as well as the caregiver. If shortness of breath is a result of being active, it may be easy to relieve just by resting. Here are some other ideas that may help the patient breathe easier.

- Stay with the patient, be calm and reassuring.
- Help the patient to a position of comfort. This will probably be in a sitting position, leaning forward slightly.
- Help the patient to slow the rate of their breathing. It helps to encourage slower, but deeper breathing.
- Look the patient in the eye and calmly remind them to breath in through the nose and out through their mouth.
- Remain with the patient, performing this breathing pattern with them.
- Encourage the relaxation of the shoulders, back and arms. Use touch and massage if the patient agrees.
- Open a window or use a fan to create movement of air around the patient.
- Some patients use relaxing music to slow their breathing and feel more comfortable. Other patients prefer a quite place.
- Pace activities so that the patient has rest periods during the day.
- Have the patient sit whenever possible while doing normal activities such as brushing teeth, showering, shaving, or talking on the phone.
- Talk to the hospice nurse if the patient is having shortness of breath, increased temperature, yellow sputum, or if the above recommendations do not help.

Relaxation Techniques

Prepare the area

1. Dim the lights.
2. Turn off the TV.
3. Use an answering machine or take the phone off the hook.
4. Play relaxing music.

Find a relaxing position

1. Sitting, feet flat on the floor, hands resting at sides.
2. Lying down, legs stretched out and flat on the bed, hands resting at side.
3. Limbs should not be crossed (creates tension). Hands should be open, not in a fist.
4. Eyes closed. Check tension in face by tightening then relaxing facial muscles.

As the music plays

1. Allow the bed or chair to support you.
2. Tense and then relax different muscle groups to check for a truly relaxed position.
3. Allow the music to move through you. It may help to focus on one aspect of the music that is particularly relaxing.

Breathing

1. Inhale through the nose slowly.
2. Feel the lungs fill complete with air.
3. Exhale slowly through the mouth, as if the opening of the mouth were only the size of a pin.
4. Think “relaxation in” and “relaxation out” with each breath.

Begin to think of a place and time where relaxation, happiness, and safety are felt

1. Look all around this place.
2. Smell the aromas.
3. Hear the sounds.
4. Taste foods.
5. Feel textures.
6. Remind yourself to relax and enjoy this place.

Prepare to leave this place of relaxation, happiness, and safety

1. Keep your eyes closed.
2. Feel the clothes and surfaces next to your skin.
3. Smell the familiar odors.
4. Hear the sounds of the room.
5. Open your eyes when you are ready.

Fade the music and continue to stay relaxed and rest for at least 30 minutes. Relaxation takes practice. A hospice team member will be glad to help you learn this process. It is helpful to practice relaxation at the same time each day.

Tips for the Caregiver

For most people, taking care of a person who is seriously ill is a new experience. As with all new experiences, there are also new feelings. You should know that these feelings are not unique to you alone, but shared by many who care for a terminally-ill person. Accept these feelings. They are neither good nor bad, they are your feelings.

- **You may feel guilty or angry**
  Expressing negative emotions can be difficult in these times of stress. Avoiding discussions of painful feelings puts up walls. Keep the two-way relationship going.

- **There may be times of humor and laughter**
  As strange as it may sound, a good joke is great medicine. Take the time to see the humor in the moment, it helps everyone feel good.

- **There is much to be done and feeling overwhelmed is common**
  Be specific about your needs when friends and family ask "what can I do to help?" People often want to help, but need specific tasks. Accept the offer, give the necessary directions, and then trust them with the responsibility of your request. Prioritize, because you cannot do it all. Accept that some of your everyday tasks will go undone, or get done less frequently.

- **Caring for another feels good**
  Meeting needs and sharing care tasks that bring comfort to the patient often helps us see the best in ourselves and in each other.

- **Anxious feelings and worries often intrude on thoughts and sleep time**
  Share your worries with your hospice team. They can often provide the information or reassurance you need. They have experience to share with you and they want to help reduce your anxiety.

- **You may feel resentment toward others because they are able to do everyday things while you are busy caring for the patient**
  This is hard and it's even harder when you are losing a loved one and they are not. Don't go through this alone. Draw in your circle of support, and take time for yourself. Plan time off from caregiving. Celebrate special events, holidays, and occasions.

- **Appreciate yourself**
  What you are doing is very special. Give yourself credit for this caring work you are providing. It is truly a gift from the heart.

- **What can you do for yourself?**
  - Go for short walks
  - Write in a journal
  - Plan for the future
  - Seek spiritual assistance
  - Talk to someone, such as family, friends, or clergy
  - Seek help from your family, friends, and/or a hospice volunteer, to arrange time to spend doing things you enjoy

Spiritual Care

Spirituality is central to what makes us human. In recognizing that we are much more than physical beings, hospice provides spiritual care to any patient or family.

A chaplain can:

- Assist with exploration with oneself, others, God, a higher power, and nature.
- Help the patient and family work through anxiety, fear, pain, frustration, and confusion.
- Act as a companion to patient and family on the journey towards death.
- Explore the meaning and sense of being connected with life and death.
- Assist the patient or family to reconnect with their church or congregation for support.
- Assist the patient and family with the preparation of funeral or memorial services.

Spiritual care is useful as a means of increasing the patient's physical comfort. The following signs and symptoms may indicate a need for spiritual support:

- Sleeplessness
- Substance abuse
- Acting out
- Displacement
- Projection
- Depression
- Over sleeping
- Affect change

If you are interested in a visit by the spiritual counselor, you may talk to your hospice nurse or social worker, or you may call hospice and ask for the chaplain.

Volunteer Assistance

Hospice trains men and women interested in caring for others. Each volunteer is unique in their interests, skills, life experience, and talents. Volunteers receive extensive training and are individually evaluated. The hospice team will discuss the use of a volunteer with you before asking a volunteer to join the team.

Among the many ways hospice volunteers help:

- Companion for the patient
  - Assist with arts, crafts and sewing
  - Play games, cards, checkers, or do puzzles
  - Read books, newspapers or magazines
  - Watch TV
- Provide breaks so the caregiver may leave for short intervals
- Transportation to appointments, shopping, or place of worship
- Errands, such as grocery shopping
- Light housekeeping, laundry and simple meal preparation
- Letter writing to friends and family
- Assistance with hobbies or sports
- Organize bills and personal files
- Outings for patient
- Record audio tapes to send to family members
- Specialized services may be available. Ask your hospice nurse for more information

Final Days

The staff of hospice supports you in caring for your loved one during the final stages of life. Everyone's life is unique, and so is everyone's journey toward death. This is a difficult time; people may not know what to expect. We hope this information will help you be more informed and prepared.

From one to three months before death, it is common for a person to focus inward. There is a shift away from the outer, more social world. This is not a withdrawal of love, but a need to focus energy inward. Your presence is still very important to your loved one, and even though you may be well informed about the process, it is natural for you to also feel confused and upset.

Signs and symptoms of approaching death

As the patient prepares for the final stages of life, you many notice physical changes taking place. Not all of these signs will appear at the same time, and some may not appear at all. Your hospice team will help you identify these changes and support you through this difficult time.

Call if you see any of the following signs or symptoms of approaching death.

- The patient will have decreased need for food and drink because the body functions are slowing down gradually. There may be difficulty in swallowing. The mouth may become dry and will need to be kept moist. The patient will not experience hunger, the body no longer needs nutrition.
- The patient will gradually spend more time sleeping during the day, and at times be difficult to arouse. This symptom is a result of a change in the body's metabolism. Try to spend time with the patient during the times of greatest awareness.
- It is common for a person to become restless and pull at the bed linens. The patient may become increasingly confused about time, place and identify of close and familiar people. Reminders as to what day and time it is, and who is in the room, will be comforting. Soft music and dim lights may be calming. Keep the side rails on the bed up for safety.
- The patient may have visions of people and things you cannot see. Visions are not necessarily frightening to the patient, and are often comforting.
- Incontinence (loss of control) of urine and bowel movements may become a problem. Your hospice nurse can help you obtain pads to place under the patient for more comfort and cleanliness. Your nurse may suggest a catheter (a tube placed in the bladder). You may notice a decrease in the amount of urine and it will be darker in color.
- The patient may have moist-sounding breathing. This is caused by relaxed vocal cords and a small amount of oral secretions collecting in the back of the throat. The patient does not feel any discomfort from this, and may not even be aware of it. Elevating the bed of the bed, or turning the patient on their side will usually quiet the breathing sounds.
- Clarity of hearing and vision may change. Keep a soft light on in the room. Assume that the person can hear, since hearing is thought to be the last of the senses to diminish. Explain what you are doing.
- The patient's arms and legs may become cool to the touch and bluish in color. You may notice that the underside of the body is much darker in color. These symptoms are a result of blood circulation slowing down, and do not necessarily indicate that the person is too cold. Fevers are common as well.

- You may notice a change in breathing patterns. There may be 10-30 second periods of no breathing. This is referred to as periods of apnea. This symptom is very common and may occur in the final stages of life.
- Pain and discomfort may diminish as death approaches, but continue to give medications as directed by the hospice nurse.

Final Arrangements

Your hospice nurse, social worker, or bereavement coordinator are available to assist you as needed during this difficult time. Your hospice team will ask you to identify a funeral home.

Your funeral home can be very helpful in planning a memorial or funeral service that will honor the wishes of your loved one. The funeral home will also provide you with information and guidance on writing an obituary to remember your loved one.

Please consider identifying hospice for your memorial contributions. Memorial contributions made in the memory of loved ones to hospice will touch the lives of future hospice patients and families.

What to do at the time of death

You do not have to call hospice immediately. If you prefer, you may spend some quiet time with your loved one. Call us when you are ready.

- If you are having a hard time and don't know what to do first, call hospice.
- **Do not call 911, the police, fire department, or ambulance.**
- Call your hospice nurse.

  In Monroe County
  Monday through Friday, 8:00 a.m. to 4:30 p.m. at **585-787-8315**
  All other times (day or night) call **585-787-2233** and ask to speak to the hospice nurse on call.

  In Ontario or Yates Counties
  800-253-4439 at any time.

- The hospice nurse will offer to make a visit to pronounce the time of death and provide support. If you feel you do not need the nurse to visit, your funeral home will be called when you are ready. The time of death, as it will appear on the death certificate, is when the hospice nurse visits or when the funeral home arrives.
- If a visit is not made by the hospice nurse, the nurse can still assist you by making the necessary telephone calls to the following:
  1. Funeral Home
  2. Physician
  3. Other services (home health aide, social worker, pastoral care, and volunteers)
  4. Vendors (for equipment)
  5. Any other calls as requested by the family

Disposal of controlled substances and prescription drugs

The hospice nurse or designee will provide you with instructions regarding the proper disposal of all controlled substances in the home upon discontinuation of the use of the controlled substance, or at the time of the patient's death. Controlled substances may be disposed of using one of the following methods.

Option 1

Call your city or county government's household trash and recycling service (see the blue pages in your phone book) and ask if a drug take-back program is available in your community. Some counties hold household hazardous waste collection days where prescription and over-the-counter drugs are accepted at a central location for proper disposal.

Information is also available online at **http://www.dec.ny.gov/chemical/63826.html#Central**

Option 2

Take your prescription drugs out of their original containers.

- Mix the drugs with an undesirable substance, such as cat litter or used coffee grounds. Put the mixture into a disposable container with a lid, such as an empty margarine tub, or a sealable bag. Do not conceal discarded drugs in food, to prevent consumption by scavenging humans, pets, or wildlife.
- Conceal or remove any personal information, including Rx numbers, on the empty containers by covering with permanent marker or duct tape, or by scratching it off.
- The sealed container with the drug mixture and the empty drug containers can be placed in the trash.

- Patches need to be cut open, squeezed onto a piece of paper towel or toilet tissue, cut into pieces and disposed of in the trash.
- It is recommended that the following medications be flushed down the sink or toilet: Diuladid/Hydromorphone (tablets or liquid), Duragesic/Fentanyl patch, Morphine sulfate/Morphine (tablets or liquid), MS Contin (tablets), Oxycodone Hydrochloride (tablets, capsules, liquid), Oxycontin (tablets).

Bereavement Support

- One of the special services that hospice offers is the Bereavement Program. Because patients and their families are important to us, our relationships with the family continues after the patient's death.
- It is common and normal for anyone who has experienced the death of a loved one to have many emotions and feelings that are intense, confusing, and sometimes overwhelming.
- Some of these feelings include denial, anger, depression, abandonment, and guilt. During the bereavement period, there will be difficult times, as well as times when growth and healing are felt. Each person moves through the grief process in a unique way. There will be variations within each family. Reaching out for each other, restoring old relationships, or creating new ones, can help in the healing process. Those of us involved in hospice work find that hope, however it may be defined, is an important emotion during this time.
- There is no way for the patient (whose death may be near) or the surrounding loved ones, to be fully prepared for the loss. The knowledge that physical death does not diminish shared memories may give some comfort during this difficult time.
- Please contact hospice at any time if you are having difficulty after the death of your loved one, and ask for the bereavement coordinator.

Family Grievance Procedures

Hospice is committed to respond to any and all concerns or complaints. We encourage you to speak with us as soon as you have a concern, before it might become a big problem for you. If you have a complaint about the care or services provided, we urge you to take the following steps.

1. Talk the problem over with your hospice nurse or social worker. Most problems can be resolved this way.
2. If your problem is not resolved, or you would just like to talk to someone else, please call hospice and ask for the Hospice Director.
2. If a problem occurs in the evening or on the weekend, and you have talked to the on-call staff without resolution, please call back and ask to speak with the Hospice Administrator on-call.
4. If your complaint has still not been addressed to your satisfaction, call the CEO at **585-274-4250**.
5. If you are not satisfied with the results of the steps taken above, you have the right to refer the problem to the New York State Department of Health Hotline, **1-800-628-5972,** which can be called 24 hours a day, seven days a week. The hotline is manned by the Division of Home and Community Base Care staff, from 10:00 am to 4:00 pm, Monday through Friday. You may leave a message if you are calling during off hours.

Appendix

Patient Name ______________________________

Patient # ______________________________

Episode # ______________________________

☐ **Visiting Nurse Service**

☐ **Ontario-Yates Hospice**

Informed Consent and Hospice Notice of Election Form

My signature on this statement certifies that I have received an explanation of the services provided by the hospice, and that I consent to receive care from the hospice, to begin on the start of care date. I have received, reviewed, and had explained to me information on:

- Advance directives (e.g., Appointing your Health Care Agent, New York State Proxy Law, DNR, MOLST)
- Eligibility for hospice care
- Medicare/Non Medicare Hospice Benefit Election
- Notice of Privacy Practices
- Patient Rights & Responsibilities
- Available hospice services

Goals of the Hospice Program

Hospice care for my terminal illness is palliative (comfort-oriented), not curative in its goal. Hospice care emphasizes relief from my symptoms, such as pain and discomfort. It addresses my emotional and spiritual needs and those of my family.

Hospice Services

Services may include, but are not limited to, nursing care, physician care, medical social work services, counseling services, spiritual care, home health aide services, volunteer services, physical therapy, occupational therapy, speech therapy, nutritional counseling, medical supplies, durable medical equipment, and medications for palliation of symptoms related to terminal diagnosis. The Hospice Interdisciplinary Group determines the exact services offered to me based on my needs and those of my family, and records these in my hospice plan of care. Bereavement follow-up will be offered for a period of thirteen months; services may include counseling and support groups.

Attending Physician

I acknowledge that the identified attending physician, ______________________ is my/my representative's choice.

Caregiver

Hospice services do not replace care by my family or others, but provide professional and volunteer support for my hospice care.

I authorize ______________________________ to act as my primary caregiver to work with Hospice Interdisciplinary Group to ensure a safe plan of care by others.

Inpatient Hospice Care

Short-term inpatient hospice care is provided at a contracted facility for intensive symptom management as determined by the Hospice Interdisciplinary Group. If I choose to be admitted to a hospital or a facility that does not have a contract with hospice or has not been prearranged by hospice, that admission will be considered a decision to revoke my hospice benefit election.

Financial Responsibility

1. The Medicare/Medicaid Hospice benefit/private health insurance charges for hospice care have been explained to me and I understand the services offered. I have been given the opportunity to discuss any financial concerns I may have.
2. I understand that hospice only pays for services, equipment, medications, and supplies that are related to my terminal diagnosis and included in my plan of care.
3. I understand that my Medicare/Medicaid/Private Insurance will not cover treatments intended to cure my terminal illness, prescription drugs to cure or prolong life, ambulance services, emergency room visits, or hospitalizations unless they are arranged by hospice or they are unrelated to my terminal illness. I understand that I must contact hospice before I pursue any of these services, or I will have to pay the entire cost.
4. I understand that I am financially responsible for services, equipment, medications, and supplies related to the terminal illness, not preauthorized by hospice. Hospice is not responsible for any care not preauthorized by their Hospice Interdisciplinary Group.
5. I understand that any hospice services provided by another hospice other than hospice will not be covered by my Medicare/Medicaid/Private Insurance unless provided under arrangements made by hospice.

6. If I have Medicare Part A, I understand that the Medicare Hospice Benefit takes the place of Medicare Part A for treatment of my terminal illness and I waive the rights to Medicare benefits related to my terminal illness while enrolled in hospice.
7. I understand that payment to my attending physician and treatment for medical conditions unrelated to my terminal illness will continue to be made by my regular health insurance plan. I can continue to receive services covered by my health insurance plan for treatment of any condition not related to the terminal illness for which I am choosing hospice care.

Hospice Plan of Care

I understand that I and my family are encouraged to participate with the Hospice Interdisciplinary Group in establishing the variety, frequency, and intensity of services I use. I also understand that I have access to my hospice plan of care and may attend the Interdisciplinary Group meetings to participate in discussion about my services needed or used.

Eligibility and Benefit Periods

The Medicare hospice benefit consists of two initial 90-day benefit periods and an unlimited number of 60-day benefit periods. I acknowledge that my eligibility for hospice care is determined at the start of the first benefit period, and for each subsequent benefit period, using Medicare criteria for hospice eligibility.

Discharge from Hospice

I understand that hospice care may be discontinued if the Hospice Interdisciplinary Group determines that I no longer meet the Medicare hospice eligibility criteria. I will receive a minimum of 48 hours' notice of discharge and I have the right to appeal this decision. In the future, if I am deemed to be eligible for hospice care, I may choose to re-elect my hospice benefit.

Transfer to Another Hospice Program

I may choose to receive hospice care from another hospice program; however, I understand that I may change my enrollment to another hospice program once during a benefit period. To change programs, I must inform hospice so that arrangements for the transfer can be made.

Revocation

I understand that I may revoke this consent and notice of election and withdraw from the hospice program at any time by signing a revocation statement, which will be given to me upon my request. If I revoke this election, I understand that I will forfeit any remaining days of the election period. My insurance benefit previously waived by my electing hospice benefit will be fully reinstated. I may choose to re-elect my hospice benefit at a later date if eligible.

Release of Information

Hospice will need to access medical records concerning my illness and to consult with my medical providers. I authorize any medical providers who have attended to me or any hospital, skilled facility, home health agency, or health organization that has cared for me to furnish hospice, or its representative, with any and all information which may be requested regarding my past or present medical condition. I authorize hospice, in its discretion, to examine, release, and discuss, confidentially, my case history as appropriate to fulfill its legal obligations and to educate its directors, staff, and associates. I consent to the release of information required for processing claims for hospice care and medical benefits from my medical record at hospice to Medicare/Medicaid fiscal intermediary, government agencies, or insurance companies.

Private Insurance Authorization

I hereby authorize any insurer or other organization from whom I am entitled to receive payment for hospice services, to make payment for such services directly to hospice. I accept responsibility for any deductibles and co-payments that apply.

I certify that I have read and understand this Informed Consent and Hospice Notice of Election Form in its entirety. I have also read and understand additional information provided by the hospice. I hereby authorize services to be provided by the hospice to begin on the hospice start of care date.

SIGNATURE, PATIENT OR LEGAL REPRESENTATIVE	NOTICE OF ELECTION DATE
SIGNATURE, HOSPICE REPRESENTATIVE	DATE

Patient Name ______________________________

Patient # ______________________________

Episode # ______________________________

☐ **Visiting Nurse Service**

☐ **Ontario-Yates Hospice**

Hospice Family Contact Sheet

Please complete the following information to identify family members for bereavement services and Release of Information.

Name: ______________________________ **Phone:** ________________

Address: ______________________________

Relationship to patient:______________________________

☐ Bereavement ☐ Release of Information

Name: ______________________________ **Phone:** ________________

Address: ______________________________

Relationship to patient:______________________________

☐ Bereavement ☐ Release of Information

Name: ______________________________ **Phone:** ________________

Address: ______________________________

Relationship to patient:______________________________

☐ Bereavement ☐ Release of Information

Optum

Instructions for patient/family member for medications paid for by Hospice.

Present the card

Present the Optum prescription benefit card when dropping off or picking up your prescriptions. Your card can be used at most national chain store pharmacies, Wegmans, and many independently-owned pharmacies.

Inform the pharmacy

If you forget the card, inform the pharmacy that the medications should be covered by hospice. You may have to provide the patient's name, social security number, date of birth, and gender to obtain the medication.

Coverage declined

If you are billed for medication that should be covered by hospice, please ask the pharmacy to call us. We are available 24 hours a day, even on weekends and holidays.

Please note:

- Not all patient medications are covered by hospice. **The patient is responsible for the payment of any medications not related to the terminal illness and not covered by hospice.** If you have any questions regarding this, please discuss it with your hospice nurse.
- Hospice covered prescriptions are limited to a maximum 15-day supply unless otherwise noted by hospice.

Medication Schedule

MEDICATION NAME	HOSPICE APPROVED	DOSE OR # OF TABS	FREQUENCY	TIMES OF DAY TO TAKE MEDICATION	PURPOSE	SIDE EFFECTS

Advance Directive Forms

Planning in advance for your medical treatment

Your right to decide about treatment

Adults in New York State have the right to accept or refuse medical treatment, including life-sustaining treatment. Our Constitution and state laws protect that right. This means you have the right to request or consent to treatment, to refuse treatment before it has started, and to have treatment stopped once it has begun.

Planning in advance

Because of illness or injury, sometimes people are unable to talk to a doctor and decide about treatment for themselves. You may wish to plan in advance to make sure that your wishes about treatment will be followed if you become unable to decide for yourself, for a short or long period of time. If you don't plan ahead, family members or other people close to you may not be allowed to make decisions for you and follow your wishes.

In New York State, appointing someone you can trust to decide about treatment if you become unable to decide for yourself is the best way to protect your treatment wishes and concerns. You have the right to appoint someone by filling out a form called a Health Care Proxy. A copy of the form and information about the Health Care Proxy are available from your health care provider. There is also a form on page 58.

If you have no one you can appoint to decide for you, or do not want to appoint someone, you can also give specific instructions about treatment in advance. Those instructions can be written and are often referred to as a Living Will.

You should understand that general instructions about refusing treatment, even if written down, may not be effective. Your instructions must clearly cover the treatment decisions that must be made. For example, if you just write down that you do not want "heroic measures," the instructions may not be specific enough. You need to state the kind of treatment you do not want, such as a respirator, or chemotherapy, and describe the medical condition when you would refuse the treatment, such as when you are terminally ill or permanently unconscious with no hope of recovering. You can also give instructions orally, or by discussing your treatment with your doctor, family members, or others close to you.

Putting things in writing is safer than verbal instructions, but neither method is as effective as appointing someone to decide for you. It is often hard for people to know in advance what will happen to them, or what their medical needs will be in the future. If you choose someone to make decisions for you, that person can talk to your doctor and make decisions that they believe you would have wanted, or that are best for you, when needed. If you appoint someone and also leave instructions about treatment in a Living Will, in the space provided on the Health Care Proxy form or in some other manner, the person you select can use these instructions as guidance to make the right decision for you.

Deciding about cardiopulmonary resuscitation

Your right to decide about treatment also includes the right to decide about cardiopulmonary resuscitation (CPR). CPR is an emergency treatment to restart the heart and lungs when your breathing or circulation stop. Sometimes doctors and patients decide in advance that CPR should not be performed, and the doctor gives the medical staff an order not to resuscitate (DNR order). If your physical or mental conditions prevent you from deciding about CPR, someone you appoint, your family members, or others close to you can decide. A brochure on CPR and your rights under New York law is available from your health care provider.

Health Care Proxy

Appointing your Health Care Agent in New York State

The New York Health Care Proxy Law allows you to appoint someone you trust—for example, a family member or close friend—to make health care decisions for you if you lose the ability to make decisions yourself. By appointing a health care agent, you can make sure that health care providers follow your wishes. Your agent can also decide how your wishes apply as your medical condition changes. Hospitals, doctors and other health care providers must follow your agent's decisions as if they were your own. You may give the person you select as your health care agent as little or as much authority as you want. You may allow your agent to make all health care decisions, or only certain ones. You many also give your agent instructions that he or she has to follow. This form can also be used to document your wishes or instructions with regard to organ and/or tissue donation.

About the Health Care Proxy Form

1. This form gives the person you choose as your agent the authority to make all health care decisions for you, including the decision to remove or provide life-sustaining treatment, unless you say otherwise in this form. "Health Care" means any treatment, service or procedure to diagnose or treat your physical or mental condition.
2. Unless your agent reasonably knows your wishes about artificial nutrition and hydration (nourishment and water provided by a feeding tube or intravenous line), he or she will not be allowed to refuse or consent to those measures for you.
3. Your agent will start making decisions for you when your doctor determines that you are not able to make health care decisions for yourself.
4. You may write on this form examples of the types of treatments that you would not desire and/or those treatments that you want to make sure you receive. The instructions may be used to limit the decision making power of the agent. Your agent must follow your instructions when making decisions for you.
5. You do not need a lawyer to fill out his form
6. You may choose any adult 18 years of age or older, including a family member or close friend, to be your agent. If you select a doctor as your agent, he or she will have to choose between acting as your agent or as your attending doctor because a doctor cannot do both at the same time. Also, if you are a patient or resident of a hospital, nursing home or mental hygiene facility, there are special restrictions about naming someone who works for that facility as your agent. Ask staff at this facility to explain those restrictions.
7. Before appointing someone as your health care agent, discuss it with him or her to make sure that he or she is willing to act as your agent. Tell the person you choose that he or she will be your health care agent. Discuss your health care wishes and this form with your agent. Be sure to give him or her a signed copy. Your agent cannot be sued for health care decisions made in good faith.
8. If you have named your spouse as your health care agent and you later become divorced or legally separated, your former spouse can no longer be your agent by law, unless you state otherwise. If you would like your former spouse to remain your agent, you may note this on your current form and date it or complete a new form naming your former spouse

9. Even though you have signed this form, you have the right to make health care decisions for yourself as long as you are able to do so, and treatment cannot be given to you or stopped if you object, nor will your agent have any power to object.
10. You may cancel the authority given to your agent by telling him or her or your health care provider orally or in writing
11. Appointing a health care agent is voluntary. No one can require you to appoint one.
12. You may express your wishes or instructions regarding organ and/or tissue donation on this form.

Frequently asked questions

Why should I choose a health care agent?

If you become unable, even temporarily, to make health care decisions, someone else must decide for you. Health care providers often look to family members for guidance. Family members may express what they think your wishes are related to a particular treatment. However, in New York State, only a health care agent you appoint has the legal authority to make treatment decisions if you are unable to decide for yourself. Appointing an agent lets you control your medical treatment by:

- Allowing your agent to make health care decisions on your behalf as you would want them decided.
- Choosing one person to make health care decisions because you think that person would make the best decisions.
- Choosing one person to avoid conflict or confusion among family members and/or significant others. You may also appoint an alternate agent to take over if your first choice cannot make decisions for you.

Who can be a health care agent?

Anyone 18 years of age or older can be a health care agent.

How do I appoint a health care agent?

All competent adults, 18 years of age or older, can appoint a health care agent by signing a form called a Health Care Proxy. You don't need a lawyer or a notary, just two adult witnesses. Your agent can not sign as a witness, nor can your alternate agent. You may use the form on page 58, but you don't have to.

When would my health care agent begin to make health care decisions for me?

Your health care agent would begin to make health care decisions after your doctor decides that you are not able to make your own health care decisions. As long as you are able to make health care decisions for yourself, you will have the right to do so.

What decisions can my health care agent make?

Unless you limit your health care agent's authority, your agent will be able to make any health care decisions that you could have made if you were able to decide for yourself. Your agent can agree that you should receive treatment, choose among different treatments, and decide that treatments should not be provided, in accordance with your wishes and interests. However, your agent can only make decisions about artificial nutrition and hydration (nourishment and water provided by feeding tube or intravenous line) if he or she knows your wishes, from what you have said or written. The Health Care Proxy form does not give your agent the power to make non-health care decisions for you, such as financial decisions.

Why do I need to appoint a health care agent if I'm young and healthy?

Appointing a health care agent is a good idea even though you are not elderly or terminally ill. A health care agent can act on your behalf if you become even temporarily unable to make your own health care decisions (such as might occur if you are under general anesthesia, or have become comatose because of an accident). When you are able to make your own health care decisions again, your health care agent will no longer be authorized to act.

How will my health care agent make decisions?

Your agent must follow your wishes, as well as your moral and religious beliefs. You may write instructions on your Health Care Proxy form or simply discuss them with your agent.

How will my health care agent know my wishes?

Having an open and frank discussion about your wishes with your health care agent will put him or her in a better position to serve your interests. If your agent does not know your wishes or beliefs, your agent is legally required to act in your best interest. Because this is a major responsibility for the person you appoint as your health care agent, you should have a discussion with the person about what types of treatments you would or would not want under different types of circumstances, such as:

- Whether you would want life support initiated/continued/removed if you are in a permanent coma
- Whether you would want treatments initiated/continued/removed if you have a terminal illness
- Whether you would want artificial nutrition and hydration initiated/withheld, continued or withdrawn, and under what types of circumstances

Can my health care agent overrule my wishes or prior treatment instructions?

No. Your agent is obligated to make decisions based on your wishes. If you clearly expressed particular wishes, or gave particular treatment instructions, your agent has a duty to follow those wishes or instructions unless he or she has a good faith basis for believing that your wishes changed or do not apply to the circumstances.

Who will pay attention to my agent?

All hospitals, nursing homes, doctors and other health care providers are legally required to provide your health care agent with the same information that would be provided to you and to honor the decisions by your agent as if they were made by you. If a hospital or nursing home objects to a treatment option (such as removing certain treatment), they must tell your agent BEFORE or upon admission, if reasonably possible.

What if my health care agent is not available when decisions must be made?

You may appoint an alternate agent to decide for you if your health care agent is unavailable, unable, or unwilling to act when decisions must be made. Otherwise, health care providers will make health care decisions for you that follow instructions you gave while you were still able to do so. Any instructions that you write on your Health Care Proxy form will guide health care providers under these circumstances.

What if I change my mind?

It is easy to cancel your Health Care Proxy, to change the person you have chosen as your health care agent, or to change any instructions or limitations you have included on the form. Simply fill out a new form. In additions, you may indicate that your Health Care Proxy expires on a specified date or if certain events occur. Otherwise, the Health Care Proxy will be valid indefinitely. If you choose your spouse as your health care agent, or as your alternate, and you get divorced or legally separated, the appointment is automatically cancelled. However, if you would like your former spouse to remain your agent, you may note this on your current form and date it, or complete a new form naming your former spouse.

Can my health care agent be legally liable for decisions made on my behalf?

No. Your health care agent will not be liable for health care decisions made in good faith on your behalf. Also, he or she cannot be held liable for costs of your care, just because he or she is your agent.

Is a Health Care Proxy the same as a living will?

No. A living will is a document that provides specific instructions about health care decisions. You may put such instructions on your Health Care Proxy form. The Health Care Proxy allows you to choose someone you trust to make health care decisions on your behalf. Unlike a living will, a Health Care Proxy does not require that you know in advance all the decisions that may arise. Instead, your health agent can interpret your wishes as medical circumstances change and can make decisions you could not have known would have to be made.

Where should I keep my Health Care Proxy form after it is signed?

Give a copy to your agent, your doctor, your attorney, and any other family members or close friends. Keep a copy in your wallet or purse, or with other important papers, but not in a location where no one can access it, such as a safe deposit box. Bring a copy if you are admitted to the hospital, even for minor surgery, or if you undergo outpatient surgery.

May I use the Health Care Proxy form to express my wishes about organ and/or tissue donation?

Yes. Use the optional organ and tissue donation section on the Health Care Proxy form and be sure to have the section witnessed by two people. You may specify that your organs and/or tissues be used for transplantation, research, or educational purposes. Any limitation(s) associated with your wishes should be noted in this section of the proxy.

Failure to include your wishes and instructions on your Health Care Proxy form will not be taken to mean that you do not want to be an organ and/or tissue donor.

Can my health care agent make decisions for me about organ and/or tissue donation?

No. The power of a health care agent to make health care decisions on your behalf ends upon your death. Noting your wishes on your Health Care Proxy form allows you to clearly state your wishes about organ and tissue donation.

Who can consent to a donation if I choose not to stat my wishes at this time?

It is important to note your wishes about organ and/or tissue donation so that family members who will be approached about donation are aware of your wishes. However, New York Law provides a list of individuals who are authorized to consent to organ and/or tissue donation on your behalf. They are listed in order of priority: your spouse, a son or daughter 18 years of age or older, either of your parents, a brother or sister 18 years of age or older, a guardian appointed by a court prior to the donor's death, or any other legally authorized person.

Health Care Proxy

Item (1)

Write the name, home address, and telephone number of the person you are selecting as your agent.

Item (2)

If you want to appoint an alternate agent, write the name, home address, and telephone number of the person you are selecting as you alternate agent.

Item (3)

Your Health Care Proxy will remain valid indefinitely unless you set an expiration date or condition for its expiration. This section is optional and should be filled in only if you want your Health Care Proxy to expire.

Item (4)

If you have special instructions for your agent, write them here. Also, if you wish to limit your agents authority in any way, you may say so here or discuss them with your health care agent. If you do not sate any limitations, your agent will be allowed to make all health care decisions that you could have made, including the decision to consent to or refuse life-sustaining treatment.

If you want to give your agent broad authority, you may do so on the form.

Simply write:

I have discussed my wishes with my health care agent and alternate, and they know my wishes including those about artificial nutrition and hydration.

If you wish to give more specific instructions, you could say:

If I become terminally ill, I do/don't want to receive the following types of treatments. . .

If I am in a coma, or have little conscious understanding, with no hope of recovery, then I do/don't want the following types of treatments. . .

If I have brain damage or a brain disease that makes me unable to recognize people or speak, and there is no hope that my condition will improve, I do/don't want the following types of treatments. . .

I have discussed with my agent my wishes about ____________________________and I want my agent to make all decisions about these measures.

Several examples of medical treatments about which you may wish to give your agent special instructions are listed below. This is not a complete list:

- Artificial respiration
- Artificial nutrition and hydration (nourishment and water provided by a feeding tube)
- Cardiopulmonary Resuscitation (CPR)
- Antipsychotic medication
- Electric shock therapy
- Antibiotics
- Surgical procedures
- Dialysis
- Transplantation
- Blood transfusions
- Abortion
- Sterilization

Item (5)

You must date and sign this Health Care Proxy form. If you are unable to sign yourself, you may direct someone to sign in your presence. Be sure to include your address.

Item (6)

You may state wishes or instructions about organ and/or tissue donation on this form. A health care agent cannot make a decision about organ and/or tissue donation because the agent's authority ends upon your death. The law does provide for certain individuals in order of priority to consent to an organ and/or tissue donation on your behalf: your spouse, a son or daughter 18 years of age or older, either of your parents, a brother or sister 18 years of age or older, a guardian appointed by a court prior to the donor's death, or any other legally authorized person.

Item (7)

Two witnesses 18 years of age or older must sign this Health Care Proxy form. The person who is appointed your agent or alternate agent cannot sign as witnesses.

Health Care Proxy

(1) I, ______________________________ hereby appoint ____

YOUR NAME NAME OF HEALTH CARE AGENT

____

AGENT'S HOME ADDRESS AND TELEPHONE NUMBER(S)

As my health care agent, to make any and all health care decisions for me, except to the extent that I share otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) Optional: Alternative Agent

If the person I appoint is unable, unwilling, or unavailable to act as my health care agent, I hereby appoint:

____

NAME OF ALTERNATE HEALTH CARE AGENT

____

AGENT'S HOME ADDRESS AND TELEPHONE NUMBER(S)

as my health care agent, to make any and all health care decisions for me, except to the extent that I share otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(3) Unless I revoke it, or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. (Optional: If you want this proxy to expire, state the date or conditions here.)

____

SPECIFY DATE OR CONDITIONS FOR PROXY TO EXPIRE

____

(4) Optional: I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. (If you want to limit your agent's authority to make health care decisions for you or give specific instructions, you may state wishes or limitations here.)

I direct my health care decisions in accordance with the following limitations and/or instructions (attach additional pages as necessary.)

____

____

In order for your agent to make health care decisions for you about artificial nutrition and hydration (nourishment and water provided by a feeding tube or intravenously), your agent must reasonably know your wishes. You can either tell your agent what your wishes are, or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.

(5) Your Identification

YOUR NAME (PLEASE PRINT) YOUR SIGNATURE DATE

YOUR ADDRESS

(6) Optional: Organ And/Or Tissue Donation

I hereby make an anatomical gift, to be effective upon my death of:

☐ Any needed organs and/or tissues

☐ The following organs and/or tissues:

Limitations:

If you do not state your wishes or instructions about organ and/or tissue donation on this form, it will not be taken to mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.

YOUR NAME (PLEASE PRINT) YOUR SIGNATURE DATE

7) Statement by Witnesses

Witnesses must be 18 years of age or older, and cannot be the health care agent or alternate.

I declare that the person who signed this document is personally know to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

DATE	DATE
NAME OF WITNESS 1 (PLEASE PRINT)	NAME OF WITNESS 2 (PLEASE PRINT)
SIGNATURE	SIGNATURE
ADDRESS	ADDRESS
ADDRESS	ADDRESS

New York Living Will

I, ____ , being of sound mind, make this statement as a directive to be followed if I become permanently unable to participate in decisions regarding my medical care. These instructions reflect my firm and settled commitment to decline medical treatment under the circumstances indicated below.

I direct my attending physician and other medical personnel to withhold or withdraw treatment that serves only to prolong the process of my dying, if I should be in an incurable or irreversible mental or physical condition with no reasonable expectation of recovery.

These instructions apply if I am:
a.) In a terminal condition;
b.) Permanently unconscious; or
c.) Conscious but have irreversible brain damage and will never regain the ability to make decisions and express my wishes.

I direct that the treatment be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing treatment. While I understand that I am not legally required to be specific about future treatments, if I am in the condition(s) described above, I feel especially strong about the following forms of treatment.

☐ I do **not** want cardiac resuscitation

☐ I do **not** mechanical respiration

☐ I do **not** want tube feeding

☐ I do **not** antibiotics

☐ I do want maximum pain relief

☐ Additional instructions:

____

____

____

I hereby appoint:

____
NAME PHONE NUMBER(S)

____
ADDRESS

as my health care agent to make all health care decisions for me in conformity with the guidelines I have expressed in this document. I direct my agent to make health care decisions in accordance with my wishes and instructions as stated above, or as otherwise know to him or her. I also direct my agent to abide by any limitations on his or her authority as stated above or as otherwise known to him or her.

In the event my health care agent is unable, unwilling, or unavailable to serve as such, then **I appoint as my substitute health care agent** (with the same powers that I have heretofore enumerated).

NAME PHONE NUMBER(S)

ADDRESS

I understand that unless I revoke it, this living will and health care proxy will remain in effect indefinitely.

These directions express my legal right to refuse treatment under the laws of New York State. Unless I have revoked this instrument or otherwise clearly and explicitly indicated that I have changed my mind, it is my unequivocal intent that my instructions as set forth in this document be faithfully carried out.

SIGNATURE DATE

ADDRESS

Statement by Witnesses (Must be 18 years of age or older)

I declare that the person who signed this document is personally known to me and appears to be of sound mind, and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

WITNESS NAME SIGNATURE DATE

ADDRESS

WITNESS NAME SIGNATURE DATE

ADDRESS

Notes

Patient Name ______________________________

Patient # ______________________________

Episode # ______________________________

☐ **Visiting Nurse Service**

☐ **Ontario-Yates Hospice**

State of New York
Department of Health

Non-Hospital Order Not to Resuscitate
(DNR Order)

Person's name: ______________________________

Date of Birth: ________ /________ /________

Do not resuscitate the person named above.

Physician's Signature: ______________________________

Print Name: ______________________________

License Number: ______________________________

Date: ________ /________ /________

It is the responsibility of the physician to determine, at least every 90 days, whether this order continues to be appropriate, and to indicate this by a note in the person's medical chart. The issuance of a new form is NOT required, and under the law this order should be considered valid unless it is known that is has been revoked. This order remains valid and must be followed, even if it has not been reviewed within the 90-day period.

DOH-3474 (04/09)

Patient Name ____

Patient # ____

Episode # ____

☐ **Visiting Nurse Service**
☐ **Ontario-Yates Hospice**

Inpatient Hospice Agreement

Hospice Inpatient Start of Care Date ____

The hospice team is dedicated to working with you in developing a plan of care that meets your individual needs. Please understand that hospice is expected to provide services under strict guidelines mandated by Medicare and other insurance companies.

Admission and continued stay in the inpatient setting on hospice is for the purpose of managing acute medical symptoms or unstable conditions that cannot be managed in alternate care settings. When those symptoms are effectively managed or the condition stabilizes, alternative plans must be put into place. Potential options may include transfer to home with continuing hospice services, transfer to a skilled nursing facility or assisted living, or in some situations, transfer to a comfort care home.

Hospice staff is obligated to inform you of the above information at the time of hospice inpatient admission. Hospice staff are available to help you make the best decision possible.

By signing below, you acknowledge that you read the information on this form, had it explained to you, and had the opportunity to ask questions.

____
PATIENT OR LEGAL REPRESENTATIVE DATE

____
HOSPICE REPRESENTATIVE DATE

Patient Name ____

Patient # ____

Episode # ____

☐ **Visiting Nurse Service**
☐ **Ontario-Yates Hospice**

Medicare/Non-Medicare Benefit Revocation

Effective ________/______/________, I elect to revoke election of the Medicare/Non-Medicare Hospice Benefit.

1. I understand that I am revoking the hospice benefit for the remaining days left in the current benefit period.
2. I understand that any Medicare/Non-Medicare benefit I have waived to receive the hospice benefit coverage will be resumed effective the date of the revocation.
3. I further understand that if I choose, I may receive hospice benefits at a later date, utilizing an election period not previously utilized.
4. I have read and understand the above statements.

____

SIGNATURE OF BENEFICIARY OR LEGAL REPRESENTATIVE DATE

____

SIGNATURE OF HOSPICE REPRESENTATIVE DATE

UR
MEDICINE | **Home Care**