



*Caring for Jefferson County Since 1985*

1398 Gotham Street Watertown NY 13601

[www.jeffersonhospice.org](http://www.jeffersonhospice.org)

315.788.7323

## HELPFUL INFORMATION FOR HOSPICE FAMILIES

*“You matter because you are you,  
You matter to the last moment of your life,  
And we will do all we can,  
Not only to help you die peacefully,  
But also to live until you die.”*

*Dame Cicely Saunders  
Founder of the first modern day Hospice in London, England*



# **DO NOT CALL 911**

## **TO CONTACT**

### **Hospice of Jefferson County**

### **315.788.7323**

#### **Call 315.788.7323**

- **24 Hours A Day**
- Please do not hesitate to call again if you do not hear from a nurse within 15 minutes
- The Hospice Office Business Hours are Monday through Friday 8:00AM to 4:30PM

**During non-business hours (evenings, nights, weekends, holidays) your call will go through our answering service.**

1. Select “2” to talk to the answering service.

AT THIS TIME SAY:

I AM CALLING HOSPICE – THEN GIVE **YOUR NAME**

“I AM CALLING REGARDING **(PATIENTS NAME)**”

“PLEASE CALL ME BACK AT **(PHONE NUMBER)**”

\*\*\*It is not necessary to provide any other information about the patient problem to the answering service staff\*\*\*

2. The answering service will immediately contact the on-call nurse who will call you back as soon as possible.
3. Call 315.755.4095 if the first number cannot be reached.



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This packet of information is designed to help you. Please do not hesitate to ask your Nurse or Social Worker any further questions or concerns you may have. You can contact Hospice of Jefferson County at 315.788.7323, 24 hours a day, 7 days a week.



# *Hospice of Jefferson County Values*

## *H* OPE

- We instill hope & assist in finding meaning while living each day to the fullest.

## *O* UTREACH

- We embrace religious, spiritual, ethnic and cultural diversity.

## *S* ERVICE EXCELLENCE

- We devote ourselves to continuous improvement, excellence & professionalism.
- We are proud of our attitude, behavior, teamwork & reputation.
- We are dependable & accountable.

## *P* ATIENTS

- We put our patients and families first in all we do.
- We advocate for patient empowerment and choice.

## *I* NTEGRITY

- We do the “right” thing.

## *C* OMPASSION

- We are kind, caring, comforting, and passionate.

## *E* XPERTISE

- We are experts at caring for all who are experiencing life-limiting illness & loss.

***Welcome to Hospice of Jefferson County...***

**YOU  
YOUR FAMILY  
OTHER CAREGIVERS  
YOUR DOCTOR  
HOSPICE OF JEFFERSON COUNTY STAFF**

***... are now a part of your Hospice Team.***

Hospice care is different for each patient and caregiver. Coping with a serious illness will lead to a wide range of feelings. There will be times that you feel overworked, overwhelmed and unsure of what you should do next. There will also be times when you feel so blessed to be able to spend this time with the people you love. This handbook is designed to help you cope with unfamiliar issues and give you the confidence that you will be able to get through what lies ahead. You are not alone.

We will help you deal with the many unknowns that you may encounter, providing confidence and helping the whole family take better care of each other and yourselves. Often just being present provides comfort and reassurance to each other.

It is our goal to treat each person we serve with dignity, honor, and respect by providing quality care, while always remembering the patient and family must be allowed to make their own decisions. Please contact your Hospice of Jefferson County team at any time for support and guidance.

**Hospice of Jefferson County is available anytime day or night.**

**315.788.7323**

**Hospice of Jefferson County Mission**

**To provide expert, compassionate, comprehensive care and services to individuals and their loved ones experiencing life-limiting illness and loss.**

## **WE HONOR VETERANS**

Hospice feels strongly about supporting our veterans during this stage of life's journey. If you or your family members are veterans or currently serving in the military, Hospice of Jefferson County takes this opportunity to extend our deepest appreciation for your sacrifice and your willingness to serve our country. Hospice is a proud partner in the We Honor Veterans program through the VA. We want to assure you have taken advantage of all the benefits you have earned to support your care. Your Hospice Social Worker can provide you with more information or answer any questions you might have.



## **WE HONOR VETERANS**



## **AFTER HOURS SERVICE**

Hospice of Jefferson County wants you to be confident in caring for your loved one. We are available **24 hours a day, 7 days a week**, as a resource for questions or to make a visit to help you and your loved one more comfortable. We can always be reached by calling **315.788.7323**. If you are calling during non-business hours your call will be answered by Hospice of Jefferson County answering service. The answering service will relay all calls to our on-call nurse who will call you right back.

### **Reasons to call the on-call staff might include**

- A change in the condition of the patient, such as increased or new pain, decreased level of alertness, or a fall.
- The need for reassurance.
- Questions about how a medication should be used.
- Cancellation of personal care or any other scheduled visit from Hospice Staff.
- A change that leaves the patient without a care giver.
- Anything which you previously would have called the physician's office, the hospital or an emergency service.
- Any other question or concern that you feel cannot wait until your next scheduled visit with your Hospice Team.

**Call Hospice first, instead of calling 911 or going straight to the hospital.** This is probably a change from what you are used to doing. This allows those who know your care best, including your advance directives, medications and care plan, to make sure your wishes are honored and your care is maximized. If you still need to go to the hospital, the Hospice Team can arrange for this and make sure the care plan that you have established stays in place.

When you do call the Hospice answering service, they will ask you certain questions, which are outlined below. Please stay off the phone after calling to allow the on-call nurse to call you back.

### **Information the on-call staff will ask for**

- Patient's Name
- Patient's Address
- Patient's Phone Number
- County of Residence
- Caller's Name
- Caller's Phone Number
- What is your concern

## **HOSPICE OF JEFFERSON COUNTY TEAM**

Hospice of Jefferson County is a team that provides service from which you and your family can draw support in an effort to gain confidence and make the most of every day. Our goal is for you and your family to receive all the support needed to feel confident in your efforts and to make the most of your time together.

### **Family Members**

Each member of your family, including you, is unique and will deal with illness in his or her own way. Facing illness or death as a family can help make this time easier, although not all families can be open and share their feelings. This is a time of uncertainty and emotional vulnerability. A family member may find it easier to share their feelings with someone outside of the family unit. You may find it helpful to talk with friends, your Nurse, Social Worker and/or Spiritual Care Counselor. They can assist your family by bringing you together to talk, listen and help one another. Children also have needs in dealing with illness and the death of a loved one. Depending on their age and maturity, illness or death may have a different meaning to them. It is important to respond to their questions honestly and in a way they can understand.

### **Friends**

Friends can be of great support and comfort for you and your loved one. They often are eager to help in whatever way they can but frequently don't know how or are hesitant, as they feel they may say or do something wrong. They will need some direction from you. You can suggest to these willing friends things that may be helpful to you at this time. Suggestions may include: preparation of meals, running errands, visiting support, giving you a break from continuous care giving, help with childcare and anything else that is useful to your situation. Some friends may be unable to cope and you may feel they have disappeared from your life during this time, but understand there may be many reasons behind their absence, some of which may have nothing to do with you or your family. Those who can provide support and demonstrate that they are comfortable in your presence will make this time memorable.

### **Spiritual Care**

Spirituality can be described as that which gives meaning to life. It refers to the human need for love, hope, value and dignity. A person's spirituality may or may not involve religious beliefs or practices.

Finding out that you or a loved one has a serious, progressive illness presents many challenges. It can present an opportunity for a person to look back at one's life and celebrate all that he or she has done. It can also be a time to reconnect with loved ones. The Hospice of Jefferson County Team is available to assist you with these challenges and opportunities.



Our Spiritual Care Counselor can be present with you and your loved ones as important decisions are made at the end of life. Spiritual Care Counselors are trained to help each person express his or her concerns and feelings without fear of being judged by others. Fear, anxiety, and even physical pain are greatly reduced when one feels listened to in the process of accepting and coping with a terminal illness.

A Spiritual Care Counselor listens and supports as a person begins to question the purpose of his or her life, suffering and the need to forgive or be forgiven. A Spiritual Care Counselor offers assistance as the person copes with all the changes that are occurring. Looking back at one's life can help establish a person's legacy, which is how one would like to be remembered. A Spiritual Care Counselor may also provide an honoring and caring presence for those unable to verbally express their thoughts and feelings.

Spiritual Care Counselors provide the following:

- Prayer and observance of religious practices
- Connections to a person's faith community
- Expressions of personal meaning and values
- Funeral and memorial services
- Support to family and caregivers

### **Social Workers**

Hospice of Jefferson County Social Workers are trained professionals who specialize in helping patients and families work through the many challenges that occur as our loved one's health declines. They can help you access needed resources in the community for financial or legal assistance or help you get the information you need to make informed decisions about the present and the future. Social Workers will advocate for your needs and rights and help you meet your goals which are part of your plan of care. This is all done while respecting the wishes of the patient and family.

Each patient's circumstances vary but everyone will have some major decisions to make. The Social Worker's role is to provide support, encouragement, education and practical assistance with any of these problems or concerns. A Social Worker will visit with you to complete an individual assessment and remain available to support both the patient and family throughout your care.

### **Volunteers**

Hospice of Jefferson County Volunteers can be provided for additional support to patients and families. These volunteers are specially trained to work with seriously ill patients and their families. They can offer emotional and practical support to the patient and family, such as

friendly visits, respite care, or shopping. A respite visit by the volunteer allows the caregiver to leave the home for a designated amount of time without having to worry about the patient. Volunteers can bring much needed support, however they may not provide personal care or give medications.

### **Nurses**

Hospice of Jefferson County Registered Nurse (RN) Case Managers make home visits to assess the patient's needs and comfort status. The RN informs you of expected changes in the patient's condition, and teaches you how to control the distressing symptoms. The RN will keep the physician updated of your loved one's status and obtain all orders for medication and medical equipment. The RN will help you choose and utilize the services of the other Hospice of Jefferson County team members, as you need them.

Hospice of Jefferson County Licensed Practical Nurses (LPN) also provide care in the home and are integral members of the Hospice of Jefferson County Hospice team. They are experts in providing personal care and attending to the day to day skilled needs of the patient, as well as working closely with the RN to ensure that the patient's medical needs are met.

### **Physicians**

Your primary physician remains in charge of your care while enrolled in Hospice of Jefferson County. All prescriptions and medical care are authorized by him or her. Our Nurses keep your doctor informed of all changes and you are encouraged to continue to keep all appointments to see your doctor. The Hospice of Jefferson County Medical Director is also kept up to date with your condition and is available to consult with your primary doctor as needed.

### **On Call Services**

Hospice of Jefferson County provides emergency consultation 24 hours a day, 7 days a week. An RN is available by phone to help you with concerns. The Nurse will coordinate the appropriate plan for response. The Nurse may instruct you by phone how to treat a symptom or provide care to your loved one, for example, explaining how to administer a medication. If an adequate assessment cannot be made by phone, a visit will be made. Other team members are available during on call hours and can be contacted through the on call service. Remember, you are not alone.

### **Bereavement Services**

For those experiencing emotional grief, Hospice of Jefferson County Grief Services Counselors will help you to work through the waves of feelings that accompany a change in health status. The goal is to make the most of the time left together. Feelings of

loneliness, anxiety, or fear are common and the Grief Services Counselor is experienced in helping you recognize your feelings, finding ways to cope, and assisting you in the grief process.

Services from the Grief Services team include support during early grief, throughout the illness, and after death. We offer counseling for individuals, families, and groups. We also provide education, workshops, memorial services, and much more.

Hospice of Jefferson County is available to provide answers and direction on how best to care for yourself and your loved one. Hospice of Jefferson County is there to provide support and confidence, as this is an unpredictable and emotional time.



## **CRITERIA FOR ADMISSION AND INSURANCE COVERAGE**

Hospice care is available to those coping with a serious illness when the focus has turned to making the most of every day. Your doctor and Hospice of Jefferson County's Medical Director will work together to determine if your medical condition meets the admission criteria set by federal regulations. Your Hospice of Jefferson County Interdisciplinary Team will continually reassess your medical condition to insure your continued eligibility.

Hospice of Jefferson County service is covered by Medicare, Medicaid and most private insurances. The specifics of your coverage will be discussed in full by Hospice of Jefferson County staff prior to admission. If you do not have insurance coverage, Hospice of Jefferson County may be able to provide care at a reduced rate depending on your financial situation. Again, Hospice of Jefferson County staff will meet with you prior to admission to provide more information.

## **WHAT TO EXPECT DURING THE FIRST WEEK OF CARE**

The first week or so after starting Hospice service can seem a bit overwhelming. There are many tasks to be completed, including assessments and planning to ensure that your care plan is designed specifically to best meet your needs. You will be meeting many members of our care team, many of whom will be calling you to make appointments. These team members may change over time as we work together to best meet the needs of all of our families. Rest assured that this will smooth out into a predictable and regular routine with a team of caregivers that you will know and trust.

## **A WORD ABOUT SCHEDULING**

Your Hospice of Jefferson County Team works hard to meet the needs of all the families we serve. As needs can change from day to day – or even hour to hour – our staff's schedules are kept as flexible as possible to allow them to go where they are most needed. This may mean that scheduled visits may have to be rescheduled, or another team member may need to meet with you in place of who you were expecting. Please rest assured that all of our staff are experts in what they do and communicate daily to make sure everyone is kept informed on your needs and plans. We deeply appreciate your understanding. This way you know that when you need care urgently, we will have the flexibility to respond to you as well.



## **COPING WITH SERIOUS ILLNESS**

The pathway through a serious illness may be long and slow; sometimes lasting years or it may be a rapid decline with a sudden, unexpected death. Some may go through cycles of ups and downs feeling better and worse. Others may experience a gradual decline in health. People on this pathway must readjust to the continuing changes in their daily lives. Bear in mind that not everyone can handle the thought that they might lose you. Or some people may not know what to say or do for you. As a result, relationships may change. If you can, remind them that you are still the same person you always were. Let them know it's alright to ask questions or tell you how they feel. Sometimes just reminding them to be there for you is enough. But it's also okay if you don't feel comfortable talking about it either. Sometimes certain topics are hard to talk about with others. If this is the case, you may want to talk by yourself with a member of your Hospice of Jefferson County team. You also may want to attend a support group where people share common concerns.

### **Coping of Family Members**

Family members may need time to adjust to the new stage of your illness. They may need to come to terms with their own feelings. These may include confusion, shock, helplessness, or anger. Don't try to solve every issue, instead ask your loved one what he or she may need and remain available as needs change.

Some families have trouble expressing their needs to each other. Other families simply do not get along with each other. If you don't feel comfortable talking with family members, ask a member of your Hospice of Jefferson County team to help. You could ask a Social Worker or Spiritual Care Counselor to hold a family meeting. This may help family members feel safer to express their feelings openly. This is also a place where your loved one and the family can meet with the Hospice of Jefferson County team to problem-solve and set goals. It can be very hard to talk about these things. Care goes more smoothly when everyone stays open and talks about the issues. Often talking with the people closest to you is harder than talking with anyone else.

### **Spouses and Partners**

Some relationships grow stronger during serious illness, but others are weakened. It's very common for couples to feel more stress than usual. Talk things over. This may be hard for you or your partner. If so, ask a Hospice of Jefferson County Social Worker or Spiritual Care Counselor to talk to both of you together. Be realistic about demands. You may feel guilty about any time spent away from your loved one. Spend some time apart. You need time to address your own needs. If these needs are neglected, you may have less energy and support to give. Remember, you didn't spend 24 hours a day together before the serious illness. Know that it's normal for body changes and emotional concerns to affect your sex life. Talking openly and honestly is key. But if you can't talk about these issues, you might

want to talk with a member of your Hospice Team. Don't be afraid to seek help or advice if you need it.

### **Young Children**

Children's trust is very important at this time. Children can sense when things are wrong. It's best to be as open as you can about the serious illness. They may worry that they did something to cause the illness. They may be afraid that no one will take care of them. They may also feel that you are not spending as much time with them as you used to. Although you can't protect them from what they may feel, you can prepare them.

Some children become very clingy. Others get into trouble in school or at home. Let the teacher or guidance counselor know what is going on. And with your kids, it helps to keep the lines of communication open. Try to:

1. Be honest. Tell them you are sick and that the doctors are working to help you feel comfortable.
2. Let them know that nothing they did or said caused the illness. And make sure they know that they can't catch it from others.
3. Tell them you love them.
4. Tell them it is okay to be upset, angry, or scared. Encourage them to talk.
5. Be clear and simple, since children do not have the focus of adults. Use words they can understand.
6. Let them know that they will be taken care of and loved.
7. Let them know that it's okay to ask questions. Tell them you will answer them as honestly as you can. In fact, children who aren't told the truth about an illness can become even more scared. They often use their imagination and fears to explain the changes around them.

### **Teenagers**

Many of the things that apply to young children may also apply to teenagers. They need to hear the truth about an illness. This helps keep them from feeling guilt and stress. But be aware that they may try to avoid the subject. They may become angry, act out, or get into trouble as a way of coping. Others simply withdraw. Try to:

1. Give teenagers the space they need. This is especially important if you rely on them more than before to help with family needs.
2. Give them time to deal with their feelings, alone or with friends.
3. Let your teenager know that they should still go to school and take part in sports and other fun activities.
4. Try asking a close friend, relative, or member of your Hospice team for ideas on how to provide support. You could also go to a trusted coach, teacher, or youth minister. Your Social Worker can assist you in finding a counselor or a Grief



Services Counselor can provide early support.

### **Decision Making for Family and Loved Ones**

Sometimes families are too distant, either emotionally or geographically, to work together. And, of course, some people have no family or friends at all and rely on volunteers or programs to provide support.

At times, families and loved ones get into fierce disagreements over the treatment of a seriously ill family member. All too often, care giving family members find themselves disagreeing with distant family members who may feel guilty for not “being there.” This is often seen with a distant family member questioning every decision that the caregiver makes or stating dissatisfaction with the care provided. Often times the distant family member is attempting to make up for their lack of physical presence and does not mean to cause distress to the caregiver. If there has been a history of feeling left out, arguing, or providing an unfair share of care giving, there can be deep resentment, too. For example, if one of the family members is providing all of the care and not receiving any help, resentment can set in quickly.

Often, family members need some perspective. The family member that is distant does not have the ability to physically see how their loved one is doing, and depends on the information provided by the care giving family member. A distant family member will often attempt to direct the care of their loved one.

Relationships with adult children may change due to serious illness. There may be a reliance on the adult child for care. It may be hard for a parent to ask for support. You are probably used to giving support rather than getting it. Other issues may provide challenges such as a distant relationship.

Adult children have their concerns, too. They may become fearful of their own mortality. They may feel guilty because they feel that they can't meet the many demands on their lives as parents, children, and employees.

As illness progresses, it helps to:

1. Share decision-making with your family.
2. Involve them in issues that are important to you. These may include treatment choices, plans for the future, or types of activities you want to continue.



## **ABOUT DYING**

### **DYING is an INEVITABLE EVENT...**

- The death of someone we love
- Our own death, someday

### **...that has to be FACED and ACCEPTED**

- If we are each to live fully to the end
- If we are to be prepared for it, emotionally and practically

### **Each person approaches death in a UNIQUE WAY**

#### **THE RESPONSES**

A dying person may not be able to experience all responses (due to limited understanding or refusal to consider the situation, etc.). A dying person may not have time to experience all responses, may combine them, may skip around, may hide feelings.

#### **UPS AND DOWNS**

Most dying people have periods when they continue to enjoy life. But at other times they're caught up in their own special concerns (wondering what death will be like, worrying about the family, etc.) And so they will treat different people in different ways at different times.

#### **HOPE**

This is the one attitude that holds on to the VERY END.

### **A Person's REACTIONS TO DYING**

A person who has time to react (for example, if terminally ill) generally ADJUSTS TO THE IDEA of dying with 5 RESPONSES:

#### **DENIAL**

"Refusal to believe the news"

- Is a normal reaction after the initial shock of finding out that death will happen soon.
- Allows time for a terrifying idea to "sink in" so people can "collect themselves."
- Is usually temporary. Most people stop refusing to believe they'll die soon; go on to deal with it in other ways.
- Denial may return at times during later stages. We all handle troubles better some days than others. So a person may speak of approaching death one day, plan for the far future the next.

#### **ANGER**

Usually follows denial; it helps relieve the anguish of dying. For example:

- An older person's sense of helplessness may turn to rage
- An adult may envy co-workers their new opportunities he or she can't share

- An adolescent may resent friends having a good time without him or her
- A young child may feel parents didn't give enough protection

### **Anger is a difficult (but necessary) response**

#### **For the Dying Person**

- Anger comes unexpectedly and is hard to control
- It causes guilt feelings

#### **For the People Around**

- They may become innocent targets
- It's hard to respond with understanding instead of with anger, hurt feelings, and guilt.

## **BARGAINING**

An attempt to postpone death

- The bargain usually involves a change in behavior or a specific promise in exchange for more time to live.
- Bargains are usually made in secret, often with God.
- Deadlines in bargaining include special celebrations, seeing a loved one, one more time, completing some unfinished business. If a deadline passes, the dying person will set a new one
- Bargaining is a part of hope

## **DEPRESSION**

Occurs when a dying person faces the losses that dying brings, and begins to mourn for what's already lost-health, independence, ability to meet responsibilities, uncompleted work-everything that's part of everyday life and for what's still to be lost-family, friends; all the future living that might have been.

### **Depression is:**

- A common part of preparing to die often begins when symptoms of terminal illness become impossible to ignore
- Realistic, the truth has registered: a person fully faces the fact that death is inevitable
- Very painful, grief and despair cause pain for some, quiet sorrow for others
- Unnecessary guilt and shame for causing sadness to family, friends, and for being a "burden" to them

## **ACCEPTANCE**

Of death can be reached if the person works through the many conflicts and feelings that dying brings.

- At this point, the dying person is often tired and weak
- It's a time of emotional calm-no great fear, joy or sadness: the dying person has given consent to death
- The dying person may want fewer visitors, then just one visitor...or none

Acceptance is not:

- Resignation
- Submission
- Defeat
- Doing nothing

Acceptance is:

- A healthy coming-to-terms with reality
- A gradual separation from people, life, ties, and roles
- Allowing the world to go on without him/her
- Holding on to memories
- Peace

You can help the dying person. Try to be sensitive to the dying person's needs. Try to gain an inner understanding of your own feelings about death, so you can better understand how the dying person feels.

### **Respect the right of a person to handle death in his/her own way**

- Go along with denial (but don't reinforce it)
- Don't take anger personally
- Respect the need to bargain (help make some wishes come true)
- Help to relieve guilt
- Let the person grieve
- Accept the person's death

### **Give yourself to make the dying person's last days more peaceful**

- Help meet physical needs, see that pain is relieved, run errands, etc.
- Be open about death with the dying person
- Listen to the dying person; be alert for clues to unspoken emotional needs
- Show you care, be available often
- Help the person conduct unfinished business



## **PHASES OF A SERIOUS ILLNESS**

Understanding how serious illnesses usually progress can help you cope with what is happening and what is to come. Always remember that every person takes their own course on this journey, and each journey is different.

### **Diagnosis**

The phase before the diagnosis of a serious illness is the period of time when a person suspects that he or she may be developing a serious illness. This phase is not usually a single moment, but extends throughout the period when the person has a physical examination, including various tests, and ends when the person is told of the diagnosis.

### **Acute**

The acute phase occurs at the time of the diagnosis when a person is forced to make decisions about his or her medical care.

### **Chronic**

The chronic phase is the period of time between the diagnosis and the result of treatment. It is the period when a patient tries to cope with both the demands of life, undergoing treatment, and the side effects of treatment. A person may experience losses due to the illness such as; finance, independence, pleasure, control, changes in body image, changes in bodily functions, role in the family, and so on. In the past, the period between a serious illness diagnosis and death usually lasted only a few months, and this time was usually spent in the hospital. Today, people can live for years after being diagnosed with a serious illness, and remain in their homes and the community.

### **Recovery**

In the recovery phase, people cope with the mental, social, physical, spiritual, and financial effects of the serious condition.

### **Final**

The final (terminal) phase of a serious illness occurs when death is likely. The focus changes from curing the illness or prolonging life, to providing comfort and relief from symptoms. A person may find great comfort and hope in their religious or spiritual beliefs at this time. For some people, prayer, religious sacraments, and having visits from their family are a source of comfort and peace.





## **HOW TO GIVE MEDICATIONS**

### **Pain/Respiratory Distress**

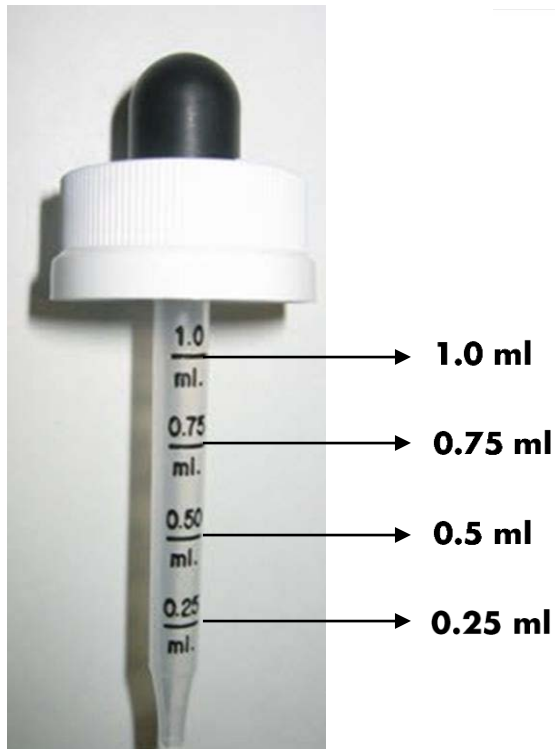
Morphine Sulfate Concentrate (Roxanol), Oxycodone Concentrate (Oxydose), and other medications may be ordered for your loved one's pain and/or respiratory distress. Your physician will order the medication and your Hospice Nurse will show you how to give it. The medication will either come with an oral syringe or a dropper as shown on the following page.

Whichever you have, draw the medication up to the dose that you were instructed to give. These medications can be given in a small amount of juice if the taste bothers the person. Otherwise, the medication can be given directly in the mouth or between the cheek and gums if the person is having difficulty swallowing. If this does not help with the pain or respiratory distress, call 315.788.7323 and talk with, the On-call Nurse or your RN Case Manager for further instructions.

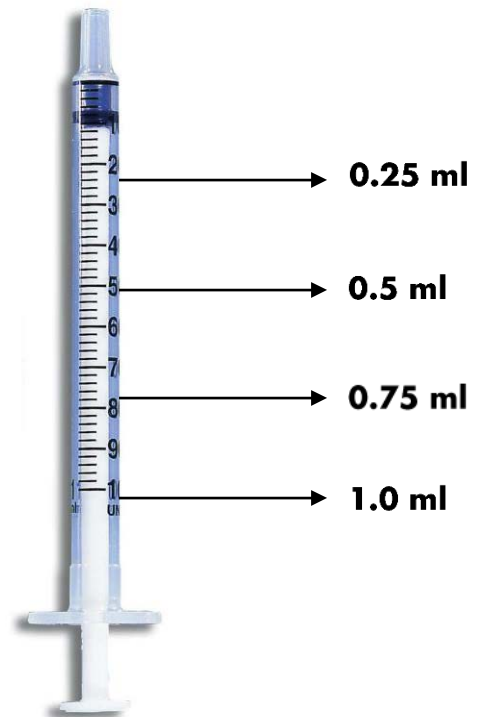
### **Anxiety/Restlessness**

Lorazepam Concentrate (Ativan) or Haldol (Haloperidol) may be ordered to help with your loved one's anxiety or restlessness. Your physician will order medication and your Hospice Nurse will show you how to give it. The medication will either come with an oral syringe or a dropper as shown on the following page. Whichever you have, draw the medication up to the dose that you were instructed to give. These medications can be given in a small amount of juice if the taste bothers the person. Otherwise, the medication can be given directly in the mouth or between the cheek and gums if the person is having difficulty swallowing. If this does not help with the anxiety or restlessness, call 315.788.7323 and talk with the On-call Nurse or your RN Case Manager for further instructions.

## **DROPPER**



## **SYRINGE**



**Your Hospice Nurse will instruct you on the dose (how much) medication should be given and when.**

**If you have any questions, please call Hospice at 315.788.7323.**

On the following page is a Medication Log. When you are giving medications that are described here, they are often dispensed as the patient's symptoms require them. Since the timing of these medication doses often vary, and since more than one person may be giving the medication, it is important to keep precise track of each time a dose is given. On the Medication Log, for each medication, write in the date, the time and the dose given. That way you or the Nurse, and anyone else involved in giving care can keep better track and avoid either giving too much or too little medication.

[illegible]

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## BEDSIDE CARE

### Changing the Sheets

When you want to change the sheets with the patient in the bed, position the patient comfortably by turning the patient toward the opposite side of the bed. Please refer to: Turning a Patient and follow the instructions.

With the patient on his or her side, pull the sheets out from the side of the bed by which you are standing. Roll these sheets lengthwise and tuck them under the patient from the head to the toes as he or she lay on the bed. Take the clean sheet and place on the unoccupied side of the bed, tucking in the side closest to you.

Roll the sheet up that is going under the patient in the same way you did with the sheet that is coming off the bed. Gradually move the patient over the old and new sheets toward the side you are standing. Maintain the patient's safety and move the patient cautiously. Move to the other side of the bed and pull both sheets getting rid of the old sheet and tucking in the clean sheet. When the sheet is in place continue making the rest of the bed.

**Note:** It is always easier to make a bed with the bed flat or at most one pillow under the patient's head.

### Turning a Patient

Here are illustrations on the technique of rolling a loved one over while in bed.

1. Remove bedclothes and all but one pillow. Cross one leg over the other leg towards you.



2. Move their arm over their chest towards you.



3. With one hand on the hips and the other behind the shoulders, roll the patient towards you onto his or her side. You can make the patient comfortable like this or wash his or her back. You may add a rolled towel or blanket behind the back for comfort. You may be able to look at the patient to tell if the patient is comfortable or not. Think of yourself resting in the bed and how you would want to be positioned.



### **Draw Sheet**

The use of a draw sheet to turn or lift a patient in bed:

When moving a patient in bed, it is useful to place a folded sheet across the bed sheets under the patient. These are normally called draw sheets or pull sheets. If the patient is in bed most of the time refer to: Changing a sheet on the bed with the patient in it.

1. Take a flat sheet and fold in half or thirds.
2. Place this folded sheet under the patient with the open end of the sheet facing the bottom of the bed.
3. Place this from the patient's mid back to mid-thigh leaving the sides of the sheet laying loosely on the bed.

### **Lifting the Patient Up in Bed with Help**

Lifting the patient up in the bed using the draw sheet with the help of two people:

1. Standing on either side of the bed, roll the sides of the draw sheet toward the patient and together move the patient up in the bed.
2. Sometimes the bottom of a mechanical bed can be raised slightly to prevent the patient from sliding to the bottom of the bed.

**Note:** Lift with your legs and not your back. Bend or flex knees; use legs and stomach muscles.

## **Lifting the Patient Up in Bed Without Help**

1. Keep the head of the bed as close to flat as the patient can tolerate.
2. With the mechanical bed, raise the level of the bed to the height of your hip.
3. Stand at the head of the bed and take hold of the draw sheet on either side of the patient. If the patient can participate, instruct the patient to lift his or her head off the bed and bend both knees with feet flat on the bed to help while you pull the sheet toward you.

## **Transfer**

Transfer patient from bed to chair:

1. First, take a moment to plan what you are going to do and the safest way to do it.
2. Place the chair close to the bed, making the bed and chair as equal in height as possible normally you will want the bed in a low position with the head of the bed raised to a sitting position, if possible.
3. Help the patient to a sitting position
4. Give the patient time in a sitting position to be sure that any dizziness subsides before helping him or her stand up.
5. Stand in front of the person being transferred, with your feet apart – this broadens your base, improving your balance and control.
6. Absorb any strain with your knees and legs, not your back – keep your back straight.
7. Flex your hips slightly.
8. Stand in front of the patient and put your arms around his or her body, placing your hands on the ribs in back.
9. Ask the patient to place his or her hands on your shoulders, not around your neck.
10. Make sure the patient places his or her feet on the ground.
11. Using your weight to balance, and keeping your knees slightly bent, gently rock the person into a standing position. Coaching the patient may help: “1, 2, 3, Up.”
12. To turn, continue to counterbalance with your weight and maintain a wide-based stance: turn on your feet, slowly turning your whole body, not twisting your trunk.
13. Gently lower the patient into the chair by bending your knees.

## **Bed Bath**

The items needed for bathing:

1. Large basin of warm water
2. Soap, washcloths and towels
3. Lightweight sheet to cover patient during the bath
4. Skin care lotion

Giving a patient a bed bath:

1. If the patient experiences pain with movement, give pain medicine  $\frac{1}{2}$  an hour before bathing.
2. Provide privacy for the patient by asking others to leave the room.
3. If using a mechanical bed, raise the bed to reduce the strain on your back. If the patient cannot tolerate a bath every day, focus on face, hands, back, underarms, and genitals.
4. To avoid chills, wash small areas at a time while keeping other areas of the body covered with light linens.
5. Begin at the patient's face and work toward the feet. Soap the skin gently, rinse and dry with towels.
6. Turn the patient on his or her side to wash the back. Apply lotion to dry skin areas as well as the back.
7. The genital area should be washed last. Washing this area daily is important to prevent bacteria growth and skin irritation. Wash area between the legs front to back and rinse and dry well.
8. Shaving, brushing, and styling hair can improve the patient's spirits and can be done around bath time.
9. When giving a bath look at the skin for redness or open areas. Notify the Hospice Nurse of any changes.



## HANDLING BOWEL ISSUES

### Constipation

Constipation is often a problem for Hospice patients. The causes vary – often constipation is a side effect of medications such as narcotics or as a result of changes in diet and activity. Sometimes the illness itself can be the issue. **THE GOOD NEWS IS THAT IT CAN BE MANAGED.** Your Hospice nurse will work closely with you to treat and prevent constipation. Almost everyone has their own “normal” routine and your nurse will want to learn what has worked in the past for you.

Experience tells us that you will probably need “help” in the form of a stool softener and a gentle vegetable laxative taken on a regular basis to counteract the cause(s) –especially if you are taking narcotics for pain control. You may also need additional interventions such as laxative suppositories or enemas on occasion.

The goal of a satisfactory bowel movement every 3 days is standard but is always individualized to meet your needs. Your Hospice nurse will help you establish what combination works best for you. **We encourage you to speak up and let us know what is or isn’t working.**

### Diarrhea

This refers to 3-4 loose watery stools accompanied by cramping pain. Please report this problem to your Hospice nurse promptly. Sometimes holding laxatives or changing the dose/frequency is all that is needed. Occasionally **Imodium** can be taken to slow down the stools and help get you back to normal. **UNCONTROLLED DIARRHEA CAN LEAD TO DEHYDRATION SO PLEASE NOTIFY YOUR HOSPICE NURSE IF YOU ARE HAVING PROBLEMS.**



# SAFE AND SECURE WITH HOSPICE

Being safe and secure in your home is extremely important to all of us at Hospice, as well as to you and your loved ones. Making small changes now can pay off in big ways later. Here are ways you can stay safe and injury free.



## Fire Safety

- Keep exits and doorways clear at all times.
- Maintain smoke detectors in good working order. You should have one for each level and replace the batteries twice a year (when you set clocks forward in the spring and back in autumn).
- NEVER smoke in bed or if you are taking medications that make you drowsy. Think of your loved ones and neighbors.
- Never use oxygen near an open flame.
- Practice how you will exit your home in case of a fire.
- Relocate bed to first floor if you need help or can't walk.
- Call 911 in case of a fire.



## Fall Prevention

- Keep pathways clear of clutter, cords and furniture.
- Remove throw rugs or tape them securely to the floor.
- Use nightlights to shine a path to the bathroom.
- Place items within easy reach beside your bed.
- Rise slowly from lying position. Place feet on floor for a few minutes before standing.
- Notify your Hospice Nurse if you feel light-headed or unsteady on your feet.
- Have a phone and emergency numbers (family, hospice, etc) close by your bed or chair especially if you are alone.
- Install grab bars in the bathroom.
- Know your limits - having someone standby when you shower or use the stairs can make the difference between staying injury free and a trip to the Emergency Dept.
- Wipe up spills right away.
- If you should fall- Call Hospice immediately. Whether you are injured or not, we want to be available to assist you.
- Wear your medical alarm necklace at all times (recommended if you stay alone).



## **Equipment Safety**

- Make sure you have been taught how to use all equipment in the home.
- The delivery person will set up and demonstrate how to use a wheel chair, walker, oxygen system or hospital bed, etc. Other equipment such as a commode, shower seat or monitor will be brought by Hospice Staff.
- Try out the new equipment before they leave to make sure you can use it correctly. Ask questions if unsure.
- Always lock wheels before transferring the patient in or out of wheelchairs, hospital beds and seated walkers.
- Some equipment such as transfer devices or medication pumps require one-on-one training and should not be used until training is received.
- Equipment is meant for the use of the Hospice patient and should not be shared. Please use it in the manner for which it was intended.
- Any equipment that is broken or not working properly should be reported to Hospice immediately. Do not attempt to fix it yourself.



## Infection Control in the Home

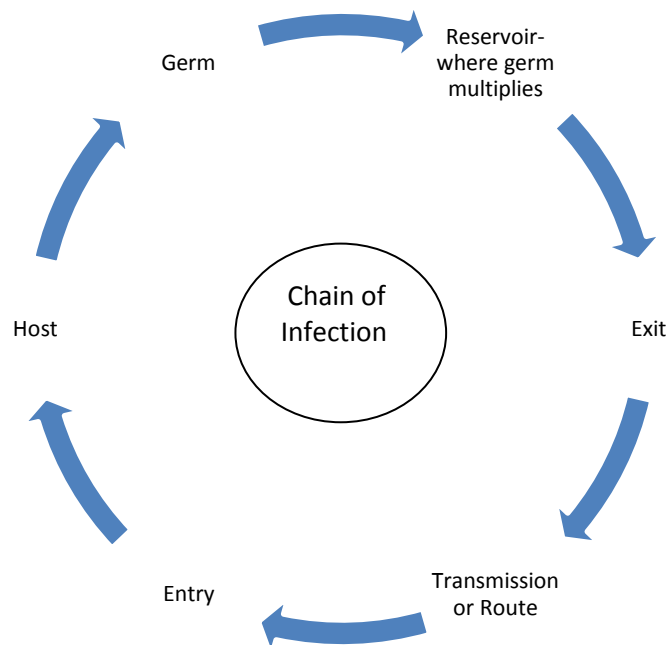
***What is infection Control?*** It's what we do to prevent the spread of infection from one source to another.

Infections can be spread

- to the patient from a caregiver or other source
- to a caregiver from a patient or other source

Persons most at risk are those whose own natural defenses against illness (immune system) are weak:

- newborns
- elderly
- people with diabetes
- people being treated for cancer, HIV/AIDS, or certain other conditions
- people with catheters or tubes inserted into veins or organs
- Caregivers and others living in the home may also be at risk if the patient has a contagious illness such as hepatitis.



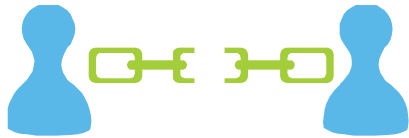
## ***How Are Infections Spread?***

**The Germ** – such as a virus, bacterium, fungus or parasite **multiplies** in a reservoir (person, plant, water, food, soil or animal) then the germ is **transmitted** by way of:

- direct contact-touching, kissing, having sex
- indirect contact- food, water, body fluid, feces, bandages, clothing or bedding contaminated with the germ
- droplets- sneezing, coughing
- other particles in the air

**And Enters the Host**

## How Can YOU Break the Chain of Infection?



1. **Practice Good Personal Hygiene**-Treat all body substances (blood, urine, vomit, feces, sputum) as infectious.
2. **Wear personal protective equipment** (latex or utility gloves, a mask, an apron or gown, in some cases goggles) *Hospice will provide you with many of these supplies and teach you when and how to use them properly.*
3. **Housekeeping**- Taking extra measures in cleaning the home, preparing food and disposing of wastes.
4. **Immunizations**- Sometimes extra protection such as flu or pneumonia shots are a good idea- not just for the patient but for caregivers and family members.

## Signs and Symptoms of Infection

*Please notify the Hospice RN if the patient develops:*

- Skin that is hot, red, swollen or has a rash
- Fever or chills
- Pus- green or yellow drainage from a wound
- Nausea or vomiting
- Persistent diarrhea
- Sore throat
- Cough
- Painful urination



# CLEANLINESS IS THE KEY!

**EVERYONE** must wash hands

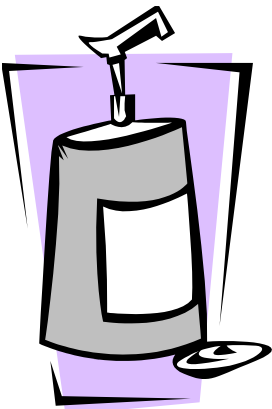
- before handling or eating food
- after using the toilet or changing a diaper
- after touching pets, money or uncooked food
- after coughing, sneezing, blowing nose
- after touching nose, eyes or mouth



**CAREGIVERS** MUST WASH HANDS BEFORE AND AFTER GIVING CARE – even if they wear gloves.

- Cleaning wounds, incisions, catheter or other tubes
- Changing bandages, handling soiled bedding, towels and clothing
- Giving mouth care or cleaning private areas

Ask if gloves are needed- but be sure to still wash hands before putting the gloves on and again after taking gloves off.



**Hand sanitizer** is very effective against germs, but washing with soap and water is preferred if hands are visibly soiled.

## HOUSEKEEPING

**Cleaning Supplies-** Keep a good supply of disinfectant, paper towels, sponges, trash bags and a pair of utility gloves in your home.

**Cleaning Solution-** 1 part Chlorine bleach to 9 parts water ( **$\frac{1}{4}$  cup bleach in 2  $\frac{1}{4}$  cups water**) is an extremely effective disinfectant for hard surface cleaning. The solution loses strength after 24 hours, so mix a new amount every day.

- Never mix bleach with other commercial cleaning products.
- Toilet brushes, mops and sponges can breed germs.
- They can be disinfected by soaking in bleach solution for 5 minutes after each use.

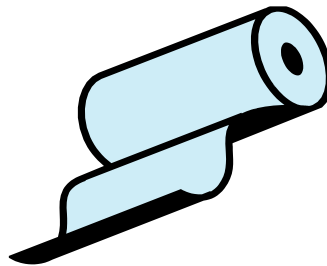
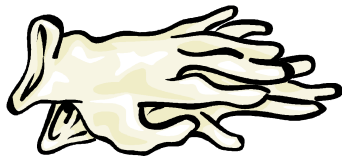


### **Keep Home Well Ventilated**

Avoid having the person with a weakened immune system take care of pet litter, cages or fish tanks.

## Clean Up Body Substance Spills Right Away

- Wear utility or latex gloves
- Wipe up the spill using paper towels and place immediately into a plastic bag.
- Use more towels to clean surface with hot water and soap or detergent. Rinse well.
- Wipe area of spill with chlorine bleach/water solution- leave on for 10 minutes, then wipe dry.
- Dispose of latex gloves in the bag. Close bag tightly and place in second bag for disposal.
- Disinfect utility gloves in bleach/water solution.



water/bleach solution



## BATHROOM

- Liquid soap is best- bar soap can breed germs
- Change towels and washcloths daily if possible
- Do not share razors, toothbrushes, drinking glasses, towels, washcloths, enema bags, combs or hairbrushes
- Clean the tub, sink , shower with a standard cleaning product or the bleach/water solution- wear utility gloves
- Disinfect the toilet by pouring FULL strength bleach in the toilet bowl. (wear gloves)
- Mop the floor weekly with a standard floor cleaner
- Pour mop water down toilet – NOT sinks.



# KITCHEN

## Store Food Carefully

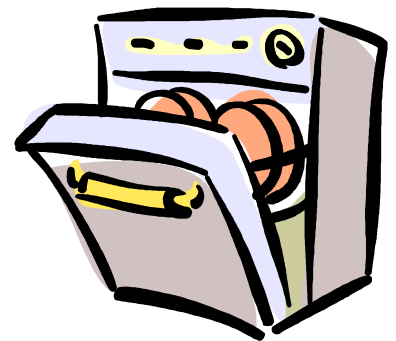
- Keep cold foods cold and hot foods hot
- Refrigerate leftovers promptly in covered containers
- Don't thaw frozen food on the counter- use microwave or thaw overnight in refrigerator

## Preparing Food

- Don't eat raw meat, fish or eggs
- Wash all fruits and vegetables under running water
- Use separate cutting boards, plates and utensils for raw and cooked foods
- Use a clean spoon each time you sample food during prep
- Don't share forks, cups, spoons during meals

## Cleanup

- Clean the can opener after each use
- Wipe down work surfaces with standard cleaners
- Wash dishes in hot soapy water and air dry- or use a dishwasher
- Patients dishes DO NOT have to be washed or stored separately unless specifically instructed to do so by your Hospice Nurse



# LAUNDRY



## **Wear Gloves**

- If laundry items are visibly soiled with body substances
- If you have cuts, cracks or sores on your hands

**Change linens** weekly or when soiled.

**Don't shake soiled bedding-***that can send germs into the air.*

## **Visibly Soiled Laundry Requires Special Care**

- 1. Liquid or semi-liquid body substances** –such as vomit, blood, urine or feces should be flushed down the toilet.
- 2. Presoak** these items to reduce stains and wash separately from other clothing.
- 3. Bleach and hot water** should be used under some circumstances- Ask the Hospice RN when it is needed.

# DISPOSAL OF CONTAMINATED WASTES



**“Sharps”**- needles, razor blades, broken glass should be placed in a puncture resistant container

A plastic laundry detergent jug is a good substitute

## Other waste

- Dressings
- Diapers
- Sanitary or incontinence pads
- Gloves used for care



**Place in a plastic bag- close tightly and then put in a heavy duty garbage bag /container**

## **“Super Bugs”**



In recent years the problem of drug-resistant bacteria and viruses has grown substantially. As a result we are seeing more people identified to be carriers of these “super bugs”. A well known example is MRSA (Methicillin-resistant *Staphylococcus Aureus*). A carrier is someone who has been previously infected and now carries a colony of the bacteria in their body all the time.

We use the same standard precautions for a carrier as we would for all patients. However, if a person is currently infectious and has difficulty following common hygiene practices, Hospice may need to add additional infection control practices such as gowns, masks and goggles when staff and family are providing care.



# Personal Protective Equipment

Refers to items used to provide a barrier against spreading germs from one person to another.

## Examples

- Gloves
- Gowns
- Masks
- Goggles



Your Hospice Team will instruct you in the use of these items and provide you with an adequate supply. Large quantities or stockpiling in the home is discouraged as these items can't be reused or returned to Hospice.



# EMERGENCY PREPAREDNESS



Emergencies can happen any time! Whether it's a winter storm, natural disaster, fire, a public health crisis, or terrorism, there is a lot you can do to be ready for the unexpected.

Being prepared is important – in saving lives and in knowing how to help yourself until family, friends, Hospice and emergency help arrive.

The Hospice team can help you with this planning and in seeing that you are cared for should a disaster occur.

We hope the following tips are helpful.

- In the event of an emergency a Hospice Team Member will contact you. If you need help before we make contact please contact us by phone at **315.788.7323**. If the phones are not working, Hospice will make every effort to contact you or provide information over the airways during the emergency.
- Keep on hand a 3 day supply of medical supplies including medications, inhalers, insulin/syringes, batteries for hearing aids, and wound supplies.
- If you require continuous oxygen and use a concentrator, make sure you keep at least one full back-up tank in case the power goes out. For extended power failures you may need to evacuate.
- Know how to turn off water, gas and electricity at the source.

# Your Emergency Plan

- Post Emergency Phone Numbers.
- Identify local and out of area family contacts.
- Discuss as a family what each member will do and how to reconnect if separated.
- Have a plan for evacuation and/or shelter-in-place.
- Make emergency kits for members of the household.
- Keep records in a safe place.
- Practice your plan with family.



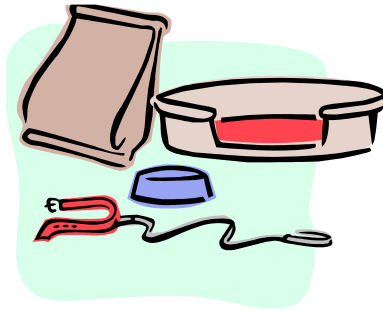
# Emergency Supply Kit



- Battery powered emergency radio, flashlights, batteries
- Whistle
- First Aid kit
- Extra keys to vehicle
- Copies of important documents (medical cards, passport, bank account numbers, insurance policies, birth/marriage certificates, important phone numbers-family, Hospice and doctors)
- Extra eye glasses
- Bottled water – 1 gallon per day per person
- Nonperishable food (canned or ready to eat)
- Manual can opener
- Cash /credit card
- Change of clothing-include rain gear and sturdy shoes
- Blankets or sleeping bags
- Fire extinguisher
- Large plastic bags (contain waste, trash or poncho)
- Toilet paper, paper towels, hand sanitizer
- Personal hygiene items
- Cell phone/charger or hard-wired phone
- Extra gas for car/ generator

## **Pet Preparedness**

- Having your own emergency kit in place will save time.
- Pet food, bowl, pet medications, immunization record, leash, bedding, travel cage or kennel, plastic bags and paper towels for disposing of waste, and a favorite toy.



**Hospice will make every effort to assist you and your family in the event of an emergency. Please make sure we have accurate phone numbers and contact information and update us if anything changes.**

## **MEDICATION SAFETY SHEET**

- KEEP ALL DRUGS OUT OF REACH OF CHILDREN OR ADULTS WITH ALTERED MENTAL STATUS.
- FOLLOW THE DIRECTIONS ON THE LABEL OR THE NEW DIRECTIONS RECEIVED FROM THE HOSPICE NURSE.
- SOME OF THE MEDICATIONS MAY BE TIME- RELEASED -  
Never crush, break, dissolve or cut any medication unless instructed to do so by the Hospice Nurse.
- KEEP MEDICATION IN ITS ORIGINAL CONTAINER UNLESS PLACED IN A “MED-MINDER”.
- ALWAYS USE THE DROPPER PROVIDED BY THE PHARMACY FOR LIQUID CONCENTRATES.
- WRITE DOWN ALL NEW DIRECTIONS FOR MEDICATIONS (especially important if more than one person is assisting the patient with their medications.)
- KEEP A WRITTEN RECORD OF WHEN MEDICATIONS ARE ADMINISTERED AND HAVE AVAILABLE FOR THE HOSPICE NURSE TO REVIEW.
- HOSPICE RN WILL ASSIST YOU IN PROPER DISPOSAL AT THE APPROPRIATE TIME.





## **ADVANCE DIRECTIVES**

It is vital that you have control over your medical care throughout your life. This can only be assured if you, your family, and your physician have discussed what you want. You then need to have the proper tools in place to ensure that the professionals taking care of you know exactly what you want as well as what you do not want. The following information may help you understand a bit more about those tools.

Your Hospice Team strongly recommends the completion of a Health Care Proxy (HCP) and a Medical Orders for Life-Sustaining Treatment (MOLST), as these will provide a recognized authority and/or actual medical order that will stand for you when you are unable to communicate for yourself. The Living Will, which is also outlined in the following pages, serves as a guide to either start conversations or provide direction for your Health Care Proxy, but does not have the power to direct medical care by itself. Hospice stands ready to answer your questions and help you in any way to get these vital protections in place.

We know these conversations and decisions can be very difficult, but they are absolutely vital. Advance Directives allow you to maintain control, no matter what your health care plans may be. You may have many questions about some of the factors involved, such as what exactly CPR entails, or what the side effects of artificial nutrition or hydration are. Your Hospice Team can answer those questions.



# 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 may 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

This is an important legal document. Before signing, you should understand the following facts:

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 this 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 the 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. 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. The person you are appointing as your agent or your alternate agent cannot sign as a witness on your Health Care Proxy form.

## **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 cannot sign as a witness. You can use the form printed here, but you don't have to use this form.

## **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 decision 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 what you have 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 again become able to make your own health care decisions, 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

## Frequently Asked Questions, *continued*

*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 or 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 some treatment options (such as removing certain treatment) they must tell you or 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 addition, 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 care 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 you want. Keep a copy in your wallet or purse or with other important papers, but not in a location where no one can access it, like a safe deposit box. Bring a copy if you are admitted to the hospital, or if you undergo outpatient surgery.

## Frequently Asked Questions, *continued*

### **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?**

Yes. As of August 26, 2009, your health care agent is authorized to make decisions after your death, but only those regarding organ and/or tissue donation. Your health care agent must make such decisions as noted on your Health Care Proxy form.

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

It is important to note your wishes about organ and/or tissue donation to your health care agent, the person designated as your decedent's agent, if one has been appointed, and your family members. 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 health care agent; your decedent's agent; your spouse, if you are not legally separated, or your domestic partner; a son or daughter 18 years of age or older; either of your parents; a brother or sister 18 years of age or older; or a guardian appointed by a court prior to the donor's death.

# Health Care Proxy Form Instructions

## 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 your 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 agent's authority in any way, you may say so here or discuss them with your health care agent. If you do not state 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 right 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 make 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.*



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 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 else 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. New York law does provide for certain individuals in order of priority to consent to an organ and/or tissue donation on your behalf: your health care agent, your decedent's agent, your spouse, if you are not legally separated, or your domestic partner, 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.

**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 a witness.

# HEALTH CARE PROXY

I, \_\_\_\_\_ hereby appoint the following person as my HEALTH CARE AGENT, to make any and all health care decisions for me except for any restrictions I have noted below. This Proxy shall take effect when and if I become unable to make my own health care decisions.

\_\_\_\_\_  
HEALTH CARE AGENT NAME PHONE

\_\_\_\_\_  
ADDRESS

\_\_\_\_\_  
ALTERNATE HEALTH CARE AGENT NAME PHONE

\_\_\_\_\_  
ADDRESS

Optional instructions or limitations on the Health Care Agent's authority, if any:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

PLEASE NOTE: If, at some future time, you cannot make decisions for yourself, New York State law prohibits your Health Care Agent from making decisions about withholding artificial nutrition and hydration from you, unless you have already made your wishes known.

If I cannot eat or drink enough because of my irreversible medical conditions: \_\_\_\_\_ I DO want artificial  
\_\_\_\_\_ I DO NOT  
nutrition (intravenous or tube feeding) and hydration (intravenous fluids).

\_\_\_\_\_  
SIGNATURE DATE

I hereby certify that I am over 18 years of age, and that the person who signed this Proxy appeared to do so willingly and free from duress and that he or she signed (or asked another to sign for him or her) this Proxy in my presence.

\_\_\_\_\_  
WITNESS WITNESS

\_\_\_\_\_  
ADDRESS ADDRESS

\_\_\_\_\_  
DATE DATE

# **DO NOT RESUSCITATE ORDERS**

## **A Guide for Patients and Families**

### **What is a do-not resuscitate order?**

A do-not resuscitate (DNR) order in the patient's medical chart instructs the medical staff not to try to revive the patient if breathing or heartbeat has stopped. This means physicians, nurses and others will not initiate such emergency procedures as mouth-to-mouth resuscitation, external chest compression, electric shock, insertion of a tube to open the patient's airway, injection of medication into the heart or open chest heart massage.

If the patient is in a nursing home a DNR order instructs the staff not to perform emergency resuscitation and not to transfer the patient to a hospital for such procedures.

### **Can I request a DNR order?**

Yes. Under New York State law, all adult patients can request a DNR order. If you are sick and incapable of deciding about resuscitation, a family member or others close to you can decide on your behalf.

Under what circumstances can a family member or close friend consent to a DNR order?

A family member or close friend can consent to a DNR order only when you are unable to decide for yourself and:

- You have a terminal condition; or
- You are permanently unconscious; or
- CPR would be medically futile; or
- CPR would impose an extraordinary burden on you given your medical condition and the expected outcome of resuscitation.

Anyone deciding for you must base the decision on your wishes, including your religious and moral beliefs, or if your wishes are not known, on your best interest.

### **What if members of my family disagree?**

They can ask for the matter to be mediated. Your physician will request mediation if he or she is aware of any disagreement among family members.

What if I lose the capacity to decide and do not have anyone who can decide on my behalf?

A DNR order can be entered only if two physicians conclude that CPR would be medically useless or if a court approves the DNR order. It would be best if you discussed the matter with your physician and left instructions in advance.

**Who can consent to a DNR order for children?**

A DNR order can be entered in the record for a patient under the age of 18 only with the consent of the patient's parent or guardian. If the minor has the capacity to decide, the minor's consent is also required for a DNR order.

**What are the advantages and disadvantages of CPR?**

Cardiopulmonary resuscitation (CPR), when successful, restores heartbeat and breathing and enables a patient to resume his or her previous lifestyle. In other cases, CPR may fail to restore basic life functions or only partially succeed; leaving the patient brain-damaged or otherwise impaired.

The success of CPR depends on the patient's overall medical condition and level of functioning before hospitalization. Age alone is not a predictor of success, although illnesses and frailties associated with advanced age often result in less successful outcomes.

**Is my right to request or receive other treatment affected by a DNR order?**

No. A DNR order is only a decision about CPR and does not relate to other treatment.

**Are DNR orders ethically acceptable?**

It is widely recognized by health care professionals, clergy, lawyers and others that DNR orders are medically and ethically appropriate under certain circumstances. For some patients, CPR offers more burdens than benefits, and may be contrary to the patient's wishes.

**Is my consent required for a DNR order?**

Yes. Your physician must obtain your consent before entering a DNR order in your record if you are mentally capable of deciding, unless a discussion about CPR and your condition would cause you severe harm. In an emergency, it is assumed that all patients would consent to CPR unless a DNR order is in the record.

**How can I make my wishes about DNR known?**

An adult patient in a hospital or nursing home can consent to a DNR order orally, as long as two witnesses are present. One witness must be a physician. You can also make your wishes known before or during hospitalization in writing, before any two adults who must sign your statement as witnesses. A living will may be used to convey these wishes as long as it is properly witnessed.

You can specify that you want a DNR order only under certain circumstances (such as if you become terminally ill or permanently unconscious) or that you wish only specific CPR procedures performed such as mouth-to-mouth breathing but not open heart massage.

Before making a decision about CPR you should speak with your physician about your overall health and the benefits and burdens CPR would provide for you. A full and early discussion between you and your doctor can avoid later misunderstandings.

**If I request a DNR order, is my physician bound to honor my wishes?**

If you don't want to be resuscitated and you request a DNR order, your physician must either:

- Enter the order in your chart; or
- Transfer responsibility for your care to another physician; or
- Refer the matter to a dispute mediation system in the hospital or nursing home. The mediation system is only authorized to mediate disputes; it cannot overrule your decision.

If mediation has not resolved the dispute within 72 hours, your physician must enter the order or transfer you to the care of another physician.

**What happens if I do not have the capacity to decide for myself?**

You are presumed by law to be mentally capable of deciding about CPR unless two physicians, or a court, determine that you no longer have the capacity to make the decision. You will be informed of this determination if you are able to understand it, and no DNR order will be written if you object.

**If I do not have the mental capacity to make a decision about CPR and do not leave instruction in advance, who will decide?**

If you lose the capacity to decide and did not leave advance instructions, a DNR order can be entered only with the consent of someone chosen by you in advance, or by a family member or another person with a close personal relationship to you. The person highest on the following list will decide on your behalf:

- A person you have selected to decide about resuscitation;
- A court appointed guardian (if there is one);
- Your closest relative;
- A close friend

**How can I select someone to decide for me?**

If you are a patient in a hospital or nursing home, you can appoint a person orally, with two witnesses present.

You can also appoint someone during or in advance of hospitalization by stating your wishes in writing and signing that statement with any two adults present. The adults must also sign your written statement.

**What happens if I change my mind after I consent to a DNR order?**

You or anyone who consents to a DNR order on your behalf can withdraw that consent at any time by informing your physician, nurses or others of the decision.

**What happens to a DNR order if I am transferred from a nursing home to a hospital or vice versa?**

The health facility where you are sent can continue the DNR order but is not obligated to do so. If the order is not continued, you or anyone who decided on your behalf will be informed and can request that the order be entered again.

**New York State  
Department of Health**

## **NOTICE OF HOSPICE PRIVACY PRACTICES**

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

### **USE AND DISCLOSURE OF HEALTH INFORMATION**

Hospice of Jefferson County, Inc [*Hospice*] may use your health information, information that constitutes protected health information as defined by the Privacy Rule of the Administrative Simplifications of the Health Insurance Portability and Accountability Act of 1996, for the purposes of providing you treatment, obtaining payment for your care and conducting health care operations. Hospice has established policies to guard against unnecessary disclosure of your health information.

### **OUR OBLIGATIONS**

We are required by law to:

- Maintain the privacy of protected health information
- Give you this notice of our legal duties and privacy practices regarding health information about you
- Follow the terms of our notice that is currently in effect

### **HOW WE MAY USE AND DISCLOSE HEALTH INFORMATION**

The following describes the ways we may use and disclose health information that identifies you ("Private Health Information"). Except for the purposes described below, we will use and disclose Health Information only with your written permission. You may revoke such permission at any time by writing to our Privacy Officer, Hospice of Jefferson County, Inc. 1398 Gotham Street, Watertown, NY 13601, 315.788.7323.

#### **For Treatment**

We may use and disclose Health Information for your treatment and to provide you with treatment-related health care services. For example, we may disclose Health Information to your attending physician, members of the Hospice Interdisciplinary Team or other personnel who have agreed to assist Hospice in coordinating your care. Hospice also may disclose your healthcare information to individuals outside of Hospice, who are involved in your medical care and need the information to provide you with medical care including family members, clergy who you have designated, pharmacists, suppliers of medical equipment or other health care professionals.

**For Payment**

We may use and disclose Health Information so that we or others may bill and receive payment from you, an insurance company or a third party for the treatment and services you received. For example, Hospice may be required to give your health plan information about you to your health insurer so that they will pay for your treatment. Hospice also may need to obtain prior approval from your insurer and may need to explain to the insurer your need for hospice care and the services that will be provided to you.

**For Health Care Operations**

We may use and disclose Health Information for health care operations purposes. These uses and disclosures are necessary to make sure that all of our patients receive quality care and to operate and manage our Hospice program. We also may share information with other entities that have a relationship with you (for example, your health plan) for their health care operation activities.

Health care operations include such activities as:

- Quality assessment and improvement activities.
- Activities designed to improve health or reduce healthcare costs.
- Protocol development, case management, and care coordination.
- Contacting health care providers and patients with information about treatment alternatives and other related functions that do not include treatment.
- Professional review and performance evaluation.
- Training programs including those in which students, trainees or practitioners in health care learn under supervision.
- Training of non-healthcare professionals.
- Accreditation, certification, licensing or credentialing activities.
- Review and auditing, including compliance reviews, medical reviews, legal services and compliance programs.
- Business planning and development including cost management and planning related analyses and formulary development.
- Business management and general administrative activities of Hospice.
- Fundraising for the benefit of Hospice.

For example, Hospice may use your health information to evaluate its staff performance, combine your health information with other Hospice patients in evaluating how to more effectively serve all Hospice patients, disclose your health information to Hospice staff and contracted personnel for training purposes, or contact you as part of general fundraising and community information mailings.



**Fundraising Activities**

Hospice may use information about you including your name, address, phone number and the dates you received care in order to contact you or your family to raise money for Hospice. Hospice may also release this information to a related Hospice Foundation. If you do not want Hospice to contact you or your family, notify Privacy Officer, Hospice of Jefferson County, Inc. 1398 Gotham Street, Watertown, NY 13601, 315.788.7323 and indicate that you do not wish to be contacted.

**Appointment Reminders, Treatment Alternatives and Health Related Benefits and Services**

Hospice may use and disclose Health Information to contact you to remind you that you have an appointment with us. We also may use and disclose Health Information to tell you about treatment alternatives or health-related benefits and services that may be of interest to you.

**Individuals Involved in Your Care or Payment for Your Care**

When appropriate, Hospice may share Health Information with a person who is involved in your medical care or payment for your care, such as your family or a close friend. We also may notify your family about your location or general condition or disclose such information to an entity assisting in a disaster relief effort.

**Research**

Under certain circumstances, Hospice may use and disclose Health Information for research. For example, a research project may involve comparing the health of patients who received one treatment to those who received another, for the same condition. Before we use or disclose Health Information for research, the project will go through a special approval process. Even without special approval, we may permit researchers to look at records to help them identify patients who may be included in their research project or for other similar purposes, as long as they do not remove or take a copy of any Health Information.

## **SPECIAL SITUATIONS**

### ***As Required by Law***

Hospice will disclose Health Information when required to do so by international, federal, state or local law.

### **To Avert a Serious Threat to Health or Safety**

Hospice may use and disclose Health Information when necessary to prevent a serious threat to your health and safety or the health and safety of the public or another person. Disclosures, however, will be made only to someone who may be able to help prevent the threat.

### **Business Associates**

Hospice may disclose Health Information to our business associates, business associate subcontractors, and data storage vendors (both electronic and hard copy), that perform functions on our behalf or provide us with services; if the information is necessary for such functions or services. For example, we may use another company to perform therapy services on our behalf. All of our business associates are obligated to protect the privacy of your information and are not allowed to use or disclose any information other than as specified in our contract.

### **Organ and Tissue Donation**

If you are an organ donor, Hospice may use or release Health Information to organizations that handle organ procurement or other entities engaged in procurement, banking or transportation of organs, eyes or tissues to facilitate organ, eye or tissue donation and transplantation.

### **Specified Government Functions**

In certain circumstances, The Federal regulations authorize Hospice to use or disclose your health information to facilitate specified government functions relating to military or veterans, national security and intelligence activities, protective services for the President or others and medical suitability determinations.

### **Workers' Compensation**

Hospice may release Health Information for workers' compensation or similar programs.

### **Public Health Risks**

Hospice may disclose Health Information for public health activities. These activities generally include disclosures to prevent or control disease, injury or disability; report births and deaths; report child abuse or neglect; report reactions to medications or problems with products; notify people of recalls of products they may be using; a person who may have

been exposed to a disease or may be at risk for contracting or spreading a disease or condition; and the appropriate government authority if we believe a patient has been the victim of abuse, neglect or domestic violence. Hospice will only make this disclosure if you agree or when required or authorized by law.

### **Health Oversight Activities**

Hospice may disclose Health Information to a health oversight agency for activities authorized by law. These oversight activities include, for example, audits, investigations, inspections, and licensure. These activities are necessary for the government to monitor the health care system, government programs, and compliance with civil rights laws.

### **Data Breach Notification Purposes**

Hospice may use or disclose your Protected Health Information to provide legally required notices of unauthorized access to or disclosure of your health information.

### **Lawsuits and Disputes**

If you are involved in a lawsuit or a dispute, Hospice may disclose Health Information in response to a court or administrative order. Hospice also may disclose Health Information in response to a subpoena, discovery request, or other lawful process by someone else involved in the dispute, but only if efforts have been made to tell you about the request or to obtain an order protecting the information requested.

### **Law Enforcement**

Hospice may release Health Information if asked by a law enforcement official if the information is: (1) in response to a court order, subpoena, warrant, summons or similar process; (2) limited information to identify or locate a suspect, fugitive, material witness, or missing person; (3) about the victim of a crime even if, under certain very limited circumstances, we are unable to obtain the person's agreement; (4) about a death we believe may be the result of criminal conduct; (5) about criminal conduct on our premises; and (6) in an emergency to report a crime, the location of the crime or victims, or the identity, description or location of the person who committed the crime.

### **Coroners, Medical Examiners and Funeral Directors**

Hospice may release Health Information to a coroner or medical examiner. This may be necessary, for example, to identify a deceased person or determine the cause of death. We also may release Health Information to funeral directors as necessary for their duties.

### **Inmates or Individuals in Custody**

If you are an inmate of a correctional institution or under the custody of a law enforcement official, Hospice may release Health Information to the correctional institution or law

enforcement official. This release would be if necessary: (1) for the institution to provide you with health care; (2) to protect your health and safety or the health and safety of others; or (3) the safety and security of the correctional institution.

## **USES AND DISCLOSURES THAT REQUIRE US TO GIVE YOU AN OPPORTUNITY TO OBJECT AND OPT OUT**

### **Individuals Involved in Your Care or Payment for Your Care**

Unless you object, Hospice may disclose to a member of your family, a relative, a close friend or any other person you identify, your Protected Health Information that directly relates to that person's involvement in your health care. If you are unable to agree or object to such a disclosure, Hospice may disclose such information as necessary if we determine that it is in your best interest based on our professional judgment.

### **Disaster Relief**

Hospice may disclose your Protected Health Information to disaster relief organizations that seek your Protected Health Information to coordinate your care, or notify family and friends of your location or condition in a disaster. Hospice will provide you with an opportunity to agree or object to such a disclosure whenever we practically can do so.

## **YOUR WRITTEN AUTHORIZATION IS REQUIRED FOR OTHER USES AND DISCLOSURES**

The following uses and disclosures of your Protected Health Information will be made only with your written authorization:

1. Uses and disclosures of Protected Health Information for marketing purposes; and
2. Disclosures that constitute a sale of your Protected Health Information

Other uses and disclosures of Protected Health Information not covered by this Notice or the laws that apply to us will be made only with your written authorization. If you do give us an authorization, you may revoke it at any time by submitting a written revocation to our Privacy Officer and we will no longer disclose Protected Health Information under the authorization. But disclosure that Hospice made in reliance on your authorization before you revoked it will not be affected by the revocation.

## **YOUR RIGHTS**

You have the following rights regarding Health Information we have about you:

### **Right to Inspect and Copy**

You have a right to inspect and copy Health Information that may be used to make decisions about your care or payment for your care. This includes medical and billing records. To inspect and copy this Health Information, you must make your request, in writing, to Privacy Officer, Hospice of Jefferson County, Inc. 1398 Gotham Street, Watertown, NY 13601, 315.788.7323. We have up to 30 days, with the option of a one-time 30-day extension, to make your Protected Health Information available to you and we may charge you a reasonable fee for the costs of copying, mailing or other supplies associated with your request. We may not charge you a fee if you need the information for a claim for benefits under the Social Security Act or any other state or federal needs-based benefit program. We may deny your request in certain limited circumstances. If we do deny your request, you have the right to have the denial reviewed by a licensed healthcare professional who was not directly involved in the denial of your request, and we will comply with the outcome of the review.

### **Right to an Electronic Copy of Electronic Medical Records**

If your Protected Health Information is maintained in an electronic format (known as an electronic medical record or an electronic health record), you have the right to request that an electronic copy of your record be given to you or transmitted to another individual or entity. We have up to 30 days, with the option of a one-time 30-day extension, to make your Protected Health Information available to you. We will make every effort to provide access to your Protected Health Information in the form or format you request, if it is readily producible in such form or format. If the Protected Health Information is not readily producible in the form or format you request your record will be provided in either our standard electronic format or if you do not want this form or format, a readable hard copy form. We may charge you a reasonable, cost-based fee for the labor associated with transmitting the electronic medical record.

### **Right to Request PHI Directly Sent to a Designated Individual**

You have the right to request a copy of your PHI be directly sent to a designated individual. This right applies to both paper and electronic information. To request a copy of your PHI to be sent to a designated individual, you must make your request, in writing, to Privacy Officer, Hospice of Jefferson County, Inc. 1398 Gotham Street, Watertown, NY 13601, 315.788.7323. You must clearly identify the designated recipient and where the information should be sent. Reasonable verification procedures will be used to verify the identity and authority of the requesting individual prior to disclosing any information.

**Right to Get Notice of a Breach**

You have the right to be notified upon a breach of any of your unsecured Protected Health Information.

**Right to Amend**

If you feel that Health Information we have is incorrect or incomplete, you may ask us to amend the information. You have the right to request an amendment for as long as the information is kept by or for our office. To request an amendment, you must make your request, in writing, to Privacy Officer, Hospice of Jefferson County, Inc. 1398 Gotham Street, Watertown, NY 13601, 315.788.7323. Hospice may deny the request if it is not in writing or does not include a reason for the amendment. The request may also be denied if your health information records were not created by Hospice, if the records you are requesting are not part of Hospice's records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy, or if, in the opinion of Hospice, the records containing your health information are accurate and complete.

**Right to an Accounting of Disclosures**

You have the right to request a list of certain disclosures we made of Health Information for purposes other than treatment, payment and health care operations or for which you provided written authorization. To request an accounting of disclosures, you must make your request, in writing, to Privacy Officer, Hospice of Jefferson County, Inc. 1398 Gotham Street, Watertown, NY 13601, 315.788.7323. The request should specify the time period for the accounting starting on or after April 14, 2003. Accounting requests may not be made for periods of time in excess of six (6) years. Hospice would provide the first accounting request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

**Right to Request Restrictions**

You have the right to request a restriction or limitation on the Health Information Hospice uses or discloses for treatment, payment, or health care operations. You also have the right to request a limit on the Health Information we disclose to someone involved in your care or the payment for your care, like a family member or friend. For example, you could ask that we not share information about a particular diagnosis or treatment with your spouse. To request a restriction, you must make your request, in writing, to Privacy Officer, Hospice of Jefferson County, Inc. 1398 Gotham Street, Watertown, NY 13601, 315.788.7323. We are not required to agree to your request unless you are asking us to restrict the use and disclosure of your Protected Health Information to a health plan for payment or health care operation purposes and such information you wish to restrict pertains solely to a health care item or service for which you have paid us "out-of-pocket" in

full. If we agree, we will comply with your request unless the information is needed to provide you with emergency treatment.

### **Out-of-Pocket-Payments**

If you paid out-of-pocket (or in other words, you have requested that Hospice not bill your health plan) in full for a specific item or service, you have the right to ask that your Protected Health Information with respect to that item or service not be disclosed to a health plan for purposes of payment or health care operations, and Hospice will honor that request.

### **Right to Request Confidential Communications**

You have the right to request that we communicate with you about medical matters in a certain way or at a certain location. For example, you can ask that we only contact you by mail or at work. To request confidential communications, you must make your request, in writing, to Privacy Officer, Hospice of Jefferson County, Inc. 1398 Gotham Street, Watertown, NY 13601, 315.788.7323. Your request must specify how or where you wish to be contacted. We will accommodate reasonable requests.

### **Right to a Paper Copy of This Notice**

You have the right to a paper copy of this notice. You may ask us to give you a copy of this notice at any time. Even if you have agreed to receive this notice electronically, you are still entitled to a paper copy of this notice. To obtain a paper copy of this notice, please contact our Privacy Officer, Hospice of Jefferson County, Inc. 1398 Gotham Street, Watertown, NY 13601 315.788.7323.

## **DUTIES OF HOSPICE**

Hospice is required by law to maintain the privacy of your health information and provide to you and your representative this Notice of its duties and privacy practices. Hospice is required to abide by the terms of its Notice as may be amended from time to time. Hospice reserves the right to change terms of its Notice and to make the new Notice provisions effective for all health information that it maintains. If Hospice changes its Notice, Hospice will provide a copy of the revised Notice to you or your appointed representative. You and your representative have the right to express complaints to Hospice and the Secretary of the Department of Health and Human Services if you, or your representative, believe that your privacy rights have been violated. Any complaints to Hospice should be made in writing to Privacy Officer, Hospice of Jefferson County, Inc. 1398 Gotham Street, Watertown, NY 13601, 315.788.7323. ***You will not be penalized for filing a complaint.***

## **CONTACT PERSON**

Hospice has designated the Privacy Officer as its contact person for all issues regarding patient privacy and your rights under Federal privacy standards. You may contact this person at Hospice of Jefferson County, Inc. 1398 Gotham Street, Watertown, NY 13601, 315.788.7323.

## **EFFECTIVE DATE**

This Notice is effective August 20, 2013

**If you have any questions about this notice, please contact Privacy Officer, Hospice of Jefferson County, Inc. 1398 Gotham Street, Watertown, NY, 13601. 315.788.7323.**

For more information on HIPAA privacy requirements, HIPAA electronic transactions and code sets regulations and the proposed HIPAA security rules, please go to the DHHS website <http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html>



## HOSPICE MEDICARE BENEFIT ELECTION

By choosing hospice Medicare benefits, I am entering an alternative payment arrangement. While I am using hospice services, the comprehensive hospice coverage substitutes for my existing benefits. Only Hospice of Jefferson County, Inc. will be able to receive Medicare payment for my supportive palliative care. Hospice care is not curative. Supportive palliative care is provided by hospice. The program's goal is not to cure my advanced, life-threatening illness, but to reduce symptoms such as pain or nausea and to provide emotional and spiritual support.

1. Exceptions to the inclusive Hospice payment are:

- A. Medicare will make payment for the services of my attending physician if he/she is not a hospice employee or is not receiving any payments from Hospice of Jefferson County, Inc.
- B. Medicare will make payment for services provided to me if I wish to be transferred to another hospice and these services are arranged through Hospice of Jefferson County, Inc.
- C. Medicare will make payment for care provided for conditions unrelated to my advanced, life-threatening illness and for which there are existing benefits.

2. Medicare will make payment to Hospice of Jefferson County, Inc. on a daily (per diem) basis. There are defined periods under the hospice benefit. Before the end of each period, Hospice will assess the appropriateness of my continuation into the next period under the hospice benefit. The periods and duration's are as follows:

First Benefit Period	90 days
Second Benefit Period	90 days
Unlimited Number of	60 Day Benefit Periods

- 3. I can choose not to continue hospice care at any time. To discontinue hospice care, I must complete a revocation statement. I can obtain this statement from any Hospice employee.
- 4. If I choose to revoke the hospice benefit at any time, I will revert to my original coverage under traditional Medicare benefits. I thereby may choose to receive care from other qualified service providers who may be paid by Medicare.
- 5. I can choose to receive hospice care from another hospice program once during each benefit period. To change programs, I must first confirm that the hospice I wish to be admitted to can admit me and on what date. I must inform Hospice of Jefferson County, Inc. of my wishes so arrangements for transfer can be made. I then must document the date I wish to discontinue care from Hospice of Jefferson County, Inc., the name of the hospice from which I wish to receive care, and the date that care will start. No benefit days will be lost by changing to another hospice program.



## **PATIENT AND FAMILY BILL OF RIGHTS**

The Hospice Patient and Family's rights are highly regarded and guide the Hospice staff in their service to the patient and family. These rights are as follows:

To be fully informed and to be given a statement of the Hospice services and related charges including charges for services not covered by third party payors or not covered by the Hospice basic rate;

To be fully informed of the patient's medical condition to the "extent acceptable to the patient";

To choose his or her attending physician;

To be allowed the free exercise of independent personal decisions and knowledge of available choices. Personal decisions may be made or secured through the execution of advanced medical directives such as the designation of a health care proxy or the preparation of a living will;

To be involved in developing the hospice plan of care;

To receive appropriate and timely care and services for the duration of the illness for which Hospice was selected without discrimination regarding race, color, creed, national origin, background or belief, sex, sexual preference, marital status, age, disability, veteran's status and level of income or ability to pay;

### **RIGHTS continued:**

To participate in decisions concerning care, including the right to refuse medication and treatment after being fully informed of and understanding the consequences of such actions;

To receive effective pain management and symptom control from the hospice for conditions related to the terminal illness;

For confidentiality of all records pertaining to the patient and family, with availability only to authorized individuals;

To be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of property;

To revoke Hospice, or to seek discharge from the hospice program, without fear of

interference, coercion, or reprisal and to receive appropriate assistance from the hospice interdisciplinary team in planning discharge and arranging for continuity of care;

To recommend changes in policies and services or to voice grievances regarding:

- Treatment or care that is (or fails to be) furnished,
- Lack of respect of one's property by those furnishing services on behalf of Hospice

to Hospice of Jefferson County Inc., to the Syracuse office representatives of the New York State Department of Health, 217 South Salina Street, Syracuse, NY 13202, 1-800-628-5972, or to any outside representatives of the patient's choice, free from restraint, interference, coercion, discrimination or reprisal.

## **PALLIATIVE MEDICAL CARE GUIDELINES**

Hospice upholds the physician-patient relationship established prior to the patient's hospice admission in accordance with the patient's wishes. These hospice medical care guidelines have been prepared to assist the patient/family and health care team in their understanding of certain medical aspects of hospice care.

Hospice care is a specialized form of treatment and services for a patient and family experiencing advanced life-threatening disease. The primary focus of care is upon pain/symptom control and other supportive measures. It is an alternative to more aggressive medical regimes that may no longer be helpful or desired.

In addition to patients with cancer, persons with other end-stage diseases such as cardiac, chronic lung, Alzheimer's, kidney and liver disease, AIDS and ALS may also be appropriate for hospice care.

Each patient's situation is evaluated by the attending physician and assessed by the hospice interdisciplinary team. Each Hospice patient has a care coordinator who is a registered nurse. The hospice medical director is available for consultation.

For a procedure and/or treatment to be considered appropriate as Hospice palliative care, the patient, primary care person, attending physician, and hospice interdisciplinary team review the treatment in light of the patient's life expectancy and quality of life at that point in time. Treatment decision-making is thus focused upon enhancing the quality of the patient's remaining life.

According to hospice regulations and in order to be covered by insurance, all services and medical treatments must be consistent with the hospice plan of care (i.e., reasonable and necessary for the palliative management of the advanced disease) and be pre-authorized by hospice.

A patient-physician decision to pursue curative or more aggressive therapy through medical intervention(s) will be respected. Patients are always free to withdraw from hospice. Under such circumstances, hospice will discuss with the patient and the attending physician the continuing appropriateness for hospice care. Upon the decision to discharge the patient, hospice will make appropriate referrals and/or affect a timely transfer to other health care and social services.

## Specific guidelines for Palliative Medical Care

1. Palliative medical care includes optimizing the patients' ability to participate in activities of daily living. Hospice provides teaching for patients and caregivers regarding the provision of safe care.
2. A **DO NOT RESUSCITATE ORDER** (DNR) is appropriate for Hospice patients and shall be consistent with New York State regulations. Hospice of Jefferson Co., Inc. does not require their staff to remain current/certified in cardiopulmonary resuscitation (CPR) therefore; the patient/family should not have the expectation of receiving CPR directly from the hospice staff. The patient has the right to pursue resuscitative measures through existing emergency medical services (for example 911), and caregivers will be instructed and/or assisted in doing so.
3. Medications will be administered for the control of pain and other symptoms in order to achieve maximum comfort relief. The goal is to keep the patient as alert and as involved in the care as possible.
4. Diagnostic tests and other assessments are appropriate when results are needed for palliation of symptoms. Testing for the purpose of evaluating progression of disease without the expectation of changing symptomatic treatment is usually no longer appropriate.
5. Hospice works with the patient, family and attending physician to evaluate the goals, effectiveness and palliative nature of treatments and therapies such as:
  - Radiation therapy
  - Chemotherapy
  - Surgery
  - Total parenteral nutrition (intravenous)
  - Enteral nutrition (feeding tube)
  - Blood transfusions
  - Intravenous antibiotics/medications/hydration
  - Spinal pain medications
  - BIPAP & CPAP

The risks, burden and benefits of such treatments, the patient's functional status and estimated prognosis, and supporting medical data will be considered when making decisions about these types of treatments.

Hospice promotes the use of the least burdensome treatment measures whenever possible.

6. Hospice provides an on-call service that is available to patients and families 24 hours a day, 7 days a week to handle questions, problems and emergencies, and to provide home assessment of problems. Ambulance or emergency room services are not covered unless authorized by the hospice plan of care.
7. Hospice rejects the practice of assisted suicide or euthanasia in the care of the terminally ill.