Hospice Buffalo is here…
to comfort, to guide,
and support.
Because we’re more than
end-of-life care,
we’re quality-of-life care.

Your Hospice Care Team

Nurse___________________________
Social Worker___________________________
Chaplain___________________________
Team Phone Number___________________________

Hospice Buffalo
225 Como Park Boulevard, Cheektowaga, NY 14227-1480 • P: (716) 686-8000 • F: (716) 686-8101 • HospiceBuffalo.com
09.2019
# TABLE OF CONTENTS

## Patient Care Guide & Summary of Services
- Urgent Medical Needs ................................................................. 1
- Hospice Services ..................................................................... 2

## Preparing for Disease Changes
- Early Stages ........................................................................ 4
- End-of-Life Phase ................................................................. 6

## Caregiving Guidelines
- Symptom Scale & Personal Care ........................................... 9
- Nutrition & Breathing Difficulties ......................................... 10
- Bowel & Bladder Care ............................................................ 11
- Pain ..................................................................................... 12
- Mental Changes/Delirium ...................................................... 13

## Facing the Food Issue .......................................................... 14

## 25 Practical Tips .................................................................. 15

## Final Stage/Dying Process ..................................................... 16

## Safety at Home
- General Home Safety ........................................................... 18
- Infection Control Practices .................................................. 19

## Emergency Preparedness
- Emergency Supply List ......................................................... 20
- Common Emergency Protection Actions ............................. 21

## Patient Bill of Rights & Responsibilities ............................... 22

## Medication Disposal ............................................................. 25

## Advance Care Planning
- Patient Self-determination Statement:
  - Healthcare Proxy, Living Will ........................................... 28
  - MOLST, Planning in Advance for Your Medical Treatment ......... 29
  - Guide to Deciding About CPR/DNR .................................... 30
  - Health Care Proxy Form .................................................. 31

## Joint Notice of Privacy Practices ............................................. 33

## Hospice Billing Statement ...................................................... 39
IT’S ABOUT HOW YOU LIVE
Hospice and palliative (comfort) care are considered the premier models of quality, compassionate care for people facing serious illness. At Hospice Buffalo, we believe that all persons who are coping with serious illness deserve to direct the course of their care, to be pain-free, to fully participate in life, and to live with grace, dignity and comfort.

We offer a collaborative team approach to expert pain- and symptom-management and provide emotional, social and spiritual support tailored to each individual’s needs and wishes. Support is available for family and caregivers as well.

A WEALTH OF SERVICES FOR YOU AND YOUR FAMILY
Hospice Buffalo was founded in 1978 and has cared for patients and their families at home, in hospitals, in assisted living facilities and in nursing homes or in other home-like settings.

We are honored to assist you and your loved ones during this difficult time of life.

If you have additional questions or wish to learn more about Hospice Buffalo and its programs, please visit our website at HospiceBuffalo.com.
AFTER HOURS AVAILABILITY: 24 HOUR A DAY/SEVEN DAYS A WEEK
Our office is open from 8:00 A.M. to 4:00 P.M. Monday through Friday. You can reach the office by calling the phone number of your assigned team. After 4:00 P.M. or on the weekends and holidays, AN ON-CALL NURSE IS ALWAYS AVAILABLE. Call your Team’s phone number and the answering service will take your name, the patient’s name, and the phone number at which you can be reached. Our on-call nurse will return your call within 20 minutes. If not, please call back and inform the answering service.

IN CASE OF MEDICAL URGENCIES, CALL HOSPICE FIRST
Call your Hospice Care Team for all medical needs and in urgent situations.
If hospitalization is required, your nurse will make the necessary arrangements with your physician for inpatient care in our hospice inpatient unit or in a contracted hospital. As a hospice patient, all health care services (i.e. hospitalizations, emergency room visits) must be coordinated by your Hospice Team or the cost of these services will not be covered.

INTERDISCIPLINARY TEAMS
Hospice Buffalo is pleased that you have chosen us to provide palliative care services. Our mission is to provide you and your family with exceptional medical care, social, emotional and spiritual support. Our specially-trained team of nurses, physicians, social workers, expressive therapists, volunteers, pastoral counselors, and home health aides offer a holistic approach to care; treating mind, body, and spirit. The Hospice team works with your physician to keep you comfortable and safe in the care setting that is most appropriate for your condition.
HOSPICE SERVICES

Our entire staff is committed to helping your loved one live comfortably by managing their symptoms during this time of advanced illness. We recognize the difficulty and stress you and your family are experiencing and encourage you to call your Hospice Care Team at any time to answer questions, discuss options, and to coordinate any additional services.

Hospice Care is provided in homes, group homes for the developmentally disabled, Nursing Homes, and Assisted Living Facilities. All services are determined by the Hospice Interdisciplinary Team in collaboration with your loved one’s attending physician. Hospice homecare services are available on an intermittent basis. We do not offer 24 hour continual care. Hospice also provides care in dedicated units within our area hospitals.

Hospice Inpatient Care is available on a short-term basis for acute symptoms that cannot be managed in the home. Inpatient care is available for short term pain- and symptom-management in our Hospice Inpatient Unit. A Do Not Resuscitate (DNR) order must be in place for inpatient care in the Hospice Inpatient Unit.

Inpatient Respite Care is available for your loved one when caregivers require a rest, but is limited to 5 days per respite stay and is based on bed availability in our Inpatient Unit.

Hospice Physician Services are available on a consultative basis to assist your loved one’s attending physician with symptom- and medication-management. Hospice physicians are able to see patients in their homes, nursing homes and hospitals. When coordinated with the attending physician, and upon request, the hospice physician may assume primary responsibility for care. A Nurse Practitioner may also serve as an attending physician.

Nursing Services are provided on a part-time, intermittent basis. Visits are at least once per week. Intermittent nursing visits are available 24 hours/day, 7 days/week. Nursing visits are based on need to maintain management of symptoms and when urgent needs arise. Nursing services are provided in collaboration with the Interdisciplinary Team and the attending physician. If there are specific physician ordered services, such as wound care or injectable medication administration, nursing visits may be as frequent as twice per day.

Social Work Services are available to all patients and families on an intermittent basis to address psychosocial and counseling needs. Qualified Social Workers provide supportive counseling, grief counseling, and are an excellent resource for community services. Social Workers also assist with discussing quality-of-life options, healthcare wishes (DNR, Health Care Proxy and MOLST), and coordinate care giving and planning for alternative living settings. A Social Worker typically visits 1-2 times per month or more often if determined by the Hospice Interdisciplinary Team in collaboration with the attending physician.

Spiritual Care is available on a part-time, intermittent basis for non-denominational, spiritual counseling, prayer, reading of scriptures, planning and conducting funeral/memorial services, and acting as a liaison with your faith community. At your request, rituals specific to your denominational practice (i.e. Sacrament of the Sick, Holy Communion, etc.) can be coordinated with your faith community, as these services are not provided directly by Hospice Buffalo Chaplains. Pastoral Care visits are typically provided 1-2 times per month, with more frequent visits if needed, based on you and your family’s needs.
**Hospice Home Health Aide Services** are available on a part-time, intermittent basis for 1-2 hours per visit, 1-5 times per week, or more often, based on your loved one’s personal care needs and plan of care determined by the Interdisciplinary Team in collaboration with the attending physician. Aide service is provided under the supervision of the Registered Nurse and are not provided for general supervision or “sitting” with your loved one. Hospice can recommend private pay agencies, or the family may choose to privately pay others to assist with additional care.

**Music Therapy Services** are available on a part-time, intermittent basis to enhance the patient’s current functional level and to promote healing and/or comfort. Visits are typically made one to two times per month but can be made more frequently based on the needs identified and determined by the Interdisciplinary Team in collaboration with the attending physician.

**Massage Therapy Services** are available on a part-time, intermittent basis. Massage therapy is typically available once a month but can be provided more frequently based on the needs identified and determined by the Interdisciplinary Team in collaboration with the attending physician. Massage therapy is a form of therapeutic touch to promote comfort and healing. This also may include the utilization of physical agents such as heat, cold, water, and neuromuscular manipulation, which, through their physiological effect, will enhance your loved one’s level of comfort.

**Volunteer Services** are available on a part-time, intermittent basis to assist with your loved one’s needs identified by the Interdisciplinary Team in collaboration with the attending physician. Volunteers are utilized for day-to-day administrative and/or direct patient care roles and are trained for a variety of roles. A volunteer can keep your loved one company while you step away for a few hours, run errands or help with tasks.

**Bereavement Services** provide grief support, counseling and education for the family and other individuals identified in the plan of care. This assistance is available for up to 13 months after the death. Bereavement services may include individual counseling sessions in the office or in the bereaved person’s home. Hospice bereavement support groups are available on a monthly basis, and are free of charge. The correspondence program includes information about the grieving process and is mailed each month. Memorial services (Times of Remembrance) are held multiple times throughout the year and all family members have the opportunity to attend.

We also provide medical supplies and equipment needed for your care and arrange for delivery to your home.

**PATIENT ADVOCACY**

Hospice Buffalo’s Patient Advocate fulfills a vital function for the patient, the family and other healthcare providers in the mission toward ensuring optimal delivery of healthcare. The Patient Advocate educates and empowers the patient and family to make informed decisions in regard to their health and health care based on their individual wishes and in keeping with their cultural, spiritual, religious and ethical beliefs. The role of our Patient Advocate is to represent the patient and family as they navigate their way through the end-of-life process. If you have any concerns about the care you are receiving or have a suggestion, please email info@palliativecare.org or call (716) 901-0278.

*Hospice Buffalo is a not-for-profit organization serving the residents of Erie County. We hope you and your family will be pleased with our services.*
THE SUBTLE CHANGES: EARLY STAGES OF DISEASE PROGRESSION

When your loved one first entered Hospice, it may have seemed as though nothing had changed. Your loved one may have been going on with his/her daily activities and in some cases, may have seemed a little bit better with the help of medications and assistance from the Hospice staff. Recently though, you may have seen some “changes” in your loved one that have you concerned. Please know that just because these changes are occurring, it does not mean that your loved one’s death is imminent. Talking about these changes is, however, a way to prepare yourself for the next phase of your loved one’s life. Please take a moment to review the following changes that you may be seeing. If there is something on the list that you do not understand, or if there is something that is happening and is not on the list, please talk to your Hospice nurse. If you would like to review this with a nurse, please let us know. It is so very important for us to help alleviate your fears and concerns. That is what we are here to do. We want you to be confident in knowing what to expect.

PHYSICAL CHANGES – Early Stages

<table>
<thead>
<tr>
<th>WHAT IS HAPPENING</th>
<th>WHAT IT MEANS</th>
<th>WHAT YOU CAN DO – YOUR HOSPICE TEAM CAN HELP YOU</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decreased Mobility</td>
<td>This could mean that your loved one’s body is beginning to lose energy and/or function, or that the disease is progressing.</td>
<td>Assist with activities. Some forms of equipment may be helpful as well as making some adjustments to the home to accommodate the change. Home Health Aides may be able to assist you. It is important to recognize your loved one’s limitations and help him/her remain as active as he/she wishes to be.</td>
</tr>
<tr>
<td>Increased Pain</td>
<td>This could be a result of not being mobile, or that the disease is progressing.</td>
<td>Adjustments to medications can be made by the doctor. You can also try some diversion activity such as music, reading, light massage, etc. Be sure to give a full description of the pain to the nurse — other treatments may be more effective.</td>
</tr>
<tr>
<td>Increased Sleep</td>
<td>This could be from decreased energy, a desire to withdraw from activity, or that the disease is progressing, causing the need for more sleep.</td>
<td>Schedule shorter events/visits. Allow your loved one to rest between events. If he/she is comfortable on the couch or in a chair, prop up his/her feet. Spend time with your loved one after he/she has rested so both of you get the maximum benefit from your time together.</td>
</tr>
<tr>
<td>Decreased Appetite/Weight Loss</td>
<td>This can result from needing less food because there is decreased energy output.</td>
<td>Encourage your loved one to eat smaller meals if possible. Present one food item at a time. Let your loved one eat his/her favorite foods. As hard as it may be, try not to force your loved one to eat. If you encourage eating and he/she still refuses, it is okay. Your loved one’s body knows what it needs and he/she would probably much rather spend time with you.</td>
</tr>
<tr>
<td>Difficulty Swallowing</td>
<td>There may be a bad taste or no taste to food because of changes to the taste buds. There may be a feeling of fullness or nausea. Your loved one may just not be hungry.</td>
<td>It can be dangerous to force food or fluid if your loved one is having difficulty swallowing. The Hospice nurse can help you determine what foods, fluids and consistencies are best. Positioning of your loved one is also important. Tell your nurse if there is any problem with swallowing.</td>
</tr>
<tr>
<td>Incontinence</td>
<td>Incontinence can be a result of relaxation of the muscles that control elimination, which can be a result of disease progression.</td>
<td>There are many products that can be used to manage incontinence and to maintain the dignity of your loved one. It is also important to protect your loved one’s skin. Your nurse can assist you with all of this.</td>
</tr>
<tr>
<td>WHAT IS HAPPENING</td>
<td>WHAT IT MEANS</td>
<td>WHAT YOU CAN DO – YOUR HOSPICE TEAM CAN HELP YOU</td>
</tr>
<tr>
<td>-------------------</td>
<td>---------------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Increased Desire To Be Alone; Withdrawal</td>
<td>Your loved one may be preparing for the physical separation that will happen when he/she dies. Your loved one may need to reflect on his/her life or what lies ahead and may need time alone.</td>
<td>This is a very difficult part of the process for you and your loved one. Your loved one may be asking you to understand and offer the space that is needed. Let him/her know how you feel and that you are there when needed. The Hospice Team can help you sort out the emotions that you are feeling.</td>
</tr>
<tr>
<td>Increased Desire To “Get Affairs in Order”</td>
<td>Your loved one may feel the need to reassign family duties and to feel assured that family and friends will be taken care of in the “right” way.</td>
<td>This is a very difficult conversation to have because it means that the reality of the situation is out in the open. Your Hospice Team can offer many helpful suggestions on how to get through these conversations. One of the greatest gifts you can give your loved one is the ability to have control over this type of discussion.</td>
</tr>
<tr>
<td>Increased Desire To Discuss Spiritual Concerns</td>
<td>Your loved one may have a desire to gather information about life after death. This may be a result of curiosity, fear or a need to confirm beliefs.</td>
<td>There are numerous resources that can assist your loved one in this quest for answers. In the same way, the answers for some may be found in nature. Whatever and wherever the search, this is a significant part of the dying experience. Your religious leader and/or the Hospice Chaplain can offer guidance and suggestions.</td>
</tr>
<tr>
<td>Increased Desire To Do Something or See Someone</td>
<td>Your loved one may tell you about a life-long dream, recent desire to add meaning to his/her life, or feel the need to resolve an issue with someone.</td>
<td>If it is possible, every effort should be made to facilitate these desires. Hospice has volunteers who can help. If the person lives far away and travel is not possible, a phone call should be encouraged. This sense of completion may have a positive effect on the way your loved one approaches death.</td>
</tr>
<tr>
<td>Talking About Memories</td>
<td>The process of remembering one’s life is a way of validating existence, reliving moments that are held dear, or a way for your loved one to assure that he/she will not be forgotten.</td>
<td>You may find that your loved one’s desire to reminisce is very painful, as it is a reminder that time is passing. The emotional feelings that your loved one may experience are very healing, giving you an opportunity to have a special role in this is a great gift. The Hospice Team has many unique ways to assist you and your loved one in creating tangible memories.</td>
</tr>
<tr>
<td>Requesting Assistance with Funeral Plans</td>
<td>Your loved one may feel a “loss of control” with the changes that are happening. He/she may have a desire to regain that control by “designing” the funeral and having input in every way possible.</td>
<td>Talking about the funeral is actually very healthy and may give your loved one a sense of control. There are many things to consider, and to have these things “figured out” in the way that your loved one wants is one less burden on you. Trying to arrange a funeral when your loved one has just died can be emotionally draining and very painful. Your willingness to engage in these conversations gives your loved one the gift of peace. We are here to help you.</td>
</tr>
</tbody>
</table>
MAKING CHANGES: PREPARING FOR END-OF-LIFE PHASE

You may begin to notice some new significant changes in your loved one’s condition. The nurse may describe these changes as “actively dying” or state that your loved one is “making changes.” Even though your loved one is entering into this stage of life, there is no way for any of us to predict when your loved one will die. Changes may occur physically, emotionally and/or spiritually. All of these changes play a great role in your loved one’s remaining time. In some cases, emotional and spiritual changes are more significant than physical ones.

You may feel as though you cannot leave your loved one. We support your need to be with him/her and encourage you to take care of yourself as well. Many caregivers fear that if they leave to spend time with their family, run an errand, or even take a shower, they may return to find that their loved one has died. Communicate with your loved one in ways that you find comfortable. Try to say what you need to say. Try to do what you need to do.

Following are some of the changes you may see. Your loved one may or may not experience all the things on the list. Our hope is that you will feel comfortable reading over what you may expect, what these changes mean and what you can do for your loved one. We also hope that you will talk to the Hospice Team about questions or concerns you may have. We are here to help you through this time.

<table>
<thead>
<tr>
<th>PHYSICAL CHANGES – End-of-Life Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>WHAT IS HAPPENING</strong></td>
</tr>
<tr>
<td>Skin Changes</td>
</tr>
<tr>
<td>Changes in Body Temperature</td>
</tr>
<tr>
<td>Changes in Level of Consciousness</td>
</tr>
<tr>
<td>WHAT IS HAPPENING</td>
</tr>
<tr>
<td>-------------------</td>
</tr>
<tr>
<td><strong>Changes in Breathing</strong></td>
</tr>
<tr>
<td><strong>Inability to Swallow</strong></td>
</tr>
<tr>
<td><strong>Restlessness and Confusion</strong></td>
</tr>
<tr>
<td><strong>Decreased Urine Output/No Urine Output</strong></td>
</tr>
<tr>
<td><strong>Changes in Blood Pressure and Heartbeat</strong></td>
</tr>
</tbody>
</table>
**Fear of:**
- Dying
- Family Well-Being
- Where They are Going
- Dying Alone
- Dying in a Specific Place

<table>
<thead>
<tr>
<th>WHAT IS HAPPENING</th>
<th>WHAT IT MEANS</th>
<th>WHAT YOU CAN DO – YOUR HOSPICE TEAM CAN HELP YOU</th>
</tr>
</thead>
<tbody>
<tr>
<td>These fears all fall under the heading of “The Unknown.”</td>
<td>Talking with your loved one may ease the fear of dying. If there are specific family members that your loved one is worried about, perhaps they can talk to each other. Ask what your loved one thinks it may be like and what he/she hopes it may be like. The most helpful thing we can do is to listen. Remember to use music and reading if this is something that has a calming effect as well.</td>
<td></td>
</tr>
</tbody>
</table>

| Sadness | Your loved one may feel a profound sadness about leaving you and the life that he/she knows. This is natural. Your loved one may not be sure if he/she will be missed or remembered. | One of the ways in which you can help is to create a scrapbook, video or collage of pictures. A collection of favorite things in a decorated box is also an idea. Let your loved one know you are doing this. Your Hospice Team can help you with this project. |

| Predicting Their Own Death | Your loved one may have a keen sense that his/her body, mind and spirit have aligned and are prepared to move on. | It is best to listen and find out what your loved one needs you to do. If this frightens you, let the Hospice Team know and we can help. |

| Seeing Spiritual Beings | Your loved one may claim to see a family member, religious figure, or what he/she describes as a light or a place. He/She may just reach up or look up or carry on a conversation with someone. This is a phenomenon that cannot be explained. It is also referred to as “transitioning.” | Listen and validate what your loved one is saying and seeing. If you have questions about this, your Hospice Team will be there for you. |

| Relief | Your loved one may feel relief that this will soon be over and his/her death will lift your burdens as well. There may be a sense that he/she has lived a full and beautiful life and is “ready.” | It may be difficult to know that your loved one is relieved to go. If possible, try to focus on the fact that he/she is at peace. |
SYMPTOM SCALE

PLEASE USE THE SCALE ABOVE TO DETERMINE THE NUMBER THAT BEST DESCRIBES:

- Shortness Of Breath
- Tiredness/weakness
- Sleep
- Pain
- Nausea
- Appetite
- Anxiety
- Depression

CAREGIVING GUIDELINES

The following guidelines will help you care for your loved one at home. Please remember that every illness progresses differently, and that every person experiences the process in a unique way. Changes that are mentioned may or may not be experienced. The goal of this information is to prepare and guide you for what might happen in the future. This information is not all-inclusive. If you have questions or concerns about anything, you may call the hospice patient line 24 hours a day. A nurse, experienced in hospice care, is available to guide you in this difficult time.

PERSONAL CARE

- Always wash your hands before and after providing care.
- To prevent infection wear gloves when likely to touch body fluids or mucous membranes (vomit, urine, blood, stool, etc.)
- Assist with personal care as needed. Encourage as much independence as possible.
- It is important to keep your loved one’s skin clean and dry, but a daily bath may not be necessary.
- Keep skin soft with lotion to help prevent cracking of the skin.
- Keep sheets as clean and wrinkle free as possible.
- Reposition your loved one frequently to relieve pressure points. Areas that are prone to pressure are the buttocks, back, hips, elbows, shoulder blades, heels, ankles, the back of the head, and the ears.
- Use a draw sheet to help with turning and repositioning. Ask the nurse for instructions.
- Back rubs and massages are soothing and relaxing. Ask the hospice nurse for instruction.
- Try to avoid leaving wet clothing or bed linen in contact with the patient. Waterproof, disposable pads are available.
- Let the Hospice Nurse know about any breaks in the skin or reddened areas. The nurse can show you how to care for these areas.
- Avoid heating pads or electric blankets. They can easily cause burns.
- Despite efforts to prevent pressure sores, they may occur. The hospice nurse will teach you ways to prevent the area from enlarging.
- Keep your loved one’s nails clean and trimmed.
- Offer mouth care several times each day:
  - Brush teeth with a soft toothbrush and toothpaste. Rinse with water.
  - Special swabs may be used when brushing is not feasible.
  - Report any mouth soreness to your hospice nurse.
  - A water-based lubricant may be used on the lips and nostrils.
**CAREGIVING GUIDELINES**

1. If weakness is a problem, provide assistance with walking. Try to allow as much independence as possible. If the patient is unable to assist, the decision not to move the person may need to be discussed.

2. Support your loved one on his or her strongest side.

3. Use side rails on the bed whenever possible. Side rails provide assistance in changing positions.

4. Always lock the wheels on the bed or wheelchair before transferring.

5. If food is a problem, be sensitive to odors that may be disturbing. Cooking odors may sometimes be unpleasant. Decreasing cooking times by using a microwave oven may help cut down on cooking odors.

6. Taste changes may occur. Sweets, or red meats, may not be tolerated. Flavorful seasonings, marinades, tart foods, and foods served at room temperature may make foods more appealing.

7. A high-calorie supplement may be appropriate. Ask your hospice nurse for suggestions.

8. If dry mouth is a problem, sweet or tart foods may improve this. Changing food consistencies, or adding sauces, gravies, or dressings to foods will make them easier to swallow. Frequent sips of water, ice chips or hard candy may be comforting. Lip salves will keep the lips moist.

9. Swallowing may be difficult. Changing consistencies and textures of solids and liquids may ease swallowing ability. For example, soft foods such as pudding or jello may be more easily tolerated.

10. Please notify the hospice nurse if the patient experiences difficulty swallowing or soreness in the mouth.

**ACTIVITY AND SAFETY**

- Irregular eating habits are to be expected. Amounts of food desired often vary. Smaller meals and snacks throughout the day may be better tolerated than three meals. Altering mealtimes and surroundings and taking plenty of time to eat may increase enjoyment. Forcing additional, undesired amounts of foods will cause discomfort. Usually, your loved one is the best judge of appropriate amounts.

- Be sensitive to odors that may be disturbing. Cooking odors may sometimes be unpleasant. Decreasing cooking times by using a microwave oven may help cut down on cooking odors.

- Taste changes may occur. Sweets, or red meats, may not be tolerated. Flavorful seasonings, marinades, tart foods, and foods served at room temperature may make foods more appealing.

**BREATHING DIFFICULTIES**

- If breathing is a problem, raise the head of the bed or prop the patient’s head with pillows.

- Encourage slow, calm breathing. Sit with your loved one, providing calming reassurance.

- Open a window or turn on a fan to promote air circulation over the patient’s face.

- If oxygen is being used, make sure it is on and functioning. A portable tank is provided in case of power failure.

- Call the Hospice Nurse if these measures do not provide relief.

**NUTRITION**

One of the basic ways family members give to one another is by preparing favorite foods. Because of this, you may feel frustrated when this avenue of support is no longer perceived as helpful to the patient. Many family members express concern that the person will “starve” if he or she is not forced to eat or drink. This is a common concern but, in reality, you will not extend the person’s life by forcing him or her to eat and drink. Often, people feel helpless over this issue. **It is natural for a person who is dying to stop eating and drinking.** Listen to the suggestions of your hospice nurse. The nurse will guide you about your family member’s need for nutrition. See guidelines to follow:

- Help your loved one change positions slowly (for example, when lying to sitting, sitting to standing)

- Remove throw rugs and other moveable objects, such as toys and shoes, from the floor.

- Wipe up floor spills immediately to avoid slipping.

- Report any equipment in need of repair to the hospice office. Do not use damaged equipment until it is replaced or repaired.

- Report any falls to the hospice nurse when they occur.
ELIMINATION/BOWEL AND BLADDER CARE

- A stool softener and laxative will be recommended by your nurse as soon as the pain medication is started. It will be adjusted as necessary.
- Establish a regular bowel regimen with the assistance of your nurse, and record bowel movements to monitor effectiveness.
- Bowels should move every 1-2 days, even if the amount of food being eaten is small.
- The normal position for defecation is the sitting position. Enhance comfort for ease of defecation; raised toilet seat, commode, pain control.
- If possible, attempts at having a bowel movement should be made 30 to 60 minutes following eating of a meal to take advantage of the movement of the intestines.
- As the amount of fluid taken in decreases, urine formation also decreases. Urine may also become darker and more concentrated.
- If bladder control becomes difficult, you may use adult diapers or absorbent pads. Families are responsible for obtaining these. A catheter may need to be placed if the bladder is full, and the patient is unable to urinate.
- If the following occur, please contact the Hospice Nurse:
  - no bowel movement in 3 or more days
  - 6-8 loose stools per day
  - blood in the urine or stool
  - no urine output in 12 hours

NAUSEA AND VOMITING

- Clear liquids, dry toast, or soda crackers may help diminish nausea. The patient should have nothing to eat or drink for 2 hours after a vomiting episode.
- Ice chips help to keep the mouth moist when unable to swallow fluids. Sipping fluids off a spoon every 10 minutes until nausea subsides may also be helpful.
- Forcing food or fluids may increase discomfort.
- Remove offensive odors, sights, or sounds. A quiet, calm environment is relaxing. Provide good ventilation.
- When food is desired, begin with clear liquids. After that, the foods offered should be bland. Avoid greasy, fried, or fatty foods.
- Encourage small portions, eaten slowly. Offer meals more frequently than three times per day.
- If antiemetics (anti-nausea medications) are ordered, try them as directed.
- Try to avoid favorite foods when nauseated. The patient may associate them with the nausea feeling and not tolerate them when nausea is resolved.
- Call the hospice nurse if nausea and vomiting last for more than 24 hours or are associated with:
  - abdominal pain
  - constipation
  - blood in vomitus

EMOTIONS

We are told that dying persons may have fears that they do not express. One is that they are a burden to their caregivers; another is that they will experience severe pain. These unexpressed (or expressed) fears often surface in behaviors that confuse caregivers. The following suggestions may be of help.

- Be sensitive to questions or statements that may indicate the person is experiencing these fears. Be reassuring, but honest.
- Anger may result from frustration experienced because of the illness. This is a common emotion that is generally not directed at anyone personally.
- Loss of control over aspects of life (for example, when to eat, sleep, bathe, or move about) sometimes makes the person feel irritable, angry, or sad. Having control, even in small ways, becomes very important. Being flexible helps.
- Sadness and crying are appropriate expressions of grieving. Respond with a willingness to listen and/or a reassuring touch. Discuss with members of the hospice team any concerns you may have.
There are numerous medications and methods to control pain. Your hospice nurse will work with you and your physician to maintain comfort. Follow these guidelines:

• When medication is being taken to control pain, addiction does not occur.
• Pain can be affected and magnified by anxiety, stress, fear, frustration, fatigue, and depression.
• Pain is unique. Pain is whatever the person who is experiencing it, says it is.
• As a general rule, medications taken by mouth are as effective as injectable medications. The oral (by mouth) route of administration is preferred.
• Pain medications may cause drowsiness for a few days (especially if the patient has not slept in days or weeks due to unrelieved pain).

Nausea may occur with increases in pain medication. This is a temporary side effect that will subside in a day or two. Ask your nurse about medications that may help.
• Repositioning or gentle massage may relieve tension and add to comfort.
• Relaxation, imagery, or distraction may help ease pain and discomfort.
• Pain medications need to be taken on a scheduled basis around the clock. This is to establish a level of medication in the bloodstream.
• “Breakthrough” medication is given on an as-needed basis.
• Record medications given to help the nurse determine if changes need to be made.

PAIN

As a patient and family, you are part of the healthcare team and therefore, share in the responsibility of safe medication use. Controlled substances play a valuable role in maintaining comfort and good symptom management when used properly. Hospice Buffalo has a policy that addresses the safe use and disposal of controlled substances in order to assure that you are well informed about how to handle medications. We have provided you with specific information related to the disposal of controlled substances, refer to the “Medication Disposal” section.

POLICY STATEMENT OF HOSPICE BUFFALO REGARDING THE SAFE USE AND DISPOSAL OF CONTROLLED SUBSTANCES

As a patient and family, you are part of the healthcare team and therefore, share in the responsibility of safe medication use. Controlled substances play a valuable role in maintaining comfort and good symptom management when used properly. Hospice Buffalo has a policy that addresses the safe use and disposal of controlled substances in order to assure that you are well informed about how to handle medications. We have provided you with specific information related to the disposal of controlled substances, refer to the “Medication Disposal” section.

IMPORTANT INFORMATION REGARDING THE SAFE USE OF PATIENT’S MEDICATIONS

• Your nurse will provide you with information regarding the name, dose and reason for the medications you are taking. In addition, your medications will be reviewed for side effects, and interactions with other medications, herbal remedies, or food. Be sure that you understand the purpose and instructions for each medication. Ask your nurse about anything that you do not understand.
• Medications should be stored in a safe place out of the reach of children.
• Always read the bottle of new medications delivered to your home to be sure they are the medications that were ordered by your physician and explained by the nurse.
• Do not stop taking medications unless you speak with your nurse or doctor.
• Be sure to inform your nurse of any herbal remedies you may be taking.
• Keep medications in their original container unless you have medications “prefilled” in a specified container to ensure that you take them correctly.
• Do not take more of any medication than you are instructed to take. If symptoms persist, call Hospice to have your medication dose changed or adjusted.
• Store medications in a dry, clean area.
• Apply gel medications with gloves, to avoid absorption by the person applying it.
• Whenever possible, have the patient sit up before swallowing.
• Moist the mouth with 1 or 2 sips of water before tablets are taken.
• Always check with your nurse to see if medications can be crushed. If it is safe to do so, crush tablets and give them on a spoon in liquid, jelly, applesauce, sherbet or ice cream.
• If the patient is unable to swallow medication, talk with your nurse about giving it in another way: i.e. liquid, suppository, injection.
Mental Changes

- There may be personality changes as the disease progresses.
- If fear is expressed, try to be reassuring. A simple touch or hug may calm the worst fears.
- Reduce the feelings of isolation by including the patient in activities. Hang a calendar in the room, and have a clock or watch accessible.
- Confusion sometimes occurs. Identify yourself by name before you speak. Speak softly, clearly, and truthfully. A night light may help decrease fear and anxiety.

- Hallucinations or “visions” may occur. Understand that these are experienced as real, and patients may even find comfort in them. Be truthful, yet open to discussing the experience.
- If the patient is experiencing fear or agitation related to the hallucinations, contact the Hospice nurse.
- Sense of hearing may be present, even if the patient appears unconscious. Use a soothing voice, and touch frequently.

Delirium

This situation may seem too much for you to bear. You may find yourself saying, “I don’t know what to do. I can’t go on like this.” Delirium is extremely difficult to manage at home. Hospice can help you cope during this time. There ARE successful ways to treat delirium.

What you can do:
- Accept help
- Take care of yourself
- Know that you are not alone
- Call your Hospice nurse

“He’s been in and out of bed all night for the last 4 days! I was so surprised that he could get himself up, he’s been so weak. And he wouldn’t keep the covers on the bed, and kept picking at the sheets. I think he was talking to someone he thought was in the room. I haven’t slept for 4 days – I can’t do it anymore!”

All too often, comments like this are heard by the hospice staff as we care for patients and their families. The behaviors mentioned above may be an indication that your loved one is experiencing a medical condition known as Delirium. There are several causes of Delirium that CAN be treated. Left untreated, Delirium can be frightening, exhausting and devastating to your loved one, you and your family.

Behaviors your loved one may be experiencing:
- Disrupted sleep cycle (up all night, sleep throughout the day)
- Vivid dreams
- A distant stare
- Picking at clothing; reaching into air
- Removing clothing and blankets
- Trying to get out of bed

If your loved one is experiencing ANY of these behaviors, please notify the Hospice Nurse.

What you may be feeling:
- Afraid of what is happening to your loved one
- Exhausted because you are not sleeping at night
- Guilty because you are losing your patience
- Confused because sometimes your loved one seems perfectly normal
- Hurt because mean things are being said
- Frustrated because you cannot fix this
- Embarrassed because your loved one is acting so strangely
- Helpless because nothing you do seems to change the situation

If you are feeling any of these emotions, please notify your Hospice Nurse.
Comments like these are frequently heard by the Hospice staff as we listen to families struggle to cope with just one of the many issues they are facing. How difficult and painful it must be for a wife to watch as her once 250-pound husband (who loved her cooking) becomes ever-thinner, yet announces that he can’t tolerate even a few bites of his favorite food. How helpless she must feel... and frightened.

In our culture, we use food to show we care and to nurture one another. Mealtime is a time of socialization and recreation. It’s often a family time and a time for sharing. With such strong meaning associated with food it is understandable that treatment decisions related to nourishment and hydration are frequently very difficult for families and society in general. We tend to believe that not eating or drinking will cause pain and suffering. Our impulse is to push the patient to eat and drink when they are no longer able to do so, and to consider IV fluids and feeding tubes.

Since hospice care is about choices, we often help families see that when their loved one is not eating or drinking it is usually the right choice for him or her at that time. While food and water contribute to a patient’s sense of well-being in the early stages of terminal illness, they can cause discomfort in later stages.

Inability to digest food and food substances during later stages of terminal illness can cause diarrhea, nausea, vomiting, constipation or impaction. These symptoms can result in increased pain and discomfort. Inability to absorb fluid can cause congestion, confusion, shortness of breath, nausea and vomiting, urinary retention and edema.

Ice chips, frequent mouth care, ointment for lips, hard candies, small sips of fluid and lots of love and caring can be more appropriate at the end of life than forcing food and fluids.

Patients who are allowed to choose to eat and drink when they are able during the end of their lives are not only spared the physical discomfort “force feeding” can cause, but they are also spared the emotional struggles with their families. Time that may have been spent arguing about food can be used more wisely to enjoy one another and make every day count. There is no reason for feelings of guilt.

As one of our nurses said, in a very gentle and loving way, “Remember, they are not dying because they are not eating; they are not eating because they are dying.”
25 PRACTICAL TIPS – how you can help those facing serious illness

SHOW YOUR CONCERN AND SUPPORT...

When someone we know faces a serious illness, most of us find it hard to know what to do. Feeling helpless and uncertain, we say “If you need anything, just call,” but we know that’s really not enough. Here is a collection of truly useful ideas you can use to show your concern and support for people who are close to you.

1. **Don’t avoid me.** Be the friend... the loved one you’ve always been.
2. **Touch me.** A simple squeeze of the hand tells me you still care.
3. **Call and tell me you’re bringing over my favorite dish.** Bring food in disposable containers so I won’t worry about returning them.
4. **Watch my children** while I take a little time to be alone with my loved one. My children also may need a little vacation from my illness.
5. **Cry with me** when I cry and laugh with me when I laugh. Don’t be afraid to share these emotions with me. Pain isolates. Help me reconnect with others.
6. **Take me out for a pleasure trip,** but know my limitations.
7. **Call for my shopping list** and make a special delivery to my home.
8. **Before you visit, call to let me know,** but don’t be afraid to visit. I need you. I can get lonely.
9. **Help me celebrate holidays (and life)** by decorating my hospital room or home, or by bringing me flowers or other natural treasures.
10. **Help my family.** Invite them out. Take them places. I am sick, but they may be suffering also. Offer to come and stay with me to give my loved ones a break.
11. **Be creative.** Bring me a book of thoughts, taped music, a poster for my wall, cookies to share with my family and friends.
12. **Let’s talk about it.** Maybe I need to talk about my illness. Find out by asking me, “Do you feel like talking about it?”
13. **Don’t always feel we have to talk.** Sitting quietly together is fine.
14. **Can you take me and/or my children somewhere?** I may need transportation to a treatment, to the store, or to my physician.
15. **Help me feel good about my looks.**
16. **Please include me in decision making.** I’ve been robbed of so many things. Please don’t deny me a chance to make decisions in my family or in my life.
17. **Talk to me about the future.** Tomorrow, next week, next year. Hope is so important to me.
18. **Bring me a positive attitude.** It’s catching. Help me respect reality.
19. **What’s in the news?** Magazines, photos, newspapers and verbal reports keep me from feeling the world is passing me by.
20. **Could you help me with some cleaning?** During my illness, my family and I still face dirty clothes, dirty dishes and a dirty house.
21. **Water my flowers.**
22. **Just send a card** to let me know you care.
23. **Pray for me** and share your faith with me.
24. **Tell me how you’d like to help me** and, when I agree, please do so.
25. **Tell me about support groups** so I can share with others.

For more resources, visit our website HospiceBuffalo.com
HOW TO HELP AS THE BODY SLOWS DOWN

As your loved one emotionally and physically withdraws from this world, caregivers can suffer from feelings of helplessness. Withdrawal is normal for the patient as he/she becomes less concerned about surroundings. This is a good time for family members to gather together, since they may have some last thoughts or expressions of love to share with your loved one.

Some people may need reassurance or approval to “let go,” so giving them permission and reassuring them that you will be OK helps the patient to feel comfortable and supported about letting go.

Tell visitors and other family members not to speak in front of the patient as if he/she isn’t there. Nothing should be said that would upset the patient should he/she overhear it. It is important that if at any time you or your family are unsure of what is happening, call Hospice. Even if you need a little reassurance or support, that is what we are here for 24 hours a day.

COMMON QUESTIONS ABOUT THE DYING PROCESS

CAN MY LOVED ONE HEAR AND UNDERSTAND?

Sometimes it is difficult to tell if your loved one can hear and understand once he/she becomes unresponsive. We encourage everyone to speak and act as though he/she can hear and understand everything. There have been many instances when loved ones who had not moved in hours or days responded to something that had been said. If someone is not able to be at your loved one’s side but wishes to speak with him/her, place the phone to his/her ear. Play some favorite music, sing a song or turn on a favorite TV show. Whatever your loved one enjoyed before may be soothing now.

HOW DO I KNOW MY LOVED ONE IS NOT IN PAIN?

If and when your loved one can no longer communicate verbally, there are many cues that tell us he/she is not in pain. We look at vital signs, the expression on your loved one’s face, the rhythm of his/her breathing and the position of the hands and legs. All of these signs indicate your loved one’s comfort level. Your Hospice Team will point these out to you.

WHY IS MY LOVED ONE HANGING ON?

The mind and spirit can play a huge role in the time someone chooses to remain. We may or may not know what your loved one is thinking about or “working through.”

Your loved one could be:
- worried about someone’s well-being
- waiting for you to give permission to leave
- waiting for someone to leave or arrive
- spending last moments with family and friends and not be ready to leave

In essence, your loved one may feel as though he/she still has a purpose here. We know how difficult this “vigil” can be. You want to be there, but it is hard to take off from work or find someone to watch the children. It is hard to try to stay awake. We are here to help you figure these things out.
COMMON QUESTIONS ABOUT THE DYING PROCESS

WHAT IF MY LOVED ONE DIES WHEN I AM NOT THERE?
It is difficult to predict the exact moment of death. There are ways of knowing when death is near, and we can help you see that progression. Sometimes it is easiest to let your loved one decide. You can tell him/her that you are going somewhere and that if he/she wants to leave, you will be OK. This way, you give your loved one the choice, taking the burden off of yourself. Remember that there were many days when you were not together, and yet you knew that you loved each other.

HOW WILL I KNOW WHEN MY LOVED ONE HAS DIED?
The Hospice Team will be able to tell you when your loved one has died. If a Team member is not present, you will know your loved one has died when breathing has stopped. Call us as soon as you can so we can help you as soon as possible. A referral for Bereavement care will be made by your hospice team. You will receive information in the mail about grief support and education groups in the near future.

WHAT WILL MY LOVED ONE LOOK LIKE WHEN HE/SHE DIES?
At the moment of death, you will not see much difference from how your loved one looked just before. You will notice that breathing has stopped. As time passes, he/she will become paler and the skin will become cooler. His/Her eyes and jaw may or may not close. You may find yourself checking over and over again for breathing. It is normal to think that you see the chest rise or hear breathing. Don’t be afraid. Your Hospice nurse will answer any questions you may have.

WHAT DO I DO WHEN MY LOVED ONE HAS DIED?
Call Hospice if you have not already done so. While you are waiting for a Hospice Team member to arrive, you can do whatever you feel comfortable doing. You can sit with your loved one. You can hold your loved one. It’s important to take the time to say goodbye. You can call friends and family. We will be there as soon as possible and will help you from there. You do not need to call 911 or the police.

WHEN YOUR LOVED ONE HAS DIED
Call Hospice if you have not already done so. While you are waiting for a Hospice Team member to arrive, you can do whatever you feel comfortable doing. You can sit with your loved one. You can hold your loved one. It’s important to take the time to say goodbye. You can call friends and family. We will be there as soon as possible and will help you from there. You do not need to call 911 or the police.

CARE OF YOUR LOVED ONE’S BODY
Once the Hospice nurse has arrived, you will be able to determine when you want your loved one’s body to be picked up by a funeral home. You may want to bathe your loved one beforehand. The Hospice nurse can do this for you, and you may help if you wish. When your loved one’s body is picked up, you may have difficulty watching him/her leave the home. We encourage you to share your fears, concerns and sadness.
GENERAL HOME SAFETY

FIRE SAFETY
• Smoke detectors should be present on each level of the home.
• Change batteries every six months (spring and fall)
• Develop family escape plan.
• Have furnace, fireplace and wood stove cleaned and inspected every year.
• Keep kerosene space heaters three feet from walls and furniture.

ELECTRICAL SAFETY
• Run extension cords along walls, not under rugs.
• Replace frayed or broken cords.
• Never overload electrical outlets.
• Keep electrical appliances away from sinks, tub, and shower areas.
• Only use electrical appliances that are listed by a testing laboratory.

LIGHTING
• Hallways, stairways and bathrooms should be properly lighted with accessibility to light switches at entrances.
• Switches and lamps should be easy for the person to reach.
• Use translucent light shades or frosted bulbs to reduce glare.

KITCHEN
• Do not use stove or oven for heat.
• Store cleaning supplies away from food and in original containers.
• Keep all cleaning supplies out of the reach of children.
• Set utensils, foods and other needed items at a convenient height on stable shelves.
• Do not wear loose clothing around the stove.
• Place heavier objects on the ground or low level shelves. If there is inadequate space, install shelves or cupboards at a convenient height.
• Provide a reaching device to prevent the use of unstable chairs or step stools.

BATHROOM
• Make sure faucets and towel bars are easy to reach.
• Put non-skid rubber mats inside bathtub.
• Install grab bars on bathroom walls (especially near the toilet and shower).
• Keep water temperature no higher than 105°.
• Place non-skid flooring strips or carpeting to avoid slipping.
• Provide an elevated toilet seat or install a safety frame for ease of use.
• Use the same safety precautions in both down-stairs and upstairs bathrooms to lessen the use of stairways.
• Keep a night light on during the night

FLOORS AND HALLWAYS
• Remove clutter and low-lying objects like coffee tables which can trip a person or lead to bruising or other injuries if the person walks into them.
• The best modification is to clear the path the person uses the most and provide stable furniture as support. A lack of furniture can be a hazard as it offers no support for a person to use when walking through a room.
• Use non-skid carpet runners rugs to alleviate slippery floors and hold down carpet edges.

STAIRWAYS
• Provide secure non-slip handrails and non-skid step edges.
• Repair worn steps and apply contrasting non-skid tape for visibility.

FURNITURE
• Furniture should provide ample seating and facilitate ease of rising.
• Provide chairs with armrests.
• Adjust the mattress height for getting in and out of bed.
The following information is provided in order to prevent patients or family members from contracting or spreading an infectious disease, like the common cold or even a more difficult to treat infection like Methicillin-resistant Staphylococcus aureus (MRSA); Vancomycin-resistant Enterococci (VRE); Clostridium difficile (C. diff.)

**Hand Hygiene:** Hand hygiene is the number one way to decrease the spread of infectious or communicable diseases and antibiotic-resistant organisms, such as: Methicillin-resistant Staphylococcus aureus (MRSA), Vancomycin-resistant Enterococci (VRE), and Clostridium difficile (C. diff.). Hand hygiene should be performed before and after any wound care, any contact with your own or someone else’s blood, mucous membranes, non-intact skin, urine, feces, or sputum or contact with contaminated surfaces, whether or not gloves are used.

**Hand Disinfection:** If hands are not visibly soiled, an alcohol-based hand rub may be applied to the palm of one hand in the amount recommended by the manufacturer. The product should be vigorously rubbed between hands, fingers, and nail beds until the surface of the hands is dry.

**Hand Washing:** Hands should be washed before eating, after using the restroom, and whenever hands are visibly soiled. Wet hands first with water, then apply soap. Rub soap between hands, fingers, and nail beds vigorously for at least 15 seconds, covering all surfaces. Rinse hands under running water and dry thoroughly with a disposable towel. Use towel to turn off faucets, then dispose of the towel.

**Cough Etiquette:** To help control the spread of influenza, colds, and other respiratory illnesses, ‘cough etiquette’ should be used at all times:

- “Cover your cough” by coughing or sneezing into the crook of your arm, or into a disposable tissue which is then thrown out.
- Perform hand hygiene after coughing or sneezing into tissue.

**HELP PREVENT THE SPREAD OF ILLNESS DURING COLD AND FLU SEASON!**

- Avoid crowds and people with acute respiratory illnesses.
- Practice good hand hygiene and cough etiquette.
- Stay home when you’re sick.
- Ask your physician about flu shots.
Being prepared for an emergency due to a natural event (snowstorms, tornadoes, floods) or man-made event (power failures, terrorist attacks) or influenza pandemic outbreak is important.

**Call Hospice Buffalo 686-8000:**
- For any service related problems (e.g. medication, equipment, supplies, safe shelter, etc.)
- If you leave your home to temporarily live with a family member or friend, so that we know that you are safe!

Emergency assistance may be delayed, so it is important for you to plan ahead.

**EMERGENCY SUPPLY LIST**
- Flashlight
- Battery powered radio
- Extra batteries
- First aid kit
- Utility knife
- Local map
- Toilet paper, paper towels, tissues
- Feminine hygiene products
- Soap
- Garbage bags
- Duct tape
- Extra cash + Credit cards
- Blankets, sleeping bags
- Hard wire phone
- “Charged” cell phone, charger
- Gasoline for generator
- Extra keys
- Copies of documents (medical cards, passport, bank account #s, insurance policies, birth and marriage certificates, names and phone numbers of doctors)
- Fire extinguisher
- Change of clothing, rain gear, sturdy shoes
- Can Opener
- Eating Utensils

**GENERAL INFORMATION**
- Have a plan for how to contact family
- If there is a need to evacuate, have a plan for where to go

**MEDICATIONS**
- Know the names of your medications
- Keep at least a week’s supply on hand
- If you are diabetic, keep a 2 week’s supply on hand
- Keep a supply of medicines for fever, such as acetaminophen or ibuprofen on hand
- Keep a supply of anti-diarrheal medication on hand

**MEDICAL NEEDS**
- If you have electric medical equipment such as oxygen concentrators and suction machines you need to arrange ahead for a back up power supply
  - Ask your equipment supplier about an alternative power source for electric equipment
  - Register with your local electric company customer service department to be put on a priority list. This priority list helps the electric company to restore power as soon as possible to those who use electric medical equipment.

**FOOD**
- 5-7 days non-perishable food i.e. dry cereal, granola bars, canned food and juices, peanut butter, dried fruit, nuts, crackers, (see next page for suggested items)
- 1 gallon of water per person

**LIST OF SUGGESTED SHELF-STABLE FOODS TO KEEP ON HAND**

<table>
<thead>
<tr>
<th>BREADS/CEREALS/PASTA</th>
<th>FRUITS/VEGETABLES</th>
<th>SNACKS/DESSERT</th>
<th>DRINKS/SOUPS</th>
<th>MISCELLANEOUS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canned spaghetti products</td>
<td>Fruit canned in own juice</td>
<td>Granola bars</td>
<td>Tomato/V8 juice</td>
<td>Pet food</td>
</tr>
<tr>
<td>Cold cereals</td>
<td>Dried fruits</td>
<td>Individual pudding cups</td>
<td>Progresso soups (no need to add water)</td>
<td>Baby food-canned or jarred, formula</td>
</tr>
<tr>
<td>Instant tea</td>
<td>Pickled beets</td>
<td>Crackers</td>
<td>Broth packets</td>
<td></td>
</tr>
<tr>
<td>Instant cereals</td>
<td>Any canned vegetable</td>
<td>Peanut butter</td>
<td>Canned Juice</td>
<td></td>
</tr>
<tr>
<td>Instant dry milk</td>
<td>German potato salad</td>
<td>Pop Tarts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instant breakfast drinks</td>
<td>Three bean salad</td>
<td>Cheese spread in a can</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Individual bags of potato chips</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**NOTE:**
- Make sure to check expiration dates and rotate foods as needed.
- Consider adding additional items not listed above based on your personal needs and preferences.

---

**NYSEG - 1-800-572-1111**
**NATIONAL GRID - 1-800-642-4272**
IN THE EVENT OF AN ATTACK

TRAPPED IN DEBRIS
- Tap on a pipe or wall so that rescuers can hear where you are.
- If possible, use a flashlight or whistle to signal rescuers regarding your location.
- Cover your mouth with a handkerchief or clothing

EXPLOSION
- Remain calm
- If objects begin to fall, take cover under a desk or sturdy table
- Exit the building as quickly as possible

RADIATION EXPOSURE
- Highest-risk areas are those in which buildings are likely to be destroyed by blast or fire, or where a person would be in the open for the first 2 weeks.
- Shielding: place the most heavy, dense materials available between you and the source of the radiation.
- Distance: the more distance between you and the source of the radiation, the less radiation you will receive.
- Time: most radioactivity loses its strength fairly quickly. Limiting the time spent near the source of radiation reduces the amount of radiation exposure you will receive

FIRE
- Stay low to the floor at all times and exit the building as quickly as possible
- Use a wet cloth to cover your nose and mouth
- Use the back of your hand to feel closed doors. If the door is not hot, brace yourself against the door and open it slowly. Do not open the door if it is hot. Seek another escape route.
- Use appropriate fire exits and stairs, not elevators

COMMON EMERGENCY PROTECTION ACTIONS

Shelter-in-Place or Evacuation

Shelter-in-place means to stay indoors. If shelter-in-place is recommended, move all people and pets inside. Local officials will provide instructions on necessary actions.

These can include:
- Closing all windows and doors
- Taking emergency supply kit with you
- Turning off air-conditioning, ventilation systems
- Closing fireplace damper
- Taping around doors, windows, exhaust fans, or vents
- Wetting towels and placing them in the crack under the door
- Staying away from windows

Stay in the room and listen to emergency broadcasts on radio and TV until told to evacuate. Evacuation means to leave the area of actual or potential hazard.

- If an evacuation is ordered, follow the instructions of local officials regarding evacuation routes and the location of shelters
- Take emergency supply kit with you
- Close car windows and air vents and turn off heater or air conditioner

In the event of a Pandemic (Communicable Disease Outbreak), refer to “Infection Control Practices.”
PATIENT BILL OF RIGHTS AND RESPONSIBILITIES

Hospice Buffalo recognizes that patients and families have the right to individualized care that addresses the physical and psychosocial stresses brought about by illness, the right to dignity and as much independence of choice as possible, and the right to an active role in the development of the plan for care, based on personal needs and preferences. During the initial assessment visit, and in advance of receiving care, each patient will receive this notice verbally and in writing.

EACH PATIENT HAS A RIGHT TO EXERCISE HIS/HER RIGHTS AS A PATIENT:

CARE AND SERVICES:

• Adequate, appropriate and timely care and services for the duration of participation in the program without regard to race, color, sex, religion, national origin, handicap, citizenship status, sexual orientation, or source of payment.

• To be fully informed of my rights as evidenced by written acknowledgement prior to or at the time of admission.

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

• Considerate, respectful care and treatment with full recognition of dignity and individuality.

• Have ones’ property & person treated with respect.

• Be fully informed in advance of all treatments and changes in the plan of care, and to be told how services will be provided and the name and functions of any person or affiliated agency providing care and services.

• Participate and make informed decisions in planning for and developing the hospice plan of care and services.

• Independent personal decisions and knowledge of available choices.

• Receive effective pain management and symptom control from hospice for conditions related to the terminal illness.

• Formulate advance directives that are to be respected by hospice and participate in any ethical issues regarding his/her care with resolution of any conflict in care decisions.

• Refuse care or treatment or medications, to participate in any proposed research, to the extent permitted by law, and to be informed of the expected consequences of his/her action.

• Adequate, appropriate and timely care and services for the duration of the illness for which hospice was selected.

• Choose one’s attending physician.

• Be given a statement of services provided by Hospice and of related charges including charges not covered by third party payors or not covered by the basic Hospice rate.
CONFIDENTIALITY, PRIVACY AND SECURITY:

• Privacy, safety and security to the extent consistent with providing adequate health care. This shall not rule out discreet discussion of the patient’s case or examination by appropriate health care personnel.

• Privacy and confidentiality of all records pertaining to treatment, except as otherwise provided by law, third party payment contracts or if transferred to another health care service or institution. All patient information regarding access and confidential maintenance shall be in accordance with State & Federal regulations.

• May approve or refuse release of patient/family records to any individual outside of Hospice except in the case of the patient’s transfer to a health care facility, or as required by law or third party payment contract.

RECEIVE INFORMATION:

• Prior to the initiation of care, receive information about the services covered under the hospice benefit that includes information about the scope of services that hospice will provide and specific limitation on those services.

• Be fully informed of his/her terminal medical condition, to the extent desired, concerning diagnosis, treatment, medications and prognosis in terms the patient can reasonably be expected to understand.

• Receive information necessary to make decisions regarding care to be received in a language and format that can be understood.

• Be informed about any continuing health care requirements at the time of discharge and/or transfer to another level of care.

• Be informed and given a copy of the agency’s policies concerning advance directives and “Do Not Resuscitate” services that includes a description of State law.

• Be verbally informed in an understandable language and manner, as well as given a copy of this Bill of Rights and Responsibilities.

• Be informed in an understandable manner regarding the written copy of the agency’s drug policies and procedures, including policies and procedures pertaining to the process of managing the safe use and disposal of controlled drugs.

REQUEST INFORMATION:

• Request the name of the physician responsible for coordination of care.

• Request the name, title, function and/or affiliation of any person providing care and health care services.

• Request the name, address and the telephone numbers of the agency and provider agencies servicing him/her.

• Request clinical record disclosure through a written request directed to the attention of the agency Director of Medical Information as permitted in accordance with State and Federal Law.
VOICE CONCERN AND DISSATISFACTION

• Voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of the hospice. In addition, the patient has the right to voice complaints and recommend changes in policies and services to agency staff, the New York State Department of Health or any outside representative of choice. The expression of such complaints shall be free from restraint, interference, coercion, discrimination, reprisal, or unreasonable interruption of services for exercising said rights.

• It is recommended that all complaints be expressed to the agency (i.e., through your primary nurse). If there is any question about a violation of your rights or possible deficiencies in the care received, it is encouraged for you to contact the agency Administrator.

• The investigation of complaints will include the issuance of a written response to all written complaints and to oral complaints if requested by the individual making the oral complaint, explaining the finding and decisions rendered by the program within fifteen (15) days of receipt of such complaints. If not satisfied or designee is not satisfied by the response, the patient (or designee) may appeal to a member or committee of the governing authority of the agency who will review the appeal within 30 days of the receipt of the appeal.

• If not satisfied with the agency’s response, the patient may complain to the New York State Health Department by calling 1-800-628-5972, Monday through Friday between the hours of 10:00 a.m. and 4:00 p.m., except State Holidays. In addition to the above mentioned issues, the purpose of the New York State Hotline (1-800-628-5972) is to receive complaints or questions about local home health agencies and hospices. This hotline may also be used to lodge complaints concerning the implementation of the Advance Directives requirement.

PATIENT RESPONSIBILITIES

EACH PATIENT HAS THE RESPONSIBILITY TO:

• Understand that as a patient you may be “discharged for cause” when the hospice determines that the patient’s or other person’s behavior is disruptive, abusive or uncooperative in assuring a safe and effective plan of care or that the hospice’s ability to operate effectively is seriously impaired.

• Be under medical supervision as required by the agency.

• Supply accurate and complete medical history information to his/her physician and the agency.

• Cooperate in giving full and honest information about financial and environmental factors which affect health status or impede health care.

• Tell the physician and/or appropriate agency personnel about any changes in his/her health status and make it known if he/she does not understand or cannot follow directions.

• To observe and carry out the reasonable health care recommendations of physicians, nurses and other health care staff.

• Cooperate in making adequate physical arrangements in his/her home to allow for safe and appropriate care as it relates to him/herself or agency staff.

• Keep appointments or inform the agency when he/she cannot.

• Have the availability, if necessary, of a family member, or substitute, able and willing to participate in care and/or care planning.

• Be reasonably considerate and cooperative with all agency personnel and associated workers and volunteers.

• Avoid discriminating against health workers because of race, color, creed, sex, religion, age, national or ethnic origin, or sexual orientation.
DISPOSAL OF UNUSED MEDICATION

Federal and New York State law does not allow Hospice Buffalo to accept and dispose of unused medications from patients that have passed away while receiving Hospice care. Please read the following handout to learn how to safely dispose of your loved one’s unused medication.

WHO MAY DISPOSE OF UNUSED MEDICATIONS?

You may dispose of a member of your household’s unused or unwanted pharmaceutical controlled substances. But, if that person is not a member of your household, you may not dispose of their pharmaceutical controlled substances on their behalf. Only ultimate users may dispose of pharmaceutical controlled substances.

An ultimate user, which includes a household member of the person or pet that was prescribed the medication, may transfer pharmaceutical controlled substances to authorized collectors or law enforcement via a collection receptacle, mail-back package, or take-back event.

If someone dies while in lawful possession of pharmaceutical controlled substances, any person lawfully entitled to dispose of the decedent’s property may dispose of the pharmaceutical controlled substances.

HOW DO I DISPOSE OF UNUSED MEDICATIONS?

Drug Take-Back Events
Law enforcement may conduct take-back events at any time. Please listen for notifications through your local news and pharmacies.

Mail Back Programs
You may dispose of unwanted pharmaceutical controlled substances in a mail-back package supplied by an authorized collector. You must use the mail-back package that was provided by the authorized collector or one of their partners. The mail-back package must meet certain specifications, including having a unique identification number.

Collection Receptacles
Members of the public may call the DEA’s Registration Call Center at 1-800-882-9539 to find a collection receptacle location near them. There are several permanent collection receptacles located in many towns. Please see the attached sheet. Many of the local pharmacies (CVS, Rite Aid, Walgreens, Wegman’s, etc.) are also registered collectors. Please call your local pharmacy to see if they have collection receptacles or know which locations have them.

In Home Disposal
Unused medications may be disposed of in the household trash if the other options are not available. Please follow the instructions provided by the Environmental Protection Agency on how to properly and safely dispose of medications in the trash.
HOW TO DISPOSE OF MEDICINES PROPERLY

DON’T: Flush expired or unwanted prescription and over-the-counter drugs down the toilet or drain unless the label or accompanying patient information specifically instructs you to do so.

DO: Return unwanted or expired prescription and over-the-counter drugs to a drug take-back program or follow the steps for household disposal below.

1ST CHOICE: DRUG TAKE-BACK EVENTS
To dispose of prescription and over-the-counter drugs, call your city or county government’s household trash and recycling service and ask if a drug take-back program is available in your community. Some counties hold household hazardous waste collection days, where prescription and over-the-counter drugs are accepted at a central location for proper disposal.

2ND CHOICE: HOUSEHOLD DISPOSAL STEPS*

1. Take your prescription drugs out of their original containers.

2. Mix drugs with an undesirable substance, such as cat litter or used coffee grounds.

3. Put the mixture into a disposable container with a lid, such as an empty margarine tub, or into a sealable bag.

4. Conceal or remove any personal information, including Rx number, on the empty containers by covering it with permanent marker or duct tape, or by scratching it off.

5. The sealed container with the drug mixture, and the empty drug containers, can now be placed in the trash.

* Drug Disposal Guidelines, Office of National Drug Control Policy, October 2009
**LIST OF SECURE PHARMACEUTICAL DROP BOXES:**
**ALPHABETICAL BY TOWN OR CALL (716) 472-1998**

<table>
<thead>
<tr>
<th>NAME</th>
<th>ADDRESS</th>
<th>TOWN</th>
<th>METHOD/TIMES</th>
<th>NOTES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canisius College Public Security Building</td>
<td>2001 Main St. Bosch Building</td>
<td>Buffalo</td>
<td>Secure drop box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Erie County Sheriffs Office</td>
<td>10 Delaware Ave. Lobby</td>
<td>Buffalo</td>
<td>Secure drop-box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Erie Community College Public Safety</td>
<td>121 Ellicott St.</td>
<td>Buffalo</td>
<td>Secure drop box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>New York State University Police</td>
<td>Bissell Hall</td>
<td>Buffalo</td>
<td>Secure drop-box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Medaille College Public Safety Office</td>
<td>2 Agassiz Circle</td>
<td>Buffalo</td>
<td>Secure drop box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Erie County Sheriff Substation</td>
<td>6185 Goodrich Rd.</td>
<td>Clarence</td>
<td>Secure drop box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Erie County Sheriff Substation</td>
<td>Colden Town Hall</td>
<td>Colden</td>
<td>Secure drop box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Depew Police Department</td>
<td>85 Manitou St.</td>
<td>Depew</td>
<td>Secure drop box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Erie County Sheriff Substation</td>
<td>Elma Town Hall</td>
<td>Elma</td>
<td>Secure drop box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Erie County Sheriff Substation</td>
<td>1856 Whitehaven Rd.</td>
<td>Grand Island</td>
<td>Secure drop box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Town of Hamburg Police</td>
<td>S6100 South Park Ave.</td>
<td>Hamburg</td>
<td>Secure drop box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Kenmore Police Department</td>
<td>2395 Elmwood Ave.</td>
<td>Kenmore</td>
<td>Secure drop-box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Lancaster Police Department Criminal Justice Building</td>
<td>Lancaster Town Bldg. 529 Pavement Rd.</td>
<td>Lancaster</td>
<td>Secure drop-box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Erie Community College South Public Safety</td>
<td>4041 Southwestern Blvd. Building #5</td>
<td>Orchard Park</td>
<td>Secure drop box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Erie County Sheriff Substation</td>
<td>Springville Town Hall</td>
<td>Springville</td>
<td>Secure drop box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
<tr>
<td>Erie Community College North Public Safety</td>
<td>6205 Main St.</td>
<td>Williamsville</td>
<td>Secure drop box 24/7 access</td>
<td>No sharps, needles, or aerosol inhalers</td>
</tr>
</tbody>
</table>
This statement is provided by Hospice Buffalo in accordance with the Federal Patient Self-Determination Act of 1990 and the New York State laws governing health care decision making. These laws require home health agencies to provide written information about the agency’s policies regarding patient’s rights to make health care decisions and to execute advance directives.

Hospice Buffalo respects the rights of each adult to participate in health care decision making to the maximum extent of his or her ability, and respects all rights consistent with New York State law. We have instituted specific policies and procedures to ensure that a patient’s health care decisions are followed.

**STATEMENT I: DOCUMENTATION OF INFORMATION TO PATIENTS**

Hospice Buffalo will provide the following written information to each adult patient prior to, or at the time of, admission to the agency for care:

1. The following material prepared by the New York State Department of Health
   1.1 Planning in Advance for Your Medical Treatment
   1.2 Do Not Resuscitate Orders: A Guide for Patients and Families
   1.3 Appointing Your Health Care Agent: New York State’s Proxy Law

2. The Hospice Buffalo Policy regarding the right of each adult to make health care decisions and to formulate advance directives (this document). Hospice Buffalo will ask every person to sign a document acknowledging the receipt of this information and the status of his or her advance directive. Hospice Buffalo will document in the patient’s medical record whether or not the patient has executed an advance directive. The agency will ask for a copy of any advance directive already in place, and if made available to the agency, a copy of such advance directive shall be included in the patient’s medical record. The patient’s advance directives will be respected by Hospice Buffalo.

**STATEMENT II: COMPLIANCE WITH THE LAW**

Hospice Buffalo will comply with all applicable Federal and State laws regarding advance directives.

**STATEMENT III: NON-DISCRIMINATION**

Hospice Buffalo will not restrict the provision of care or otherwise discriminate against any individual based on whether or not the individual has executed an advance directive.

**STATEMENT IV: EDUCATION**

Hospice Buffalo will promote education to staff and the community on issues regarding health care decision making.

**STATEMENT V: ADVANCE CARE PLANNING**

For the purposes of this statement, an “Advance Directive” is a written instruction relating to the provision of health care when an adult becomes incapacitated. This includes but is not limited to, a Health Care Proxy (HCP), a Living Will, MOLST (Medical Orders for Life Sustaining Treatment) and consent to or a request for the issuance of a Do Not to Resuscitate (DNR) order. Your forms should be reviewed and updated annually, based on your condition.

A. **Health Care Proxy** - A document which delegates to another adult, known as a health care agent, the authority to make health care decisions on behalf of the individual making the appointment, if in the future, that individual becomes incapable of making his or her own health care decisions.

B. **Living Will** - A document which contains specific instructions concerning an individual’s wishes about the type of health care choices and treatments that he or she does or does not want to receive, but does not designate an agent to make health care decisions. Any patient who presents a Living Will shall be encouraged to complete a Health Care Proxy form, as there is no law in New York State recognizing Living Wills.
C. MOLST (Medical Orders for Life Sustaining Treatment) - A form that documents a patient’s treatment preferences concerning life sustaining treatment. Completion begins with a conversation or a series of conversations between the patient, the patient’s health care agent or proxy and a qualified, trained health care professional that defines a patient’s goals of care, reviews possible treatment options and ensures shared, informed medical decision-making for patients with serious health conditions. Conversations may be initiated by any qualified and trained health professional, however a licensed physician must always confer with the patient and/or the patient’s health care agent or proxy about the patient’s diagnosis, prognosis, goals for care, treatment preferences and consent by the appropriate decision maker. The physician must sign the orders decided from that discussion.

D. Consent to or Request for the Issuance of an Order Not to Resuscitate (A “DNR Order”) - The documented consent to, or request for, a doctor’s order not-to-resuscitate (A “DNR Order”). Under such an order, health care providers are not to attempt cardiopulmonary resuscitation (“CPR”) in the event that the patient suffers cardiac or respiratory arrest. A request for such an order can be expressed in a Living Will, Health Care Proxy or MOLST. This physician order must be written on the New York State Department of Health “Non-hospital DNR Order” form when a person is not hospitalized. This physician order may also be written in the MOLST.

YOUR RIGHT TO DECIDE ABOUT TREATMENT

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

PLANNING IN ADVANCE FOR YOUR MEDICAL TREATMENT

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

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

If you have no one you can appoint to decide for you, or do not want to appoint someone, you can also give specific instructions about treatment in advance. These instructions should be written and are often referred to as a Living Will. You should understand that general instructions about refusing treatment, even if written down, may not be effective. Your instructions must cover specific treatment decisions. For example, if you just write down that you do not want “heroic measures,” the instructions may not be specific enough. You must describe the kind of treatment that you do not want, such as a respirator or chemotherapy, and describe the instance when you would refuse the treatment, such as when you are temporarily ill or permanently unconscious with no hope of recovering. You should also give instructions orally by discussing your treatment wishes with your doctor, family members or others close to you.

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

DECIDING ABOUT CPR: DO-NOT-RESUSCITATE (DNR) ORDERS

WHAT DO CPR AND DNR ORDERS MEAN?

CPR - cardiopulmonary resuscitation - refers to the medical procedures used to restart a patient’s heart and breathing when the patient suffers heart failure. CPR may involve simple efforts such as mouth-to-mouth resuscitation and external chest compression. Advanced CPR may involve electric shock, insertion of a tube to open the patient’s airway, injection of medication into the heart and in extreme cases, open chest heart massage.

DNR - do-not-resuscitate order tells medical professionals not to perform CPR. This means that doctors, nurses and emergency medical personnel will not attempt emergency chest compressions when the patient’s heart stops. Hospice Buffalo treats patients for all symptoms while alive, and allows a natural death.

DNR orders may be written for patients in a hospital or nursing home, or for patients at home. Hospital DNR orders tell the medical staff not to resuscitate the patient if cardiac arrest occurs. If the patient is in a nursing home or at home, a DNR order tells the staff and emergency medical personnel not to perform emergency resuscitation and not to transfer the patient to a hospital for CPR.

DECIDING ABOUT CARDIOPULMONARY RESUSCITATION (CPR)

Your right to decide about treatment also includes the right to decide about cardiopulmonary resuscitation (CPR). CPR is emergency treatment to restart the heart and lungs when your breathing or circulation stops.

Sometimes doctors and patients decide in advance that CPR should not be provided, and the doctor gives the medical staff an order not to resuscitate (DNR order). If your physical or mental condition prevents you from deciding about CPR, someone you appoint, your family members, or others close to you can decide. A brochure on CPR and your rights under New York law is available from your health care provider.

Hospice Buffalo will treat any patient symptoms in collaboration with the family and team physician. Patient comfort is our goal.
New York Health Care Proxy

(1) I, __________________________________________________________________________________, hereby appoint:

Agent’s Name: ___________________________________________________________________________

Agent’s Home Address: _____________________________________________________________________

Agent’s Telephone Numbers: __________________________________________________________________________
as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

This proxy shall take effect only when and if I become unable to make my own health care decisions.

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

Alternate’s Name: ___________________________________________________________________________

Alternate’s Home Address: _____________________________________________________________________

Alternate’s Telephone Numbers: __________________________________________________________________________

(3) Unless I revoke it, this proxy shall remain in effect indefinitely or until the date or condition I have stated below. (Optional: If you want this proxy to expire, state the date or conditions here.) This proxy will expire (specify date or conditions):

___________________________________________________________________________________________

___________________________________________________________________________________________

(4) Optional Instructions: I direct my agent to make health decisions in accordance with my wishes and limitations as stated below, or as he or she otherwise knows. (attach additional pages as necessary)

___________________________________________________________________________________________

___________________________________________________________________________________________

My agent knows my wishes regarding artificial nutrition and hydration.
(5) Your Identification (please print)

Your Name:__________________________________________________________________________________________________________

Your Signature:_________________________________________________________________________________ Date ________________

Your Address:________________________________________________________________________________________________________

(6) Optional: Organ and/or Tissue Donation

Upon my death, I wish to donate my organs, tissues or body parts:
(check any that apply and note limitations)

________ Any needed organs and/or tissues

________ Only the following organs and/or tissues

____________________________________________________________________________________________________________________

My donation is for the following:

___ transplant    ___ therapy    ___ research    ___ education    ___ any use

(7) Statement by Witnesses (Witnesses must be 18 years of age or older and cannot be
the health care agent or alternate.)

I declare that the person who signed this document is known to me and appears to execute
this proxy willingly and of his or her own free will. He or she signed (or asked another to
sign for him or her) this document in my presence.

Name of Witness 1 (please print): ____________________________________________________________________________________

Signature: __________________________________________________________________________________________Date: ____________

Address: ______________________________________________________________________________________________________

Name of Witness 2 (please print): ____________________________________________________________________________________

Signature: __________________________________________________________________________________________Date: ____________

Address: ______________________________________________________________________________________________________
THIS SECTION DESCRIBES HOW YOUR MEDICAL INFORMATION MAY BE USED AND DISCLOSED AND HOW YOU CAN ACCESS IT. PLEASE REVIEW IT CAREFULLY.

This Notice describes the privacy practices of Hospice Buffalo, Inc., and its affiliates, (individually referred to as the “Provider” and collectively referred to as the “Providers”, “we” or “our”). We are an organized system of legally separate health care providers recognized as an Organized Health Care Arrangement (“OHCA”) under the Health Insurance Portability and Accountability Act, as amended (“HIPAA”). We are committed to maintaining your confidentiality and protecting your health information.

This Notice describes your rights and our duties regarding your Protected Health Information related to the care and services we provide to you in our facilities, other health care and residential facilities and your home. It also applies to our health care professionals including but not limited to physicians, nurses and aides that provide care to you. Each Provider will follow the terms of this Notice and we will use and share your Protected Health Information with each other, as necessary, for the purposes of treatment, payment and health care operations.

We are required by law to:
- maintain the privacy of your Protected Health Information;
- provide you with this Notice of our legal duties and privacy practices relating to your Protected Health Information; and
- abide by the terms of the Notice that are currently in effect.

WITH YOUR CONSENT WE MAY USE AND DISCLOSE YOUR PROTECTED HEALTH INFORMATION FOR TREATMENT, PAYMENT AND HEALTH CARE OPERATIONS

You will be asked to sign a consent allowing us to use and disclose your Protected Health Information to others to provide you with treatment, obtain payment for our services, and run our health care operations. We will initially limit the use and disclosure of your Protected Health Information, to the extent practicable, to a limited data set (a limited data set does not include your direct identifiers) or, if needed, to the minimum necessary to accomplish the intended purpose of such use, disclosure or request. Here are examples of how we may use and disclose your health information.

For Treatment. We will use and disclose your Protected Health Information to health care professionals to provide you with health care services. For example, we may consult with a physician located at another location to determine how best to treat you.

For Payment. We may use and disclose your Protected Health Information to others in order for us to bill and receive payment for your health care services. For example, we may include your health information in our claim to your insurance company, Medicare or Medicaid, in order to receive payment for your services. We may also disclose your health information to other health care providers so that they can receive payment for their services.

For Health Care Operations. We may use and disclose your Protected Health Information to others for our business operations. For example, we may use your Protected Health Information to maintain and improve patient care, evaluate our services and educate our staff.
WE MAY USE AND DISCLOSE YOUR PROTECTED HEALTH INFORMATION FOR OTHER SPECIFIC PURPOSES

As Required By Law. We will disclose your Protected Health Information when and as required by law to do so.

Business Associates. We may share your Protected Health Information with our vendors and agents who create, receive, maintain or transmit Protected Health Information for certain functions or activities on behalf of the Provider. These are called our “Business Associates” and include any subcontractor that creates, receives, maintains or transmits Protected Health Information on behalf of the Provider. For example, we may give your health information to a billing company to assist us with our billing for services, or to a law firm or an accounting firm that assists us in complying with the law and for improving our services. To protect and safeguard your health information we require our Business Associates and subcontractors to appropriately safeguard your information.

Family and Friends Involved in Your Care. Unless you object, we may disclose your Protected Health Information to a family member or close personal friend, including clergy, who is involved in your care or payment for that care.

Personal Representative. If you have a personal representative, such as a legal guardian, we will treat that person as if that person is you with respect to disclosures of your Protected Health Information. If you become deceased, we may disclose your health information to an executor or administrator of your estate, to the extent that person is acting as your personal representative or to your next of kin, as permitted under state and federal law.

Disaster Relief. We may disclose your Protected Health Information to an organization assisting in a disaster relief effort.

Public Health. We may disclose your Protected Health Information for public health activities including the reporting of disease, injury, vital events, defective medical devices or problems with medications, recalls of products, and the conduct of public health surveillance, investigation and/or intervention. We may also disclose your information to notify a person who may have been exposed to a communicable disease or may otherwise be at risk of contracting or spreading a disease or condition if a law permits us to do so.

To Avert a Serious Threat to Health or Safety. We may use and disclose your Protected Health Information when necessary to prevent a serious threat to your health or safety or the health or safety of the public or another person. However, any disclosure would be made only to someone able to help prevent the threat.

Health Oversight. We may disclose your Protected Health Information to health oversight agencies authorized by law to conduct audits, investigations, inspections, licensure actions or other legal proceedings. Oversight agencies include government agencies that oversee the health care system, government benefit programs, other government regulatory programs and civil rights laws.

Reporting Victims of Abuse, Neglect or Domestic Violence. If we have reason to believe that you have been a victim of abuse, neglect or domestic violence, we may use and disclose your Protected Health Information to notify a government authority if required or authorized by law, or if you agree to the report.

Law Enforcement. We may disclose your Protected Health information for certain law enforcement purposes or other specialized governmental functions. Examples of law enforcement purposes include limited requests for the purpose of identification and location of a suspect, fugitive or missing person; or disclosure under certain circumstances pertaining to victims of crime.
Judicial and Administrative Proceedings. We may disclose your Protected Health Information in the course of certain judicial or administrative proceedings, such as responses to subpoenas, discovery request or other lawful process.

Research. In general, we will request that you sign a written authorization before using your Protected Health Information or disclosing it to others for research purposes. However, we may use or disclose your health information without your written authorization for research purposes provided that the research has been reviewed and approved by a special Privacy Board or Institutional Review Board.

De-identified Information. We may use your Protected Health Information to create “de-identified” information or we may disclose your information to a Business Associate so that the Business Associate can create de-identified information on our behalf. When we “de-identify” health information, we remove information that identifies you as the source of the information, health information is considered “de-identified” only if there is no reasonable basis to believe that the health information could be used to identify you.

Limited Data Set. We may use and disclose a limited data set that does not contain specific readily identifiable information about you for research, public health, and health care operations.

Coroners, Medical Examiners, Funeral Directors, Organ Procurement Organizations. We may release your Protected Health Information to a coroner, medical examiner, funeral director or, if you are an organ donor, to an organization involved in the donation of organs and tissue.

Military and Veterans. If you are a member of the armed forces, we may use and disclose your Protected Health Information as required by military command authorities. We may also use and disclose Protected Health Information about foreign military personnel as required by the appropriate foreign military authority.

Workers’ Compensation. We may use or disclose your Protected Health Information to comply with laws relating to workers’ compensation or similar programs.

National Security and Intelligence Activities; Protective Services. We may disclose Protected Health Information to authorized federal officials who are conducting national security and intelligence activities or as needed to provide protection to the President of the United States, or other important officials.

Inmates. If you are an inmate of a correctional institution or under the custody of a law enforcement official, we may disclose your Protected Health Information to the correctional institution or law enforcement official as 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) for the safety and security of the correctional institution.

YOUR AUTHORIZATION IS REQUIRED FOR OTHER USES OF YOUR PROTECTED HEALTH INFORMATION

Your Protected Health Information is kept confidential and used only for the purposes of providing your Hospice care. Hospice Buffalo will meet with you personally if we have other requests to release your Protected Health Information. To change or revoke your authorization, please contact our Privacy Officer at (716) 989-2076. If you revoke your authorization, we will no longer use or disclose your Protected Health Information for the purposes covered by the authorization, except where we have already relied on the authorization.
Fundraising. We may contact you or your personal representative to raise money for the Provider. We may also share your demographic information with the Hospice Foundation of WNY, Inc., an affiliated charitable foundation that may contact you or your personal representative to raise money on our behalf. You must provide us with your written authorization for our use of your information for fundraising and you also have the opportunity to opt out or restrict your receiving future fundraising communications. Your request to opt out of receiving future fundraising communication will revoke any prior authorizations and you will not receive any future communications.

Marketing, Treatment Alternatives and Health-Related Benefits. In most circumstances, we are required by law to receive your written authorization before we use or disclose your health information for marketing purposes. Under no circumstances will we sell our patient lists or your health information to a third party without your written authorization. We may contact you to provide information about treatment alternatives or other health-related benefits and services that may be of interest to you.

YOUR RIGHTS REGARDING YOUR HEALTH INFORMATION
You have the following rights with respect to your Protected Health Information. If you wish to exercise any of these rights, please submit your request to our Privacy Officer.

Right of Access to Protected Health Information. You have the right to inspect and obtain a copy of your Protected Health Information, subject to some limited exceptions. Your request must be in writing to our Privacy Officer. You have the right to access your information in electronic format, if available. We must allow you to inspect your records within 10 days of your request. If you request copies of the records, we must provide you with copies within a reasonable time but not more than 30 days if the records are maintained onsite or 60 days if the records are maintained off-site. Under certain circumstances, we may extend the time to provide you with copies for an additional 30 days. We may charge a reasonable fee for our costs in copying and mailing your requested information or provision of information in electronic format.

In certain limited circumstances, we may deny your request to inspect or receive copies. If we deny access to your Protected Health Information, we will provide you with a summary of the information, and you have a right to request review of the denial. We will provide you with information on how to request a review of our denial and how to file a complaint with us or the Secretary of the Department of Health and Human Services. Contact our Privacy Officer if you have any questions regarding access to your medical records.

Right to Receive Notice of a Breach. We will notify you by first class mail or by e-mail (if you have indicated a preference to receive information by e-mail), of any breaches of Unsecured Protected Health Information as soon as possible, but in any event, no later than 60 days following the discovery of the breach. A “Breach” means the unauthorized access, acquisition, use, or disclosure of Protected Health Information which compromises the security or privacy of Protected Health Information, except: (1) an unauthorized person to whom such information is disclosed would not reasonably have been able to retain such information; (2) any unintentional acquisition, access, or use of Protected Health Information by an employee or individual acting under the authority of a covered entity or business associate (a) was made in good faith and within the course and scope of the employment or other professional relationship of such employee, or individual, respectively, with the covered entity or business associate; and (b) such information is not further acquired, accessed, or used or disclosed by any person; or (3) any inadvertent disclosure from an individual who is otherwise authorized to access Protected Health Information at a facility operated by a covered entity or business associate to another similarly situated individual at the same facility provided that any such information received as a result of such disclosure is not further acquired, accessed, used, or disclosed without authorization. The Provider must notify you of any breach unless we can demonstrate, based on a risk assessment, that there is a low probability that the Protected Health Information has been compromised.
“Unsecured Protected Health Information” is information that is not secured through the use of a technology or methodology identified by the U.S. Department of Health and Human Services to render the Protected Health Information unusable, unreadable and undecipherable to unauthorized users. The notice is required to include the following information:

- a brief description of the breach, including the date of the breach and the date of its discovery, if known;
- a description of the type of Unsecured Protected Health Information involved in the breach;
- steps you should take to protect yourself from potential harm resulting from the breach;
- a brief description of action we are taking to investigate the breach, mitigate losses, and protect against further breaches; and
- contact information, including a toll-free number, e-mail address, Website or postal address to permit you to ask questions or obtain additional information.

In the event the breach involves 10 or more individuals whose contact information is out of date, we will post a notice of the breach on the home page of our web site or in a major print or broadcast media. If the breach involves more than 500 individuals in the state or jurisdiction, we will send notices to prominent media outlets. If the breach involves more than 500 individuals, we are required to immediately notify the Secretary of Health and Human Services. We are also required to submit an annual report to the Secretary of a breach that involved less than 500 individuals during the year and will maintain a written log of breaches involving less than 500 individuals. Notification to the Secretary will occur within 60 days of the end of the calendar year in which the breach was discovered.

**Right to Request Restrictions.** You have the right to request restrictions on the way we use and disclose your Protected Health Information for our treatment, payment or health care operations. You also have the right to request restrictions on the way we disclose your Protected Health Information to a family member, friend or other person who is involved in your care or the payment for your care. To request a restriction, you must submit a written request to our Privacy Officer.

We are not required to agree to your requested restriction, and in some cases, the law may not permit us to accept your restriction. However, if we do agree to accept your restriction, we will comply with your restriction except in the case of an emergency or if the use or disclosure is required by law. If your restriction applies to disclosure of information to a health plan, for payment or health care operations purposes and is not otherwise required by law and where you paid out of pocket, in full, for items or services, we are required to honor that request.

**Right to an Accounting of Disclosures.** You have the right to request an “accounting” of our disclosures of your Protected Health Information. This is a listing of certain disclosures of your Protected Health Information made by the Provider or by others on our behalf, but does not include disclosures made for treatment, payment and health care operations or certain other purposes unless the records are maintained in an Electronic Health Record. Records maintained in an Electronic Health Record will include disclosures made for treatment, payment, health care operations and other purposes.

You must submit a request in writing to our Privacy Officer, stating a time period that is within six years or less from the date of your request. Where an Electronic Health Record is used, we will provide you with an accounting of disclosures for a three year period. You are entitled to one free accounting within one 12-month period. For additional requests, we may charge you our costs.

We will usually respond to your request within 60 days. Occasionally, we may need additional time to prepare the accounting. If so, we will notify you of our delay, the reason for the delay, and the date when you can expect the accounting.
Right to Request Amendment. If you think that your Protected Health Information is not accurate or complete, you have the right to request that the Provider amend such information as long as the information is kept in our records. Your request must be in writing to our Privacy Officer and must state the reason for the requested amendment. We will usually respond within 60 days, but will notify you within 60 days if we need additional time to respond, the reason for the delay and when you can expect our response. We may deny your request for amendment, and if we do so, we will give you a written denial including the reasons for the denial and an explanation of your right to submit a written statement disagreeing with the denial.

Right to a Paper Copy of This Notice. You have the right to obtain a paper copy of this Notice, even if you have agreed to receive this Notice electronically. You may request a copy of this Notice at any time. You may obtain a copy of this Notice by calling our Privacy Officer and requesting that a copy be mailed to you.

Right to Request Confidential Communications. You have the right to request that we communicate with you concerning personal health matters in a certain manner or at a certain location. For example, you can request that we speak to you only at a private location such as your home, rather than at work. Your request must be in writing to our Privacy Officer. We will accommodate your reasonable requests.

COMPLAINTS
If you believe that your privacy rights have been violated, you may file a complaint in writing with us or with the Office of Civil Rights in the U.S. Department of Health and Human Services. To file a complaint with us, or for more information regarding filing a complaint, contact our Privacy Officer. No one will retaliate or take action against you for filing a complaint.

CHANGES TO THIS NOTICE
We reserve the right to change this Notice and to make the revised or new Notice provisions effective for all Protected Health Information already received and maintained by the Provider as well as for all Protected Health Information we receive in the future. We will promptly revise and distribute this Notice whenever there is a material change to the uses or disclosures, your individual rights, our legal duties, or other privacy practices stated in this Notice and will mail a copy of the revised Notice to you or your personal representative. You can obtain a copy of this notice by contacting our Privacy Officer.

FOR FURTHER INFORMATION
If you have any questions about this Notice or would like further information concerning your privacy rights, contact our Privacy Officer at:

Privacy Officer
c/o The Center for Hospice & Palliative Care
225 Como Park Boulevard
Cheektowaga, New York 14227
(716) 989-2076
**HOSPICE BUFFALO BILLING STATEMENT**

**Purpose**
Hospice Buffalo is required by regulation to provide a statement of related charges for the services that we provide. The information contained in this Billing Statement addresses insurance authorization requirements, co-payments, deductible information and gross charges that may be incurred while receiving services.

**Authorization**
While receiving Hospice Buffalo services, it is necessary for you to notify your Nurse or Hospice Representative of any medical appointments that you are planning or have scheduled. Such appointments include but are not limited to laboratory services, physician visits, x-rays, radiation, chemotherapy, and blood transfusions. Medication changes should always be discussed with your nurse to determine whether they are covered under your hospice benefit or under another insurance plan.

If you do not receive prior authorization from Hospice Buffalo for medical appointments or medical care, Hospice cannot assure coverage by your insurance. You will be responsible for all uncovered charges. Hospice will advocate on behalf of the patient with the insurance provider but cannot assume responsibility for unauthorized charges.

**Copayment and Deductibles**
Should your insurance provider require a copayment or deductible, Hospice Buffalo will confirm eligibility for coverage and notify you if your insurance is not covering services. You will be informed of all charges and billed according to the directives established by your insurance company. All non-covered charges are your responsibility. Charges will be billed directly by the Hospice Buffalo Billing Department.

It is the policy of Hospice Buffalo to provide care on the basis of the patient’s medical need rather than ability to pay. In order for us to be able to determine ability to pay, it is necessary to have a financial disclosure form completed. Hospice staff will assist you with completing the form. No patient will be denied services if inability to pay is determined by Hospice Buffalo.

**Fee Schedule**
While receiving care during enrollment with Hospice Buffalo, the following fee schedule for services applies as defined by the individual’s plan of care. Hospice is reimbursed on a daily rate, depending on the level of care provided. The following fees are estimates — due to changes in our health care reform regulations, the fees may be subject to change. Hospice staff will advise you regarding fee changes as they occur.

- Routine home care, the fee is approximately $205 per day.
- Respite Inpatient Care, the fee is approximately $205 per day.
- Acute Inpatient Care, the fee is approximately $880 per day.

**Questions or concerns regarding billing, please contact our business office at (716) 686-1900.**
MEDICARE HOSPICE BENEFIT REVOCATION

PATIENT INFORMATION

Name: ___________________________________________________________________________________________

Address: _________________________________________________________________________________________

Telephone Number: _________________ ____________________________________________________________

Medicare Number: ______________________________________________________________________________

I hereby revoke election of the Medicare Hospice Benefit which is providing coverage of my hospice care.

I understand that Medicare coverage of hospice care is forfeited for any remaining days in this benefit period.

I also understand that I may at any time, again elect to receive hospice coverage for any other hospice election period that I am eligible to receive.

_________________________________________________________  ________________________________
Effective Date of Revocation  

_________________________________________________________  ________________________________
Signature of Patient  Date
This is a sample of a statement that you will be receiving from Medicare. It is not a bill, but simply a statement informing you of the amount billed and paid by Medicare.

If you have any questions that were not answered, feel free to call the Hospice business office at (716) 686-1900.
# FAMILY NOTES/PATIENT OBSERVATIONS

<table>
<thead>
<tr>
<th>DATE/TIME</th>
<th>QUESTION/COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Thank You

We thank you for the privilege of assisting you with the care of your loved one. We salute you for all you have done to surround your loved one with compassionate care, to provide your loved one with comfort and calm, and to enable your loved one to leave this world with a special sense of peace and love.

You have given your loved one the most beautiful and sensitive gift we humans are capable of, and in giving that gift, have given yourself a wonderful gift as well.

~ Your Hospice Buffalo Care Team

A Legacy of Love

Hospice & Palliative Care provides support to patients and their families during life’s most challenging — yet meaningful — time. As an acute illness progresses, patients and families realize that every day is precious. Hospice Buffalo provides services to all patients in need and their families regardless of their ability to pay. It is with community support that we are able to meet these needs. Contributions in the form of memorials may be requested by you at the time of your loved one’s passing. If you wish to designate memorial donations to the Hospice Foundation, please inform your funeral director. Donations may be made to:

The Hospice Foundation of WNY
225 Como Park Blvd., PO Box 590
Buffalo, NY 14240-0590

The Hospice Foundation can be reached at (716) 686-8090. Thank you for your consideration and support of Hospice Buffalo.

Best,

Patrick T. Flynn,
Foundation President
Hospice Buffalo is here…

to comfort, to guide,

and support.

Because we’re more than

dead-end care, we’re quality-of-life care.

HOSPICE BUFFALO

225 Como Park Boulevard, Cheektowaga, NY 14227-1480 • P: (716) 686-8000 • F: (716) 686-8101 • HospiceBuffalo.com

09.2019