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## **ON CALL PROCEDURE**

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The Center for Hospice and Palliative Care, Inc. is open Monday through Friday, 8:00 a.m. to 5:00 p.m. (closed for holidays). We realize a patient's condition may change at any time and you may have important caregiving questions. You are never alone with your concerns. **Our on-call system is designed to assist you when our office is closed.** Following are the phone numbers for contacting an on-call nurse:

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### **HOSPICE OF ST. JOSEPH COUNTY**

**Call: (574) 243-3100**

**Toll Free: (800) 413-9083**

### **MARSHALL COUNTY HOSPICE**

**Call: (574) 935-4511**

**Toll Free: (800) 774-2784**

### **HOSPICE OF ELKHART COUNTY**

**Call: (574) 264-3321**

**Toll Free: (866) 264-3321**

**In ALL Instances:**

**Ask that the Hospice nurse on call be paged**

**Leave YOUR NAME, the PATIENT'S NAME, the PHONE NUMBER, and COUNTY OFFICE that serves you**

**The answering service will page the nurse on call and he/she will return your call.**

**This process can take up to 15-20 minutes.**

**If the call is not returned within 20 minutes, PLEASE CALL AGAIN**

**Please remain off the phone to keep your line open until the nurse calls you.**

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## **Availability 24 Hours a Day**

A Hospice nurse is available to you by phone 24 hours a day.

The on-call nurse receives a daily update on all patients we serve and will help answer your question.

**Some** examples of when you may need to talk to an on-call nurse are:

- If you have questions about medicines
- If a patient's condition has changed (i.e., can no longer swallow medicine, is no longer responsive, has a different breathing pattern)
- If you have questions about pain control or other symptoms
- If you become increasingly anxious, fearful or unsure

## **Calling the Physician**

Patients and families are asked to call the Hospice nurse before calling the physician. The Hospice nurse can possibly answer your question, help you decide whether to call the physician, or can call for you. **If you do speak with the physician** and have not talked to the Hospice nurse, please notify the Hospice nurse so Hospice will know what has occurred.

## **Concerns About Rehospitalization**

We urge you to call us first when questioning if a patient needs to go to the hospital. In most cases, it is possible for the Hospice nurse to visit and handle the situation in your own home. Transporting a seriously ill person to an unfamiliar setting can be traumatic. **However**, if the situation cannot be dealt with in the home and the patient needs to go to the hospital, the Hospice nurse can assist you to make sure the transition is as smooth as possible for the patient. Staff can also advise you on insurance requirements so that insurance coverage is not interrupted.

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## THE HOSPICE TEAM

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Hospice works together as a team to meet the physical, emotional, and spiritual needs of the patients and families in our care. You and the patient's physician are a part of this team. We want to be sensitive to the wide variety of needs that may develop during the time we are involved with you.

The following are the primary team members and how they can assist with your care and concerns.

### **NURSE**

A Hospice registered nurse admits a patient into Hospice services. The nurse you meet on the admission is not the nurse who will be the patient's primary nurse. A primary nurse will be assigned following the first home visit. A primary nurse will coordinate the patient's care, along with other nurses participating in care of the patient, family and/or significant other, the patient's physician, and the Hospice team.

The home care nurses are the team members with whom you will probably have the most contact. They are all knowledgeable and caring people.

**Some** practical areas of involvement may include:

- initiating the patient's plan of care
- monitoring the patient's changing condition, especially in pain management, and reporting changes to the physician
- teaching the family about the disease process and what to expect
- coordinating care with the other Hospice team members
- supervising home health aides when assistance is needed for personal care

### **HOME HEALTH AIDE:**

Hospice home health aides are skilled at assisting with personal care activities. They are trained aides and have been educated in the Hospice philosophy of care.

**Some** potential areas of involvement may include:

- bathing, shampooing and shaving a patient
- assisting with mouth care
- providing skin care and dressing changes
- changing bed linens
- nail care

## **SOCIAL WORK:**

A Hospice Social Worker is part of every Hospice team and will meet with the patient and family to assess non-medical needs. The Social Worker is directly linked not only with the patient, but with all of the family members. This effort is to maximize the quality of life for the patient and to assist families in dealing with change.

Your Social Worker is an experienced individual who can help you talk about the changes that are happening, open up family communication, and work with you to find services you need.

**Some** practical areas of involvement may include:

- assisting the patient and family with the adjustment to changes
- helping patients recognize their abilities, despite increased limitations
- discussing ways for caregivers to care for themselves
- utilizing community resources that provide helpful services not provided by Hospice
- explaining alternative options if home care becomes overwhelming
- resolving problems with insurance, Medicare or Medicaid
- obtaining general legal information or providing referrals for matters such as power of attorney, bank accounts, safety deposit boxes, death certificates, etc.

## **SPIRITUAL CARE:**

The Hospice Spiritual Counselor is an important member of the Hospice team. As we all work together to ensure the quality of a patient's life, spiritual care touches the innermost spirit of a patient, assisting the person to find the freedom to accept all phases of their life -- the past, the present and the future.

A Spiritual Counselor is a theologically trained individual available to the patient and family members. You will find the Spiritual Counselor to be accepting and open to all beliefs. They are not there to replace your own minister, rabbi or priest, but to work jointly and be sensitive to what brings you strength during this difficult time. Spiritual care is focused on each person as an individual -- to listen to you and to learn from you. It is our hope to journey with a family as they find hope and meaning beyond the patient's illness.

**Some** spiritual areas of involvement may include:

- notification of your clergy of your involvement with Hospice services
- help in finding clergy of a particular denomination, if the patient or family members so choose
- identifying and resolving spiritual concerns affecting the patient and family
- assistance in reflecting on the mysteries of life, suffering, death and afterlife
- offering prayer, scripture reading, or sacraments
- offering a caring presence in times of need or crisis
- planning and officiating funerals for those without church involvement

## **VOLUNTEERS:**

Hospice Volunteers are a valuable resource to our patient/families. They come from diverse backgrounds and lifestyle situations. A common thread of caring and compassion unites them in their volunteering for Hospice. They are a help to us and our Hospice families, and an important part of our care team.

Our Hospice Volunteers go through a training program specific to the job they are assigned. During intermittent in-home visits, Hospice patient care volunteers are available to accomplish the following:

- stay with the patient to relieve the caregiver and provide companionship
- provide needed transportation
- read to, or write letters for the patient
- assist the patient with personal hygiene
- do small housekeeping chores
- prepare and feed the patient light meals
- become a friend of the patient and the family

Hospice Volunteers are available for in-home visits throughout the day and early evening hours. Families can receive volunteer services up to four (4) hours per visit. Hospice attempts to fit family needs with our volunteers' available hours. Ideally, the same volunteer(s) will remain with the family for as long as the patient and family require Hospice services.

**If you would like a volunteer, simply ask any Hospice staff person, or call the Coordinator of Volunteers at the Hospice office. (St. Joseph County (574) 243-3100, Marshall County (574) 935-4511), or Hospice of Elkhart County (574) 264-3321)**

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*Stop, listen, and learn about each other,  
and about each patient, each family, each  
culture, each community. When you do,  
you will improve the care of the living,  
and you improve the care of the dying.*

- Bernice Catherine Harper

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## **BEREAVEMENT COUNSELING:**

Family needs do not end with the death of a patient. The time of bereavement that follows can be very difficult. Hospice wants to offer support as you adjust to a new life without the presence of the person you cared for and loved. Our personalized program can help ease the pain and promote the changes necessary to continue a meaningful life.

A Hospice Bereavement Counselor is specially trained to assess your bereavement needs and to assist you in understanding the grief process. The counselor is sensitive to your pain and realizes that in your grief you can experience a variety of feelings. Together you work toward inner healing.

Hospice bereavement services offer the following:

- informational mailings on issues of grief throughout the first 13 months of your grief
- individual and/or family counseling
- grief support groups
- supportive phone contacts
- Interdenominational Service of Remembrance
- Camp Evergreen, for children ages 7-14
- grief support groups for children

You will regularly receive more information about these services from Hospice staff and from mailings. You may decide which is most comfortable for you. We do urge you to be open to the assistance of a compassionate counselor in dealing with your grief.

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*I gain strength, courage and confidence by every experience in which I must stop and look fear in the face . . . I say to myself, I've lived through this and can take the next thing that comes along . . . We must do the things we think we cannot do.*

- Eleanor Roosevelt

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## PHYSICAL CARE

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The following pages of this section include some very basic procedures for you to follow in delivering comfort care for the patient. Additional teaching will be provided as care-specific needs arise for your loved one. These skills, combined with the love and commitment of family and friends, can produce the very best results.

### MOUTH CARE

Cleaning a person's mouth is important to comfort. Some medicines and diseases leave the mouth dry and/or sore. Routine care will help to prevent infection and irritation in the mouth. It should be done at least once to twice daily.

#### NEEDS:

- Toothpaste or Diluted Mouthwash
- Soft Toothbrush
- Toothettes
- Cup and Bowl
- Lip Balm (Vaseline/Chapstick)

#### PROCEDURE:

1. If a patient is able to provide their own mouth care, he/she should be allowed and encouraged to do so.
2. If a patient is unable to provide their own mouth care, you can assist by brushing the patient's teeth with a small amount of toothpaste and a soft toothbrush. Assist the patient to a sitting position, or, if lying down, turn him/her to the side.
3. If a patient has dentures, they should be removed for cleaning. Brush the dentures inside and out with a soft brush. Allow the dentures to soak for a while in water or denture cleaner. Assist the patient to rinse the mouth with water or mouthwash.
4. If the patient's mouth is irritated, or if they are not able to assist with their own mouth care, you may clean the mouth with a toothette (resembles a lollipop). The sponge-like tip becomes soft when moistened with water or diluted alcohol-free mouthwash and can be used in the patient's mouth.
5. To prevent the patient's lips from cracking or drying, apply some type of lip balm. This can be applied throughout the day.

## SKIN CARE

Good skin care prevents bedsores and adds to a patient's comfort. It also provides an opportunity to touch the patient, which is an expression of love and care.

### NEEDS:

- Non-Alcohol Lotion
- Extra Pillows
- Extra Lift Sheet or Sheep Skin

### PROCEDURE:

1. As a patient becomes weaker, they have a tendency to remain in one position for long periods of time. While this is understandable, they need to be encouraged to sit up and move around to prevent skin breakdown.
2. If a patient is unable to move on their own, then you will need to assist with repositioning the patient every couple of hours. The Hospice nurse or home health aide will demonstrate how to use a lift sheet or sheepskin to make the move easier. Extra pillows will be needed for support and to avoid pressure areas. The spine should be straight, but joint areas may be more comfortable when flexed.
3. A patient's skin needs to be massaged to stimulate and increase circulation. This is important for the prevention of bedsores. The Hospice nurse will educate you on the areas most susceptible to skin breakdown. They are most likely to appear where the skin is close to the bone, such as on heels, elbows, and over the "tail bone". Gently rub these areas with lotion and inform the Hospice nurse if they become reddened.
4. Patient's skin needs to be checked regularly (daily). Areas can become raw due to moisture or friction, especially under the breasts, in the groin area, in abdominal folds, and between the buttocks.  
Cream or lotion can be used to reduce friction or the skin can be kept dry with a light dusting of powder.
5. Plastic right next to the patient's skin allows heat to build up. If you have a plastic mattress cover, put a mattress pad between the cover and bottom sheet. A sheepskin pad will also help increase air circulation. The Hospice nurse may also suggest the use of an egg-crate mattress or an alternating pressure pad to assist with maintaining good skin care.

## **BATHING**

Regular bathing (not necessarily daily) is important for the health and comfort of the patient. This can become difficult as the patient weakens. Using a bath seat in the tub or shower allows the patient to bathe in a safer and less tiring way. When this process becomes unsafe, then a bed bath is necessary.

### **NEEDS:**

Towels and Washcloths

Plastic Basin (container)

Soap

Lotion

Clean Nightgown or Pajamas

Clean Bed Linen (if linen change is needed)

Rubber Gloves (if linen is soiled from any body secretions and when cleaning urine and stool from skin)

### **PROCEDURE:**

1. Gather together all items to be used for bathing.
2. Suggest that the patient use the bedpan or toilet before starting.
3. If the patient is due for any pain medicines, have the patient take these medicines, because the comfort of the patient is always a primary concern.
4. Your Hospice nurse will go through the process of how to give a bed bath. Don't worry if you don't do it exactly the same way.
5. Use warm water and replace the water as often as necessary, but especially after washing the genital area or buttocks.
6. Respect the patient's privacy and dignity by using extra towels or a blanket to cover areas
7. Use soap mainly on areas of the body which perspire or need extra washing due to odor or drainage. Rinse well. Plain water is frequently sufficient for other areas of the body. Soaps without a lot of perfumes and additives cause fewer dry skin problems.
8. A capful of baby oil in the water will help if the patient's skin is dry.
9. Dry the skin with a soft towel, gently, yet thoroughly.
10. Lotion the patient after bathing.

## **CHANGING LINENS OF AN OCCUPIED BED**

As a patient weakens and spends more time in bed, it will become necessary to change linens while the patient remains in bed. Attempts should be made to keep the sheets fresh and free from creases and moisture.

### **NEEDS:**

Sheets and Pillow Cases  
Lift Sheet or Sheep Skin  
Incontinent Pads

### **PROCEDURE:**

1. The thought of making the bed, with the patient in the bed, can be overwhelming, but a Hospice nurse can show you how it is done.
2. If you have a hospital bed, raise the bed to a height most comfortable for you.
3. Remove pillows (unless the patient would be uncomfortable) and any top sheet/blanket. Turn the patient to one side of the bed. Leave the side rails up on that side of the bed.
4. Go to the side of the bed with patient's back facing you to loosen all bottom sheets.
5. Roll the bottom sheet(s), along with any incontinent pad, under the patient to the middle of the bed.
6. Think of making the bed in two halves. Place a fresh sheet on the bed with the middle of the sheet in the middle of the bed. If you are using a lift sheet or incontinent pad, place those in the same way.
7. Tuck in the sides, top, and bottom of your side of the bed. Then roll the other half of the bedding to the middle of the bed, tucking the roll (also contains soiled sheets) under the patient's back and legs.
8. If the bed has a side rail, put it up and assist the patient to roll towards you over the rolled linens.
9. Move to the other side of the bed and pull out the soiled sheets.
10. Unroll the clean sheets and incontinent pad. Tuck in the side, top and bottom.
11. Reposition the patient so he/she is comfortable. Replace pillows and top sheet and blanket.

## **GIVING MEDICATIONS**

Medications taken by the patient are for pain and symptom control. A patient's comfort is always of great concern and importance, whether it be physical, emotional or spiritual.

### **NEEDS:**

Ample Medication  
Medication Schedule

### **PROCEDURE:**

1. Most medications are in pill form and need to be taken with water or another liquid, such as juice, milk, or pop. The patient should have enough liquid to swallow the pill completely. A few sips of the liquid before putting pills into the mouth frequently prevents pills from “sticking.”
2. If the pills are too large or become too difficult to swallow, they can frequently be crushed; however, **ALWAYS CHECK WITH THE HOSPICE NURSE TO BE SURE THE EFFECT OF THE PILL WILL NOT BE CHANGED BY CRUSHING.** The powdered medicine can then be mixed with juice, ice cream, applesauce, pudding or some other food.
3. If the patient continues to have problems swallowing pills, many medicines come in different forms. Your Hospice nurse can discuss this matter with the doctor and perhaps the medication can be obtained in a liquid form, suppository, or a cream.
4. As a patient's disease progresses and he/she becomes weaker, the Hospice nurse and doctor may discuss stopping some medications, except those for comfort.

## **SUPPOSITORIES**

Laxatives are frequently given by suppository, but other medications for pain and nausea can also be given this way, especially if the patient is having a difficult time taking medications orally. The medicines can easily be absorbed from the rectum.

### **NEEDS:**

- Suppository Medicine
- Glove
- Incontinence Pad
- Water-Soluble Lubricant

### **PROCEDURE:**

1. Wash your hands and put a glove on the hand you will use to insert the suppository.
2. Explain to the patient what you will be doing and encourage him/her to take some deep breaths through their mouth.
3. Position patient on their side and place an incontinent pad under the patient (unless one is already in place).
4. Remove the foil wrap or covering (if present) from the suppository.
5. Apply small amount of lubricant to the suppository.
6. Using your gloved finger, push the suppository into the rectum as far as you can.
7. Remove the glove and wash your hands.

It is always best to keep suppositories in a cool place (refrigerator) so they remain firm and easy to insert.

## **ROUTINE URINARY CATHETER CARE**

As a patient's condition deteriorates, it frequently becomes necessary for a patient to have a catheter placed in their bladder due to urinary incontinence. This will be done by the Hospice nurse, but it is important that you provide routine care to prevent bladder infections and skin irritation.

### **NEEDS:**

Washcloth and Towel  
Gloves  
Bowl of Warm Water  
Soap

### **PROCEDURE:**

1. Wash your hands and put on gloves.
2. Explain what you are going to do to the patient.
3. Clean the area where the catheter enters the body, using a washcloth, soap, and warm water. Wash in a downward direction going from front to back.
4. Rinse and wash again if necessary, always in a downward direction.
5. Dry gently. Sometimes a small towel is good for this purpose.
6. See that the catheter is fastened to the upper part of the patient's leg (thigh) with a catheter strap or tape. The catheter should not be pulling on the bladder and should allow the patient some freedom of leg movement.
7. Check to see if the tubing is free of kinks, so the urine drains continuously.
8. Always place the urine bag below the level of the bladder to aid in draining. They can be attached to the bed or chair.
9. Remove gloves and wash your hands.

If it ever appears that the patient is wet with urine, check to see that the tubing from point of entering patient's bladder to the urinary bag is free from kinks. This could also result from a bladder spasm. Clean patient and be sure that incontinent pad is dry. Notify the Hospice nurse if problem continues.

## **GIVING AN ENEMA**

It may be necessary during the course of care for a patient to receive an enema to relieve constipation. The Hospice nurse will try to prevent this problem by closely monitoring the patient, but it is not always preventable. Constipation sometimes results due to the lack of mobility of the patient, but also because of medications.

### **NEEDS**

Gloves  
Disposable Enema Kit  
Water-Soluble Lubricant  
Bedpan or Commode  
Incontinent Pad

### **PROCEDURE:**

1. Place the enema in a pan of warm water for a little while. This will warm the solution to body temperature.
2. If the patient will need to use the commode, place it close to the patient's bed for easy access.
3. Wash hands and put gloves on.
4. Explain to the patient what you are going to do.
5. Turn the patient on his/her left side with their knees bent.
6. Place an incontinent pad securely under the buttocks.
7. Remove the cap from the enema and put a small amount of lubricant on the tip. Insert the tip into the rectum.
8. Encourage the patient to take deep breaths as you gently squeeze the bottle to slowly instill the fluid.
9. Remove tip from the rectum when bottle is empty.
10. Encourage the patient to retain the enema for 5-10 minutes (or as long as possible).
11. Assist the patient to a commode or onto a bedpan.
12. Clean patient's rectal area before removing gloves.
13. Wash hands.

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## **CONTROLLING INFECTIONS AT HOME**

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Avoiding infection is important for the patient and caregivers. The following information will help prevent infection or the spread of infection.

### **HAND WASHING**

Hand washing is the single most important way to prevent infection. Hand washing should be done before and after any contact with the patient, such as feeding, turning, or assisting the patient with toileting. Hand washing should also be done after contact with personal items such as bedding or care supplies. Hand washing should also be done before cooking or any time the hands feel dirty.

If possible, use a pump soap dispenser, if not, a bar of soap will work just as well. Use a clean towel or paper towel to dry hands.

### **CLEANING MEDICAL SUPPLIES**

Bedpans, urinals, and commodes should be cleaned on a regular basis with soap and water. For a more thorough cleaning, you may use a 1 to 10-bleach solution. This may be made by mixing one-cup bleach with 10 cups water. The dirty water should be poured down the toilet and not the sink.

### **GENERAL HYGIENE**

Personal items such as toothbrushes or razors should not be shared.

### **HANDLING SOILED CLOTHING**

Place the soiled clothing in a separate container or trash bag until you are able to wash. Avoid shaking the items in the air prior to washing, which will spread germs. Wash as soon as possible after soiling. If the material is colorfast, you may add one cup of bleach and use HOT water whenever possible.

### **FOOD PREPARATION**

Wash hands before preparing food. Tasting of food during cooking should be done with a clean spoon each time. The inside of the refrigerator should be cleaned on a regular basis with warm soap and water to control molds. Do not use the same sponge to clean the bathroom and the kitchen.

### **VISITORS**

Discourage visitors who have major cold symptoms or flu from visiting. Encourage visitors to wash their hands before and after the visit.

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## PHYSICAL CHANGES

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### NAUSEA

Nausea and/or vomiting may occasionally occur. It will help to:

1. Keep surroundings quiet and have patient rest.
2. Use clear liquids only--broth, jello, tea, soda--or try crackers or dry toast.
3. Keep mouth fresh and clean at all times.
4. Talk to your Hospice nurse about medication to lessen nausea.

### CONSTIPATION

Constipation is a problem many of our patients experience. It may be caused by inactivity, pain medication, or a decrease in food/fluid intake. The body generally continues to produce waste products even though the patient is not eating much. It will help to:

1. Offer fluids, juices, nectars or jello as tolerated.
2. Include fruits and vegetables if patient can tolerate them.
3. Encourage mild exercises, such as walking.
4. Let your nurse know if constipation continues--patient may need a stool softener, laxative or enema.

### DIARRHEA

Diarrhea can occasionally be a problem. There may be some stomach cramping as well as frequent watery stools. It will help to:

1. Continue to offer clear fluids.
2. Keep skin as clean and dry as possible.
3. Inform your nurse, as patient may need medication to control diarrhea.

## **INCONTINENCE**

Some patients lose their ability to control their bowels or bladder. The following may help:

1. Bed pans, adult diapers, and disposable or cloth bed pads.
2. Keep the diapers, pads, and linen changed as often as necessary.
3. Keep the skin clean and dry to prevent skin breakdown.
4. Many patients feel some embarrassment about this loss of control, so provide as much privacy as possible.

## **SHORTNESS OF BREATH**

Shortness of breath, getting air in and out of the lungs, is a problem for some seriously ill people. This can be frightening to the patient (and to the caregiver). To help you should:

1. Help the patient to stay relaxed. Remain calm and try to calm patient.
2. Have patient sit up and lean forward with arms supported on overhead table or other item.
3. Raise the head of the bed or elevate patient using pillows.
4. Open a window if it is a cool day or use an oscillating fan to increase air circulation.
5. If problem persists, notify your Hospice nurse. The patient may need oxygen or medication.

## **DECREASED APPETITE**

One of the most misunderstood and difficult things for families to deal with is a patient's lack of appetite or in many cases, no appetite. We've chosen to address this change at length, because it is so stressful for families.

As changes begin to take place within the patient's body, the hunger and need for food lessens greatly. Nothing tastes good, cravings come and go, liquids are frequently preferred to solids. This does not mean that eating should not be encouraged, but the patient's limitations and choices should be respected. The following suggestions may be helpful:

1. Honor the patient's request for certain types of food and do not be discouraged if they only eat a small portion.
2. Serve food in small portions on small plates so as not to overwhelm the patient.

Decreased Appetite (continued)

3. Frequent small meals and snacks may be tolerated better than the traditional “three meals a day.”
4. Concentrate on food or liquids higher in calories if less is being eaten.
5. Monitor the patient’s eating routine to determine if there is a particular time of day when eating is best.
6. Serve food in a comfortable and relaxing atmosphere.

As an illness and weakness progress, eating usually decreases. The body begins to shut down the functions of eating and digestion to conserve energy. This is not an uncomfortable process. Forcing a patient to eat may cause additional physical distress, such as choking, nausea, vomiting. Any questions or concerns can be discussed with the Hospice staff.

It will also become evident in the last stages of a patient’s illness that the need for fluids also decreases. We continue to stress that this is part of the natural process of dying. As fluids lessen, there may actually be relief from some uncomfortable physical symptoms. There will be:

1. Less fluid in the throat and lungs to reduce coughing and congestion
2. Decreased stomach fluids that may reduce episodes of vomiting
3. Less need for urination
4. Swelling may decrease, lessening feelings of pressure and tightness

When fluids are reduced, the concentration of natural chemical elements in the body changes. This can reduce sensation in the central nervous system, and the patient may feel less distress.

A patient’s comfort and dignity will always be our priority. We will consult and work with the physician and family to meet the patient’s needs. Staff is always available to talk with you about your feelings, especially regarding difficult issues.

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**“The role of a caregiver might be compared to a candle. A candle can help illuminate an experience, provide a path in the darkness and give courage to explore. The light can accompany individuals as they negotiate a sometimes scary and treacherous path. The journey may still be dark, but the light can make it less terrifying.”**  
- Doka (1993)

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## **PAIN CONTROL**

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Good physical pain control is an important element of Hospice care. We will all work as a team toward comprehensive management of pain and other symptoms to maintain a patient's maximum comfort.

### **DESCRIBING PAIN**

We rely on the patient to communicate their pain or discomfort as clearly as possible to the Hospice nurse. Most pain, if reported honestly, can be controlled. The Hospice nurse will ask about the location, duration, onset, and severity of the pain. The intensity of a patient's pain is typically described on a scale ranging from zero to ten. A rating of zero means no pain, one to four is a range of mild pain, five to six is moderate pain, and seven to ten describes severe pain.

### **PAIN MANAGEMENT**

The patient's primary doctor will be the person in charge of prescribing all medications. The Hospice nurse will always keep the doctor informed of a patient's pain, symptoms and changing condition. Together they will work to keep the patient as comfortable as possible to enhance their quality of life.

In many instances, a non-prescription medication is used effectively for mild pain. Common medicines, or brand names, include Tylenol, Advil, and Motrin.

Hospice patients frequently use prescription pain medication for moderate to severe pain. It is most effective and can be taken in many forms and in varying amounts. Your Hospice nurse will always instruct you in the proper use and respond to your questions and concerns. Here are a few suggestions to keep in mind:

- Allow several days for the patient's body to adjust to the new medication and for the doctor and nurse to determine the best schedule of doses and amount of medication needed.
- It is extremely important to follow the medication schedule developed for the patient. If doses are skipped, maximum comfort cannot be maintained.
- Addiction from prescription medications should never be a problem for the patient. This medication is being given for pain control, not for an emotional high. Comfort is our primary concern.
- Pain control is often helped by a pleasant and peaceful environment. Companionship can be a positive distraction. Some individuals enjoy being read to or listening to music.

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## UNDERSTANDING PHYSICAL CHANGES

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Some very distinct changes can be noted as a patient's disease progresses. We feel that even though these changes can be stressful and emotionally painful for the caregiver, talking about what you may expect can ease your fears, allowing you to continue to give the same loving support you have provided all along.

### ONE TO THREE MONTHS PRIOR TO DEATH

**WITHDRAWAL** - A patient does not make a conscious decision to withdraw from the world and the people around them. It just happens. You will notice that the patient may no longer be interested in the newspaper or favorite television programs. They may discontinue working on various hobbies that have occupied their time in the past. It is not unusual for a patient to begin to want to eliminate visitors, beginning with friends or extended family members.

**Responses** - Continue to keep the patient well informed, especially of family matters and former areas of interests. They may not respond, but that does not mean they are not hearing the information. If the patient does appreciate visitors, shorter contacts (10-15 minutes) will be less tiring. It is good to allow the patient to make their own choices.

**INCREASED SLEEP** - This is the beginning of a time when a person withdraws from everything outside of one's self and goes inside -- to "review" their life, sort things out, and hopefully come to peace with the life they lived. With this comes increased sleep (or the appearance that the person is sleeping). A morning nap is added to the afternoon nap. The patient spends more time in bed or all day in bed.

**Responses** - We want to encourage you to allow the patient to sleep more and respect their need to be alone. Their awake times will be more beneficial and meaningful to you and to the patient.

**LESS COMMUNICATION** - Don't take it personally if the patient does not want to talk. They have less energy and focusing on a conversation can be difficult. Words are seen as being connected with the physical life that is being left behind.

**Responses** - You may wish to be silent and alone with the patient during these times. Hold their hand or lie beside your loved one, communicating the comforting assurance your presence brings.

**DECREASED FOOD** - The patient's metabolism will continue changing, food is no longer being processed toward energy and health, so it is perfectly natural that eating should decline and gradually stop. This should never be confused with starvation. At this particular time in the patient's life, it is part of a bodily process of "letting go." A different energy is now needed that usually flows from a person's spiritual beliefs. This will sustain the patient.

**Responses** - Offer suggestions of small food or snacks at intervals throughout the day. Don't force food. Let the patient be in control. (See Decreased Appetite, page 16)

## **ONE TO TWO WEEKS PRIOR TO DEATH**

**MENTAL CONFUSION** - Your loved one may become increasingly confused about time, place, and identity of close and familiar people. This becomes apparent as less oxygen is available to the brain. The person often talks to people and about places and events that are of the past or unknown to others. They may be disturbed by dreams or see and converse with loved ones who have died.

**Responses** - You may want to listen closely to the patient, because he or she may say a word or phrase that contains significant information or requests. Remind your loved one of where they are, the day and time, who is present in the home and who is talking to them. This is best done in a casual, conversational manner. Your presence and frequent touch is reassuring at this time.

**RESTLESSNESS** - As the oxygen supply to the brain decreases, the patient may become restless and/or agitated. You will notice them possibly picking or pulling at their blankets or bedclothes, and demonstrating random arm movements. There is a seeming aimlessness to all physical activity.

**Responses** - You may want to talk calmly and assuredly with the patient so as not to startle or frighten them. Reassure the patient of your presence. Soft music or a backrub may be helpful.

**INCONTINENCE** - The patient's body becomes relaxed, sometimes due to the dying process, sometimes due to comfort medications. It is not uncommon for a patient to lose control of bowel and bladder function.

**Responses** - It is important to explain to the patient that what has occurred is a result of medications being taken or of their weakened condition. This is an embarrassment to the patient and they should never be blamed. Keep a chux or waterproof padding under the patient. Adult Depends or adult diapers can also be used (always refer to them as "adult"). These protective pads should be changed as soiled to keep the patient comfortable. Gently wash the groin and rectal areas after each urination or bowel movement.

**BREATHING CHANGES** - You may notice that your loved one's breathing patterns change from time to time. It can become irregular, with periods of no breathing for 10-30 seconds. These periods are referred to as "apnea". This symptom is very common and indicative of a decrease in circulation and buildup in body waste products. Respiration may increase and then again decrease, presenting no discomfort to the patient.

**Responses** - If the patient is resting comfortably, allow them to continue to rest. You can raise the head of the bed if the patient breathes more easily this way, or offer to change their position.

**BODY TEMPERATURE and PULSE** - As the patient's body continues to be unable to maintain itself, the pulse beat will usually increase significantly from a normal of 80 to upwards of 150 beats per minute. As the heart "wears down", the beat will then begin to decrease and slow down until it can no longer be felt or detected. The body temperature can also fluctuate between hot (fever) and cold due to the body's inability to control its own temperature. Perspiration can increase, often with clamminess. As circulation slows down, the patient's arms and legs will become cool and may be bluish in color, especially the nail beds.

**Responses** - Blankets can be provided or removed as needed for the patient's comfort. Never use an electric blanket at this time. Sponge the patient with a cool washcloth if this promotes comfort. Change perspiration-soaked garments and bed linens. Tylenol (liquid or suppositories) may be ordered for the patient if the patient's temperature rises to a level of discomfort.

**SPEECH, VISION, HEARING** - As a patient makes efforts to communicate with you, you may experience a sense of frustration as their speech may become difficult to understand. The lack of understanding may make you feel as though you are not "pleasing" the patient. Vision can also fail and your loved one's eyes may become dry, sunken or glazed over in an apparent stare. The last sense to be lost is hearing, and it may remain acute up until the time of death. Never say anything in the patient's presence that would make him or her feel uncomfortable or uneasy.

**Responses** - If you have difficulty understanding a patient's speech, let them know you are having difficulty and it is due to their weakness. You may want to have a list of basic needs that they can respond to with "yes" or "no". Reassure the patient that someone will always be around to provide their care. If it is apparent that vision is failing, keep the patient well-informed as to who is present, and of the day and time. A warm damp cloth can be used to remove any eye secretions, and eye drops may be given if necessary. Keep the room as light as the patient wishes, even at night. Carry on all conversations as they can be heard, but don't ask unnecessary questions of the patient if verbal communication is difficult or impossible. Soothing music may be enjoyed, as well as conversation from family and friends. This is an excellent time to express love and caring. Touch is also a good way to be with a patient by giving a gentle massage or simply holding the patient's hand.

**DAYS TO HOURS PRIOR TO DEATH** - The last few days of a patient's life can sometimes be more "tolerable" if your attitude is one of letting go and releasing your loved one from this life. Both of you are facing a separation and can frequently work on this painful task together. We encourage that you give your loved one "permission to die". In this way you release the patient from the struggle of feeling, "I know I can't stay and I don't feel like I can leave." Let the patient know you'll miss them, but you will be okay.

During these final hours, you will notice that the signs we have already talked about will become more intense as death approaches. Remember, that most of these changes occur without any discomfort to the patient. If you have questions, you are encouraged to contact Hospice. We want to be available to you, as well as to the patient.

### **PRONOUNCED CHANGES**

**SURGE OF ENERGY** - This may be more difficult to observe in some patients than in others, but frequently it appears that when you believe the patient is getting close to death, they suddenly seem a bit stronger. This may be apparent through an increase in alertness, or clearer speech, or some intake of food and/or liquids. They may even wish to sit up for a short period of time to visit. Many explain this "new energy" as being a spiritual energy that has arrived for the transition that is about to take place. For some, this "spiritual energy" is used for a time of physical expression before moving on.

**Responses** - Respond to the patient's wishes. He or she will know what they can or cannot do. Treasure the moments and be reassuring of your love.

**RESTLESSNESS** - This may increase shortly before death due to a lack of oxygen in the blood.

**Responses** - If you feel this restlessness is uncomfortable or disturbing to the patient, his or her condition can be evaluated by the Hospice nurse. Oxygen or medication can possibly be recommended. The best medicine is your presence, or that of a friend or family member.

**CONGESTION** - Oral secretions may become more profuse and collect in the back of the patient's throat. You may have heard friends refer to a "death rattle". This symptom is a result of a decrease in the body's intake of fluids and inability to cough up normal saliva production. The noise comes from the passage of air through these secretions, and is generally much more troublesome to families than to the patient.

**Responses** - Elevating the head of the bed with pillows or obtaining a hospital bed will make breathing easier. Ice chips, a straw, and cool, moist washcloths will relieve feelings of dehydration. Sometimes a dropper is helpful in giving very small amounts of fluids.

**BODY CIRCULATION** - As the patient's circulation continues to decrease, you may notice the hands and feet becoming purplish in color. The knees, ankles, and elbows may appear blotchy.

**Responses** - Not much can be done for the patient, other than to provide touch, presence, and messages of your love.

### **HOW WOULD YOU KNOW DEATH HAS OCCURRED?**

**Signs of death include:**

- No breathing
- No heartbeat
- Loss of control of bowel and bladder
- No response to shaking
- Eyelids slightly open
- Eyes fixed on a certain spot
- Jaw relaxed and mouth slightly open

**Please call Hospice**, if you feel death has occurred or have questions/concerns about any changes. **DO NOT** call police or an ambulance.

\* **On Call Procedure** – see page 1 of manual.

At the time of death, Hospice will send a staff person to assist the family. We will confirm if death has occurred, make necessary phone calls, and be available to offer support. It is at this time that care changes from the patient to the caregiver and family.

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We cannot teach the dying how to die. If we are there, however and if we are paying attention, they will teach us.

- Judith Viorst

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## JUST FOR THE CAREGIVERS

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It has been our experience that people caring for a loved one often have the tendency to forget about their own needs. Hospice feels that the caregiver is just as important as the patient. If you do not take care of yourself, you too may become ill or stressed to the point of no longer being able to care for the patient.

We want to encourage you to think of your needs too. Here are a few guidelines:

1. **Get Adequate Rest**

If your nighttime sleep is broken due to patient needs, it will be necessary for you to find time to rest or nap during the day. This can be done when the patient is also resting. You and the patient are the priority. We encourage you to put other household duties "on hold" in order to do something for yourself.

2. **Eat Healthy Meals**

Your nutritional needs will be different from the patient receiving care. For this reason, caregivers frequently don't fix meals for themselves. It is important that you eat three meals a day. You need food for energy, good health, and to avoid stress.

3. **Take Time for Yourself**

You need to be refreshed emotionally and psychologically. It is good to get away from caregiving for short periods of time. Utilize family, friends, and Hospice volunteers so you might:

- take a walk outdoors
- participate in a sport activity
- go to lunch with a friend
- go to the beautician/barber
- shop and/or run errands
- enjoy a movie
- take a leisurely bath
- read a book
- take a nap

4. **Accept Help from Others**

Other family members and friends often have the need to participate in caring for the patient or assisting you in small ways. The helplessness they feel can be helped by allowing them to be involved. Let others bring meals, run errands, sit with the patient, or take the children on an outing. You need to be honest with the people by telling them what would be helpful. Hospice volunteers are available too and want to help with these tasks.

5. **Find a "Listening Ear"**

It is healthy for you to talk about the care you are giving, as well as your honest feelings. We realize dealing with the illness of someone you love day after day changes your life and usual routines. Many people say, "I don't know how I feel." There is worry, hurt, love, anger, and at times even guilt. Talk to your friends and share these feelings and concerns. The Hospice staff are also available to listen. This is another way the Hospice Spiritual Care Counselors and Social Workers can be especially helpful to you. Voicing your thoughts reduces isolation and keeps frustration from building up.

6. **Refresh Your Spirit**

Most of us need spiritual as well as physical and emotional renewal. Perhaps it is important for you to visit your place of worship or listen to tapes of the services you've missed. Others find it helpful to read or listen to some inspirational music. You may need to set aside some quiet moments for prayer or reflection. You may find taking a walk outdoors or working in the garden enhances your spirit. The Hospice Spiritual Counselor is available to assist you as well as your loved one. A Hospice volunteer can provide respite for you and companionship for the patient while you renew yourself.

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*We do not receive wisdom,  
we must discover it within ourselves,  
after a journey through the wilderness  
which no one else can make for us,  
which no one can spare us,  
for our wisdom is the point of view  
from which we come at last to regard the world.*

- Marcel Proust

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## **TALKING TO CHILDREN ABOUT ILLNESS**

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Families and friends often attempt to protect children from illness and death, yet children are well aware of both--from T.V., movies, storybooks and games. Adults frequently see illness and death as harsh realities that we do not wish to intrude on a child's world. However, when illness involves them personally, keeping information from a child is often futile, because the child often has external cues. They sense the anxieties around them--conversations stop or change when they enter a room-- and they may see relatives visiting from distant places. Keeping information from a child can keep the child from obtaining necessary support, create additional anxiety, impair trust and complicate the child's response to a crisis.

Here are some suggested guidelines for communicating information about illness and impending death.

### **BEGIN ON THE CHILD'S LEVEL**

A child will process information differently at various ages. It is best to use simple language and to be as specific as possible. Call the disease by its name and don't be afraid to use the word "death." Talk about what the patient is able to do or not able to do. State the purpose of any special equipment that may be in the room.

### **LET THE CHILD'S QUESTIONS BE A GUIDE**

Adults often say too much, overwhelming the child with information. It is helpful to begin a dialogue with basic information and then let the child's questions direct the conversation. A child with unanswered questions will fill in their own blanks, allowing their imagination to create explanations that are often more disturbing than reality.

### **ENCOURAGE FEEDBACK FROM THE CHILD**

Talking to a child often leaves an adult wondering how the child heard their message. One is never certain how words will be understood, especially in anxiety-filled situations. It is, therefore, important to ask the child to summarize what they heard, providing you the opportunity to clarify misunderstandings.

### **PROVIDE OPPORTUNITIES FOR THE CHILD TO EXPRESS FEELINGS**

A child can experience a wide range of feelings, from sadness, anger, guilt and ambivalence to anxiety. It is important for them to have the opportunity to express these feelings with an adult who will validate the feelings and share their own feelings. Telling a child they should not feel something is discounting their emotion and cuts off further communication.

## **PROVIDE ROUTINE FOR THE CHILD**

Serious illness in a family disrupts normal routines. This is especially difficult for a child and threatens their security. They need to know they will be taken care of and that there is some stability for them. Ask the help of others to spend time with a child who is probably getting less attention. Encourage them to help the child maintain some routine activities.

## **LET THE CHILD PARTICIPATE IN PATIENT INTERACTION**

One of the most common questions is to whether or not a child should visit a seriously ill person. In most cases the decision can be left up to the child. They should always be prepared for the visit with a discussion of what they are likely to see and what changes have occurred since the child last visited. They may want to bring a drawing or a recent art project to give to the patient. Touching and talking with the patient should be encouraged and allowed. If the decision is made not to visit, then they can remain involved by sending letters, typed messages, and calling on the telephone.

## **UTILIZE OTHER RESOURCES FOR THE CHILD**

There are many resources that can encourage communication and provide help to assist a child in coping with an illness and impending death. Books and videos can be a shared experience between a child and adult to facilitate conversation. School counselors and peer support groups can be helpful by providing an alternative environment for a child to express themselves. Your Hospice social worker or spiritual counselor are also available to speak with anyone in the family. A child can also be asked to name people with whom they feel comfortable to discuss their problems. When a child is involved with others, they realize that they need not cope alone.

Other age appropriate information can be obtained from the Hospice Social Worker in helping you to deal with your child (children).

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*Should you shield the  
canyons from the windstorms,  
You would never see the  
beauty of their carvings.*

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## EASING THE BURDEN

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### **PRE-ARRANGING A FUNERAL**

Many individuals have looked ahead and pre-arranged their funeral. For others it is still a difficult task to be done. Families frequently find having this accomplished prior to a death is a relief. The fewer decisions family members have to make at times of crisis or strong emotions, the better. It also allows them time to be with each other to find support and cope with their grief.

Some advantages to pre-arranging a funeral are:

- It allows involvement of the patient, if they wish, and gives the family comfort knowing their loved ones wishes are honored.
- It ensures you have exactly the kind of funeral you want and provides time if you consider the need to make changes.
- It is easier to make arrangements in an atmosphere that isn't filled with the grief that comes with the death of a loved one.
- It minimizes the burden of decisions that have to be made at the time of a death.
- It lessens family conflicts about funeral plans.

We at Hospice recognize that every patient and family are unique. Pre-arranging a funeral may be contrary to one's belief system or personal choice. It is just an option for you to consider.

### **YOUR FUNERAL DIRECTOR**

The funeral director will meet with the family at your convenience to discuss arrangements. In accordance with law, custom and especially family wishes, they help you make choices to meet your satisfaction. Funeral Directors must also understand various religious faiths, respect the inherent dignity of humankind, and be willing to dedicate themselves to a profession that deals with people in a time of emotional need.

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## IF YOU HAVE A COMPLAINT

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The goal of Hospice is to provide you with the highest quality of care and support. Our Quality Assurance Program supervises the services that are delivered to you and continually seeks improvement.

Your feedback to us is important. If you have a problem or concern, please contact our Quality Improvement and Compliance Coordinator or an administrator at our Hospice office (574-243-3100). We want to make every effort to meet your needs **within the scope of the services we are able to offer you**. We will strive to investigate, resolve, and document complaints or dissatisfaction.

Another measure available to you, if you feel a problem has not been resolved through our Hospice Program, is the Medicare Hotline. It has been established by the State of Indiana to handle your concerns regarding Medicare home health agencies such as our Hospice.

State of Indiana Hotline  
**1-800-227-6334**

Monday through Friday  
8:00 AM to 4:40 PM

(An answering machine will record calls at all other times)

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## **ADVANCE DIRECTIVES**

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It is every individual's right to decide what treatments they want or don't want, and to communicate that decision to the doctor, family and friends. Then if a person becomes too sick to verbalize their own wishes, others will know what to do.

One way of documenting your wishes is through "Advance Directives". The following information was prepared by the Indiana State Department of Health to educate you on the ways that you can control the medical treatments you receive.

### **WHAT HAPPENS IF I BECOME UNABLE TO MAKE MY OWN MEDICAL DECISIONS?**

Unless you plan ahead, your health care decisions will be made by someone else if you become unable to consent to or refuse medical treatments for yourself. In Indiana, these decisions may be made by whomever your doctor talks to in your immediate family (meaning your spouse, parent, adult child, brother or sister) or by a person appointed by a court.

In Indiana, you can make and write down your own decisions about your future medical treatment if you wish. Or you can appoint a person you choose to make these decisions for you when you are not able to do so. You can even disqualify someone you don't want to make any health decisions for you. You can do these things by having what is called an advance directive. Advance directives are documents you can complete to protect your rights to determine your medical treatment and can help your family and doctor understand your wishes about your health care.

Your advance directive will not take away your right to continue to decide for yourself what you want. This is true even under the most serious medical conditions. Your advance directive will speak for you only when you are unable to speak for yourself, or when your doctor determines that you are no longer able to understand enough to make your own treatment decisions.

### **WHAT CAN I DO NOW TO EXPRESS MY WISHES IN CASE I LATER BECOME UNABLE TO TELL MY DOCTOR OR MY FAMILY?**

There are three ways you can make your wishes known now, before you get too sick to tell what treatment you want or don't want:

1. You can speak directly to your doctor and your family.
2. You can appoint someone to speak or decide for you.
3. You can write some specific medical instructions.

## **DO I HAVE TO FILL OUT MORE PAPERS?**

No. You can always talk with your doctor and ask that your wishes be written in your medical chart. You can talk with your family. You don't have to write down what you want, but writing it down makes it clear, and sometimes, writing it down is necessary to make it legal. When you are no longer able to speak for yourself, Indiana law pays special attention to what you have written in your advance directive about your health care wishes and whom you appointed to carry them out.

## **DO I HAVE TO DECIDE ABOUT AN ADVANCE DIRECTIVE NOW?**

No. You have the right to make an advance directive if you want to, and no one can stop you from doing so. But no one can force you to make an advance directive if you don't want to and no one can discriminate against you if you don't sign one.

## **WHICH ADVANCE DIRECTIVE SHOULD I USE?**

That depends on what you want to do. If you want to put your wishes in writing, there are three Indiana laws that are important:

1. Health Care Consent Act
2. Living Will Act
3. Power of Attorney Act

These laws may be used alone or in combination with each other. These laws are complicated and it is always wise to talk to a lawyer if you have specific questions about your legal choices.

## **WHAT IS THE INDIANA HEALTH CARE CONSENT ACT?**

The Indiana Health Care Consent Act is found in the Indiana Code at IC 16-36-1. This law lets you appoint someone to say yes or no to your medical treatments when you are no longer able. This person is called your health care representative, and he or she may consent to, or refuse, medical treatment for you in certain circumstances that you can spell out. To appoint a health care representative, you must put it in writing, sign it, and have it witnessed by another adult.

Because these are serious decisions, your health care representative must make them in your best interest. In Indiana, courts have already made it clear that decisions made for you by your health care representative should be honored. These decisions can determine which medical treatments you will or will not receive when you are unable to express your wishes. In certain circumstances and in consultation with your doctor, your health care representative may even decide whether or not food and water should be artificially provided as part of your medical treatment.

## **WHAT IS THE INDIANA LIVING WILL ACT?**

The Indiana Living Will Act is found in the Indiana Code IC 16-36-4. This law lets you write one of two kinds of legal documents for use when you have a terminal condition and are unable to give medical instructions. The first, the Living Will Declaration, can be used if you want to tell your doctor and family that life-prolonging medical treatments should not be used, so that you can be allowed to die naturally from your terminal condition. In a Living Will Declaration, you may choose whether or not food or water should be artificially provided as part of your medical treatment or whether someone else should make that decision for you. The second of these documents, the Life-Prolonging Procedures Declaration, can be used if you want all possible life-prolonging medical treatments used to extend your life.

For either of these documents to be effective, there must be two adult witnesses and the document must be in writing and signed by you or someone that you direct to sign in your presence. Either a Living Will Declaration or a Life-Prolonging Procedures Declaration can be canceled orally, or in writing, or by canceling or destroying the declaration yourself. The cancellation is effective, however, only when your doctor is informed.

## **WHAT IS THE INDIANA POWERS OF ATTORNEY ACT?**

The Indiana Powers of Attorney Act is found in the Indiana Code at IC 30-5. This law spells out how you can give someone the power to act for you in a lot of situations, including health care. You do this by giving this person your power of attorney to do certain things you want this person to do. This person should be someone that you trust. He or she does not have to be an attorney, even though the legal term for this person you appoint is attorney in fact. The person you name as your attorney in fact is given the power to act for you in only the ways that you specify. Your power of attorney must be in writing and signed in the presence of a notary public. It must spell out who you want as your attorney in fact and exactly what powers you want to give to the person who will be your attorney in fact, and what powers you don't want to give. Since your attorney in fact is not required to act for you if he or she doesn't want to, you may wish to consult with this person before making the appointment.

If you wish, your power of attorney document may appoint the person of your choice to consent to or refuse health care for you. This can be done by making this person your health care representative under the Health Care Consent Act, or by referring to the Living Will Act in your power of attorney document. You can also let this person have general power over your health care. This would let him or her sign contracts for you, admit or release you from hospitals or other places, look at or get copies of your medical records, and do a number of other things in your name. You can cancel a power of attorney at any time, but only by signing a written cancellation and having this actually delivered to your attorney in fact.

## **ARE THERE FORMS TO HELP ME WRITE THESE DOCUMENTS?**

Although Indiana law provides limited forms for some of the purposes listed above, these may not be sufficient to accomplish everything you might want. Although these laws do not specifically require an attorney, you may wish to consult with one before you try to write one of the more complicated legal documents described above.

## **CAN I CHANGE MY MIND AFTER I WRITE AN ADVANCE DIRECTIVE?**

Yes. As we mentioned above, you can change your mind about any of the types of appointments or about the living will. However, you need to make various people aware that you've changed your mind - like your doctor, your family or the person you've appointed - and you might have to revoke your decision in writing. Remember, however, that you can always speak directly to your doctor. But be sure to state your wishes clearly and be sure they are understood.

## **WHAT IF I MAKE AN ADVANCE DIRECTIVE IN INDIANA AND I AM HOSPITALIZED IN A DIFFERENT STATE, OR VICE VERSA?**

The law on honoring an advance directive in or from another State is unclear. Because an advance directive tells your wishes regarding medical care, however, it may be honored wherever you are, if it is made known. But if you spend a great deal of time in more than one State, you may wish to consider having your advance directive meet the laws of those States, as much as possible.

## **WHAT SHOULD I DO WITH MY ADVANCE DIRECTIVE IF I CHOOSE TO HAVE ONE?**

Make sure that someone, such as your lawyer or a family member, knows that you have an advance directive and knows where it is located. You should give a copy of your power of attorney document to the person you have appointed to serve as your attorney in fact. You may also decide to ask your doctor or other health care provider to make your advance directive a part of your permanent medical record. Another idea would be to keep a second copy of the directive in a safe place where it can be easily found, and you might keep a small card in your purse or wallet which states that you have an advance directive and where it is located or who your attorney in fact is, if you have named one.

## **FINAL THINGS TO REMEMBER:**

- You have the right to control what medical treatment you will receive.
- Even without a lawyer or a form, you can always tell your doctor and your family what medical treatments you want or don't want.
- No one can discriminate against you for signing, or not signing, an advance directive.
- Using an advance directive is, however, your way to control your future medical treatment.

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## FINANCIAL EXPLANATION FOR THE HOSPICE MEDICARE BENEFIT

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The patient elects to receive only comfort care for his/her disease when choosing the Hospice Medicare Benefit (HMB) program. Comfort care is directed only at reducing symptoms, relieving suffering, and maximizing comfort, dignity, and control—not curing, slowing, or reversing disease. Comfort care is the sole intent of the program.

The Center for Hospice and Palliative Care, Inc. will **only cover the costs of comfort-oriented medical care** for patients active in the HMB program.

All medically necessary expenses determined by Hospice to be related and appropriate for comfort care are paid for by Hospice under the HMB program.

The HMB program **does not cover** the costs of medications, treatments, tests, physician office visits, clinic visits, outpatient visits, hospitalizations, ambulance transportation, and emergency room visits **directed at curing**, slowing, or reversing the disease process. **This does not mean the patient cannot receive such care or treatments.** This only means that the HMB program does not pay for such care.

The patient will be responsible for all bills incurred for treatments and services **not pre-approved by Hospice**. The patient/family is encouraged to contact Hospice prior to acting on their own.

The patient/family may change their mind, revoke the HMB program, and proceed with any and all treatments available at any time, including those treatments that are not approved under the HMB program. The decision to revoke the HMB program is entirely that of the patient/family.

If the patient/family **chooses to revoke the HMB program**, treatments to cure, slow, or reverse the disease process may be covered by regular Medicare, supplemental insurance policies (if available), or the patient/family may be personally responsible for payment.

Immediately after HMB revocation, **the patient may qualify to continue receiving home care from Hospice** under regular Home Health Medicare, if he/she meets those admission requirements. Some medical supplies, which were covered by Hospice under the HMB program, may not be covered under regular Home Health Medicare. Upon revoking from the HMB program, the patient/family may be responsible for payment of those items unless they have supplemental insurance to cover those costs.

The patient **can revoke the Hospice Medicare Benefit program** at any time and re-elect the program at a later date if he/she qualifies.

**At no time will Hospice stop** Hospice home care visits **due to a patient's inability to pay** or qualify for an insurance program.

Should the Hospice Interdisciplinary Group ever determine that a patient's condition is no longer terminal, the patient will be discharged from the HMB program.

The patient/family may call Hospice anytime, 24 hours per day, 7 days a week to ask questions regarding what expenses are and are not covered under the HMB program.

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## **HOSPICE BENEFITS UNDER MEDICARE**

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### **Routine Hospice Home Care**

Services are provided on a scheduled basis by the Hospice Team, which includes the patient's own physician and/or the Hospice Medical Director, nurses, social workers, spiritual care counselors, home health aides, and trained community volunteers. They also provide:

- \* Emergency care 24 hours per day, 7 days a week
- \* Pain and symptom control
- \* In home counseling for patient and family
- \* Bereavement services

### **Short-Term Inpatient Care**

There are two levels of inpatient care. Each of these levels of care is intended for short-term periods of time and is not meant to be permanent solutions. One level is for pain control and symptom management. The other is for respite purposes.

- \* General inpatient level of care may be available for pain and symptom control that cannot take place in the home setting. This level of care may be provided in Hospice House.
- \* Respite level of care is designed to give caregivers a brief break and may be available for up to 5 consecutive days at a time. This level of care may be provided in Hospice House.

### **Periods of Acute Medical Crisis in the Home Setting**

Nursing and either homemaker or home health aide services may be covered on a continuous basis for 8 to 24 hours to achieve palliation and symptom control in the home setting. This level of care is intended for a period of crisis management for acute medical symptoms. Although an RN or LPN provides over 50% of the continuous care, homemaker or home health aide services may supplement the nursing care.

The attending physician and/or the Hospice Medical Director approves the Hospice Care Plan, which includes decisions regarding appropriate levels of care and other changes to the Hospice Care Plan at any given time.

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## UNIVERSAL PRECAUTIONS AND PATIENTS' RIGHTS

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Health care facilities providing services in which there is a risk of skin, eye, mucous membrane, or parenteral contact to human blood or other potentially infectious materials must practice Universal Precautions.

Universal Precautions means the prevention of disease transmission through the use of infection control practices with all patients.

The Center for Hospice and Palliative Care, Inc. and its affiliated entities comply with the infection control practices required by the Indiana State Department of Health (ISDH), which were adopted by Indiana law, Indiana Occupational Safety and Health Administration (IOSHA) standards and Centers for Disease Control and Prevention (CDC) recommendations. The following infection control practices include, but are not limited to, those required by the Universal Precautions Rule and are used to prevent transmission of bloodborne pathogens to patients and treating staff:

Appropriate use of protective barriers, including gloves for hand contact, masks, gowns, laboratory coats, and protective eyewear or face shields are used for procedures having the potential of creating a spray or splatter of blood or other potentially infectious materials.

Gloves, when required, are changed and hands are washed after each patient.

Heat, stable, non-disposable instruments requiring sterilization that are contaminated with blood or other potentially infectious materials are heat sterilized after treatment of each patient.

Precautions are taken to prevent injuries caused by needles, scalpels, and other contaminated sharp instruments during procedures.

Disposable contaminated sharps, needles, syringes, and other contaminated sharp objects are discarded in puncture-resistant containers.

Surfaces and equipment contaminated with blood or other potentially infectious materials that need not be sterilized are cleaned and disinfected after treatment of each patient. Disposable coverings may be used on some surfaces to prevent contamination.

Infectious waste is placed in containers labeled with the biohazard symbol; impervious to moisture and of sufficient strength to prevent expulsion.

Containers of infectious waste are stored in a secure area prior to treatment and final disposal.

Patient care staff receive training on infection control.

The infection control procedures listed and others that are not readily observable protect you from disease transmission. Indiana law requires that health care facilities be committed to appropriate use of Universal Precautions. Any deviation from this commitment should be brought to the attention of The Center for Hospice and Palliative Care, Inc. If you are not satisfied with the explanation of Universal Precautions provided by this facility, you may file an official complaint with the Indiana State Department of Health by writing to the following address: **Indiana State Department of Health c/o Universal Precautions Coordinator, 2 North Meridian, Indianapolis, IN 46204** Phone: 317-233-7825

12/96

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## PATIENT BILL OF RIGHTS

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All patients under the care of The Center for Hospice and Palliative Care, Inc. (Hospice) have a right to be notified in writing of their rights and to discuss such rights with a qualified Hospice staff person prior to initiation of services. Consistent with the laws of the State of Indiana, the patient's family, guardian, or legal representative may execute these rights when the patient is no longer able to do so. Hospice has an obligation to protect and promote these rights and will keep a copy of this executed form on file as documentation that these rights have been understood and discussed with the patient and/or family. These rights include:

### **I. DIGNITY AND RESPECT:**

Patients are entitled to exercise their rights as a patient of Hospice.

Patients, physicians and their designees, Hospice staff, other caregivers, and volunteers have the right to mutual respect and dignity. All Hospice personnel will treat patient's property with respect. All Hospice personnel are prohibited from accepting personal gifts and borrowing from patients/families/primary caregivers.

Patients have the right to voice grievances regarding treatment or care that is (or fails to be) furnished, and regarding the lack of respect for the patient's property by anyone furnishing services on behalf of Hospice and will not be subject to discrimination or reprisal for doing so. Hospice will investigate complaints and will document the existence of the complaint and the resolution.

If you believe your complaint has not been resolved by your agency, patients have the right to be advised of the availability of the toll free hotline that has been established by the State of Indiana to receive complaints and answer questions concerning Medicare home health agencies such as Hospice. The hotline number is 1-800-227-6334 and operates during the hours of 8:00 AM-4:30 PM Monday through Friday. An answering machine is used to record calls after business hours (i.e., evenings, weekends, holidays). All complaints will be investigated.

The patient has the right to be free from verbal, physical, and psychological abuse and to be treated with dignity.

### **II. DECISION MAKING**

1. Patients have the right to be notified in advance of the type of care that is to be furnished, the disciplines that will furnish the care, and the frequency of the services that are proposed to be furnished.
2. Patients have the right to be advised of any change in the plan of care before that change is made.
3. Patients have the right to participate in the planning of the care and in planning changes in the care, and to be advised that they have the right to do so.
4. Patients have the right to refuse services and/or treatment(s) and be informed of the consequences of refusing care.
5. Patients have the right to request a change in Hospice caregiver (or health care agencies) without fear of reprisal or discrimination.
6. Patients/families have the right to receive written information in advance regarding their rights to accept or

refuse treatment and to make advance directives, and this information has been received.

Patient Bill of Rights (continued)

**III. PRIVACY**

1. Patients have the right to confidentiality with regard to information about their health status, social or financial circumstances, and about what takes place in the home setting.
2. Patients have the right to be advised that Hospice has internal policies and procedures to safeguard clinical records against loss, destruction, and unauthorized use and will release patient clinical records and information only as required by law or with the patient's prior consent.
3. Patients or legal representative have the right to access their clinical records, unless certain exceptions apply. Patients shall be advised of the agency's policies and procedures regarding the accessibility of clinical records.

**IV. FINANCIAL**

1. Patients have the right to be advised before care is initiated, of the extent to which payment for services rendered by Hospice may be expected by Medicare, Medicaid, or any other federally funded or aided program to the Hospice agency.
2. Patients have the right to be informed of any charges that will not be covered by Medicare or other sources.
3. Patients have the right to be informed of any charges for which the patient may be liable.
4. Patients have the right to be informed orally and in writing of any changes in charges and/or payments as soon as possible, but no longer than 30 calendar days from the date Hospice becomes aware of a change.
5. Patients have the right to access, upon request, all bills for services the patient has received, regardless of whether they are paid out-of-pocket or by another party.
6. Patients have the right to be informed of the ownership status of Hospice and its affiliation with any entities to whom the patient is referred.
7. The patient has the right to request a written notice in advance of receiving care, or during the initial evaluation visit before the initiation of treatment, a listing of all individuals or other legal entities who have an ownership or control interest in the agency.

**V. PATIENT CARE**

1. Patients have the right to appropriate and compassionate care regardless of race, age, gender, creed, national origin, handicap, marital status, sexual orientation, source of payment, or the ability to pay for services rendered by Hospice.
2. Patients have a right to be advised to call Hospice in the event of an emergency 7 days a week, 24 hours a day:  
Hospice of St. Joseph County - (574) 243-3100 or (800) 413-9083  
Marshall County Hospice - (574) 935-4511 or (800) 774-2784  
Hospice of Elkhart County - (574) 264-3321 or (866) 264-3321

Patient Bill of Rights (continued)

3. Patients have the right to exercise all civil and religious liberties.
4. Patients have the right to be advised that Hospice or the patient's physician (with reasonable notice) may be forced to refer the patient to another source of care if the client's refusal to comply with the plan of care threatens to compromise Hospice's commitment to quality care. Services are never terminated due to an inability to pay for care rendered by Hospice.
5. Patients shall be advised of any change in the plan of care, including reasonable discharge notice.

**VI. PATIENT RESPONSIBILITIES**

1. Patients have the responsibility to provide complete and accurate information about all matters pertaining to their health.
2. Patients have the responsibility to treat staff with respect.
3. Patients have the responsibility to provide a safe environment for which care is to be given.
4. Patients have the responsibility to inform Hospice when you are not able to keep a home care appointment.
5. Patients have the responsibility to ask questions if you do not understand instructions or information give to you.
6. Patients have the responsibility to assist Hospice with billing and/or payment issues to help processing third party payments.
7. Patients have the responsibility to identify a medical Power of Attorney, Health Care Representative, or another individual authorized to make medical determinations on behalf of the patient in the event the patient is unable to do so.

*Revised 01/03*

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## EXPLANATION AND CONSENT

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I have read, understood, and abide with these sentences:

1. The Hospice program is intended for patients who have a life expectancy that can be measured in weeks or months and not years. Hospice provides services that help to ease pain, and control symptoms related to the patient's terminal illness. Hospice provides services that try to satisfy the physical, emotional, social, and spiritual well-being of the patient and the caregivers.
2. Hospice helps caregivers to keep the patient as comfortable as they can. Hospice will not take measures to shorten or lengthen the patient's life.
3. Hospice staff make regularly scheduled visits to the home. During these home visits, Hospice staff check on the patient and help the caregiver by teaching important caregiving skills. Hospice staff do not stay or provide someone who will stay with the patient all the time. A Hospice staff member is available by telephone twenty-four (24) hours a day, seven (7) days a week to answer questions. A home visit can be made anytime due to an emergency. Trained Hospice volunteers are also available for providing an occasional break for caregivers.
4. Hospice staff will discuss patient and caregiver needs on a regular basis and make suggestions to help meet those needs. If necessary, Hospice will attempt to insure the flow of care in inpatient and outpatient settings. If the patient needs to move to a different hospice program, Hospice will help arrange for the move.
5. Hospice sends bills to the proper insurance companies, including Medicare and Medicaid. These insurance companies pay Hospice for the care I receive in my home. If I should decide to pay on my own, Hospice will bill me based upon what I can afford to pay. I will not be turned down because I cannot afford to pay.
6. I can decide to stop receiving hospice services at anytime.
7. I have read and understand the "Hospice Patient's Bill of Rights." Any questions about it and the care I will receive from Hospice have been answered.
8. Hospice may release or obtain any of my medical records to or from any other home care agency, hospital, nursing home, doctor's office, or insurance company.

*Revised 05/01*

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## DISCLOSURE STATEMENT

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The Center for Hospice and Palliative Care, Inc. (“Hospice”) supports the concept of family/community oriented health care and is committed to the premise that all individuals and families have the right to self-determination and to achieve their maximum potential. As part of these goals, Hospice recognizes that patients and their families have a number of rights. These rights include: participation in health care decisions and planning of future actions, obtaining high quality health care, assistance in the process of dying ,and assistance in achieving and maintaining comfort and human dignity.

In meeting a patient’s health-related goals and ensuring his or her maximum comfort and dignity, Hospice provides the following Core Services:

- Physician services;
- Nursing services;
- Medical Social Work services;
- Counseling services
  - \* Spiritual Care Counseling
  - 574 \* Bereavement Counseling
- Volunteer services.

When medically necessary and indicated in the individual hospice patient’s plan of care, other services provided by Hospice are as follows:

- Physical therapy
- Occupational therapy
- Speech Language Pathology
- Home Health Aide/Homemaker
- Nutritional counseling
- Short-term inpatient/respite care

As part of its mandate for patient care, Hospice can also provide certain medical supplies to patients, based on physician’s orders and the patient’s plan of care. Listed below are those supplies that Hospice is able to provide, when appropriate and approved:

- Durable medical equipment such as hospital beds, bedside commodes, wheelchairs, etc.
- Medical supplies such as dressings, adult incontinence supplies, oral hygiene supplies, etc.
- Other personal comfort care items based upon an individual patient’s needs.

Generally, these supplies are available to a patient either through pick up or delivery to the home. How the supplies will be made available will depend on the type of supply and the need of the patient, and will be agreed to between Hospice and the patient before the provision of services and supplies begins.

All services and supplies shall be dispensed to the patient based solely on that individual’s needs and pursuant to a physician’s orders, and a patient has the right to refuse any component of the hospice’s services or supplies.

Disclosure Statement (continued)

If a patient, his/her family or his/her legal representative disagrees with a service provided or action taken by Hospice, or if an individual wishes to register a complaint regarding the quality or nature of the care and/or supplies received, a Complaint Form can be obtained from any Hospice staff member. This form should be completed and returned directly to the President in the self-addressed stamped envelope provided, or, a patient and/or his/her family may call the Hospice office, Monday through Friday, 8:00 a.m. to 5:00 p.m. and ask to speak to any administrator to have his/her complaint documented.

Once Hospice administration receives the formal Complaint, it will initiate an internal investigation into the matter. Based on that investigation, a brief report of the allegations will be written, whether those allegations were substantiated, and what action, if any, the Hospice will take as a result. This report will be made available to the individual initiating the complaint.

If an individual disagrees with the findings or the actions taken, he/she may appeal the issue to the Hospice administration. The findings and actions will be reviewed and a written statement will be issued either confirming the initial findings or reversing the findings and ordering new actions to be taken.

Hospice is part of a regulated community, overseen by the Indiana State Department of Health. Any questions or complaints that are not addressed to an individual's satisfaction by Hospice may be addressed by calling the Department's toll-free number: 1-800-227-6334.

*Revised 5/01*

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## HOW CAN YOU HELP HOSPICE?

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Many Hospice families ask how they can help Hospice of St. Joseph County, Marshall County Hospice, or the Hospice of Elkhart County. There are many ways. In order to fulfill our mission to provide care to the terminally ill in our community, regardless of the patient's ability to pay, we depend on the generosity of our community - financially and through volunteer involvement. There are several ways in which you can offer support of our efforts.

### EDUCATE YOUR COMMUNITY

We count on those who have experienced Hospice care to share information regarding our programs and services. Your testimonial is of great value to Hospice -- you can educate your friends, co-workers fellow club members, etc. Some family members even write **letters to the editor** of their local paper regarding the benefits of Hospice care. If you are not comfortable speaking to groups, we offer a volunteer **Speaker's Bureau** that can deliver the message of Hospice for you. Let us know of speaking opportunities, health fairs, or other ways we might educate your community.

You can also **teach your physician** and his/her staff about Hospice care. Share stories of how Hospice has helped your family. Let them know Hospice is a gift they can give their terminally ill patients and tell your loved one's physician that you appreciate their support of Hospice care.

### BECOME A VOLUNTEER

Many Hospice volunteers become involved with Hospice because a loved one has received Hospice services. Although we encourage family members and friends to take time to heal emotionally from their loss, we have found that those who have had Hospice care for their loved ones become wonderful patient care volunteers.

In addition to providing patient care in homes and at Hospice House, our volunteers participate on the Board of Directors, become involved in special committees (such as personnel, community relations/fundraising, finance and quality assurance), serve on the Speakers' Bureau, offer support in a variety of clerical duties as Office Volunteers or provide emotional support to grieving families as Bereavement Volunteers.

### MEMORIAL DONATIONS

Throughout the year, many members of the community make donations to Hospice in memory of friends or family members who have died. This is a special way of remembering a loved one. These donations are listed in the memorial section of our newsletter, the BEACON, which is published three times each year.

## **DIRECT MAIL CAMPAIGNS**

Two times each year Hospice mails a letter to our friends and family members asking for financial support of our program. In March, we mail our **“Friends of Hospice”** letter, which provides information on services provided throughout the year and how they have been funded. In November, we mail our **“Annual Appeal”**, which typically shares a story of one or several of the patients we have cared for in the last year and what that care meant to the patient and family.

## **SPECIAL EVENTS**

The **Helping Hands Dinner** is an annual celebration which recognizes the professional and personal contributions a person (or, in some cases, more than one person) has made to improve the quality of life in our community. The elegant evening includes an hors d’oeuvres reception and dinner, which is held at the Joyce Athletic Center on the University of Notre Dame campus.

Since 1986, The **Walk For Hospice** has taken place on the second Sunday in October. Now, the Walk For Hospice is held on that same day in both South Bend, Plymouth, and Elkhart. We count on Hospice families and friends to form teams, obtain pledges and participate in the Walk. The Walk not only raises funds to support our programs, but also generates publicity about Hospice, allowing us the opportunity to educate members of the communities we serve.

In addition, there are several small special events held throughout the year. From time to time you may also see notices in the paper of events that are held to benefit Hospice of St. Joseph County, Marshall County Hospice, or Hospice of Elkhart County. We would appreciate your support of these events and the businesses that are so generous in giving to Hospice.

## **PLANNED GIVING**

Wills, charitable gift annuities, charitable remainder unitrusts and life insurance are some of the most common ways to make a planned gift to Hospice. In planned giving, the donor makes a decision to now to make a gift to Hospice, but the funds will not be received until a later date. There are many benefits to planned giving, including: donors can make a larger gift than if making one outright; donors can create a permanent memorial; and the possibility of income, estate, and capital gains tax savings.

The Center for Hospice and Palliative Care, Inc. has established designated organization funds through community foundations to provide permanent annual support. If you would like additional information on planned giving, please contact The Center for Hospice and Palliative Care, Inc. at 574-243-3100, or the following community foundations:

Community Foundation of St. Joseph County	(574) 232-0041
Community Foundation of Marshall County	(574) 935-5159
Community Foundation of Elkhart County	(574) 295-8761

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## DONATED SUPPLIES – COMMUNITY RESOURCES

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Frequently, patients and family members ask us where they may be able to donate medical equipment, medicines, and/or unused supplies during or following the care of a patient. We have put together a resource listing from the counties served by our Hospice of some of the agencies and organizations that will accept a variety of items. Although Hospice is always appreciative of donations, we cannot accept these items because we are not licensed as a durable medical equipment supplier or pharmacy.

### ELKHART COUNTY

Diabetic Youth Foundation 707 Bower Street Elkhart, IN 46514 574-293-5281	insulin, glucometer test strips
United Cancer Services Of Elkhart County 2397 US 33 East Elkhart, IN 46517 574-875-5158	DME, some bandages, nutritional drinks M-F 9:00-3:00
United Labor Agency for Community Services 3322 Middlebury Street Elkhart, IN 46516 574-522-2899	wheelchairs, walkers, canes, no lift chairs, no hospital beds M-Th 8:00-4:30 F 8:00-4:00 Call ahead to inquire prior to dropping off items
Church Services International 574-293-4366 Contact Person: Ramona Kelly	(sends supplies to developing countries) syringes, gloves, tape, opened diapers, colostomy supplies, diabetic supplies, vitamins No medications Call in evening to arrange pickup

## MARSHALL COUNTY

American Legion 1040 E Jefferson Plymouth, IN 46563 574-936-8827	beds, wheelchairs, commodes, walkers, canes, shower chairs
Area 2 Council on Aging/REAL Services 121 E LaPorte Street Plymouth, IN 46563 574-936-3175	wheelchairs, walkers, canes, lift chairs, commodes, shower chairs
Marshall County Neighborhood Center 402 W Garro Street Plymouth, IN 46563 574-936-3388	wheelchairs, lift chairs, hospital beds, sheets, walkers, canes, commodes, shower chairs
Marshall-Starke Development Center 1901 Pidco Drive Plymouth, IN 46563 574-936-9400 Contact Person: Christi Rice	diapers, Depends
Salvation Army 113 Water Street Plymouth, IN 46563 574-936-8822	sheets, blankets, wheelchairs, shower chairs, commodes, walkers, canes
St. Joseph's Health Center 116 E Washington Street Plymouth, IN 46563 800-854-5312 574-941-2264 Contact Person: Connie Deery	medications – no narcotics
American Legion 120 N First Street Argos, IN 46501 574-892-6509	wheelchairs, walkers, canes, commodes, shower chairs, beds

## **STARKE COUNTY**

American Legion  
707 S Heaton Street  
Knox, IN 46534  
574-772-4393

wheelchairs, walkers, canes, commodes,  
shower chairs, beds

Starke County Council on Aging  
311 Culver Road  
Knox, IN 46534  
574-772-7070  
Contact Person: Cecilia Torres

wheelchairs, walkers, canes, commodes,  
shower chairs

VFW Post 748  
1511 S Heaton Street  
Knox, IN 46534  
574-772-2298

wheelchairs, walkers, canes, shower chairs,  
beds, commodes

## **FULTON COUNTY**

Council on Aging  
625 Pontiac Street  
Rochester, IN 46975  
574-223-6953  
Contact Person: Terry Moore

wheelchairs, walkers

## ST. JOSEPH COUNTY

Disability Rights Commission 3812 York Street Mishawaka, IN 46544 574-255-1333 Contact Person: Laurence Phillips	bath seats, commodes, crutches, canes, walkers, toilet side rails, Jevity or food supplements
Dujarie House Brothers of Holy Cross Notre Dame, IN 46556 574-287-1839 Contact Person: Steve Castner	walkers, wheelchairs, canes, crutches
Indiana Health Center 1901 W Western Avenue South Bend, IN 46619 574-234-9033 ext 139 Contact Person: Leona Hill	oncology supplies, wheelchairs, crutches, canes, unopened medications (accept open also—but they throw them away)
Muscular Dystrophy Association 314 W Catalpa Drive Mishawaka, IN 46545 574-259-9912	walkers, wheelchairs, lifts, suction equipment, etc.
Portage Manor 53308 Portage Road South Bend, IN 46628 574-272-9100 Contact Person: Paul Kizka	walkers, canes, commodes, bath seats, incontinent supplies (will pick up)
St. Joseph Health Center 326 S Chapin Street South Bend, IN 46601 574-232-4070 Contact Person: Luke	medicines – over-the-counter unopened prescriptions all kinds of equipment
United Health Services 711 E Colfax Avenue South Bend, IN 46617 574-234-3136 Contact Person: Judy Cobb	wheelchairs, walkers, commodes, canes, raised toilet seats, crutches, ostomy supplies, urostomy pouches & wafers, hearing aids, syringes, lancets, unopened insulin, Depends

VFW  
110 N Main Street  
Walkerton, IN 46574  
574-773-7223

canes, wheelchairs, walkers

VFW Post 9820  
4829 Linden Avenue  
South Bend, IN 46619  
574-237-9820  
Contact Person: Linda Bradbury

wheelchairs, crutches, canes, commodes,  
walkers, bath chairs

VFW Post 1167  
1047 Lincoln Way East  
South Bend, IN 46601  
574-287-8144  
Contact Person: Tom Weaver

wheelchairs, walkers, canes, crutches, commodes

VFW Post 360  
1307 E Jefferson Blvd  
Mishawaka, IN 46545  
574-255-4125  
Contact Person: Ed Sanders

canes, walkers, wheelchairs, commodes