

Center for Hospice
and Palliative Care



Family Handbook

OUR MISSION

To improve the quality of living

updated July 2009

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INTRODUCTION

The Center for Hospice and Palliative Care, Inc. (CHAPC), is an independent community-based, not-for-profit organization providing comfort and support to all people facing the end-of-life. Our program provides an environment allowing a person with a progressive or incurable illness to live each day in his or her own way—in comfort and dignity, with hope, and with personal satisfaction and worth.

Licensed as both a Hospice program and a Home Health Care program, CHAPC:

- Allows patients to remain and live at home in dignity while providing support services to the family as well as the patient.
- Accepts Medicare, Medicaid, private/commercial insurance payments and financial support to pay for services. No patient is ever turned away due to an inability to pay for his or her care.
- Promotes an understanding of life and living, as well as death and dying, among patients, their families, health care professionals, and the community.
- Provides services to residents of Health Care Facilities and their families. The focus is on comfort care for those who are no longer seeking care.

Licensed Hospice Care Program

The Hospice Care Program requires a physician to certify that a patient's terminal illness has a life expectancy of six months or less if the disease follows its normal course. Hospice patients have chosen not to pursue curative, aggressive treatments. An interdisciplinary team will determine on a case-by-case basis whether a patient is appropriate for this program. The goal is always to maintain quality of life and symptom control.

Licensed Home Health Care Program (Palliative Care)

The Home Health Care Program is for patients who have made the choice to pursue aggressive or life-extending treatment for a progressive or incurable illness, and desire pain management and symptom control in their own home. The individuals seeking life-prolonging illnesses have an undetermined life expectancy. Many aspects of this Palliative Care Program are applicable early in the course of an illness. The goal is the achievement of the highest quality of life for patients and their families.

All of our patients, in either program, have access to our team, which includes the patient's own physician and/or the CHAPC medical director, nurses, hospice aides, social workers, spiritual care counselors, and volunteers. Emergency care is available 24 hours a day, 7 days a week. Bereavement services are offered to educate and support people through the natural process of grief.

We hope the materials in this handbook will be of help to you and serve as a guide. Please remember that the services of **The Center for Hospice and Palliative Care, Inc.** are always just a phone call away.

ON CALL PROCEDURE

The Center for Hospice and Palliative Care, Inc. wants you to know that you are never alone with your concerns. Our business hours are 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. **Our on call staff is available to assist you when our office is closed.** Please do not hesitate to call at any time. Following are the phone numbers for contacting an on call nurse:

TOLL FREE: (800) 413-9083

OR

SOUTH BEND OFFICE

(574) 243-3100

PLYMOUTH OFFICE

(574) 935-4511

ELKHART OFFICE

(574) 264-3321

When calling the On Call Service:

- **Ask that the nurse on call be paged.**
 - **Leave YOUR NAME, the PATIENT'S NAME, the PHONE NUMBER, and the 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.**
-
-

Once again, we are available 24 hours a day. Call us at any time!

Availability 24 Hours a Day

A 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 the decision is made to take the patient to the hospital
- 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 CHAPC nurse before calling the physician. Our 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 our nurse, please notify our nurse so we will know what has occurred.

Concerns About Re-hospitalization

- We urge you to call us first when questioning if a patient needs to go to the hospital. It is possible for our 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 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.

THE CHAPC TEAM

The Center for Hospice and Palliative Care, Inc. (CHAPC) 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.

MEDICAL DIRECTOR

The Hospice Medical Director is a licensed physician with experience and knowledge in the hospice philosophy of care and comfort care. Our physician does not take the place of a patient's own physician, but works as a member of the hospice team in overseeing the delivery of quality care to all hospice patients.

The hospice medical director's services and responsibilities may include:

- Consulting with an attending physician regarding pain and symptom management
- Reviewing patient eligibility for hospice services
- Participating in admissions and recertification decisions
- Providing coverage and support to the hospice team during and after normal business hours
- Acting as a medical resource for the interdisciplinary team
- Acting as a liaison to physicians in the community

NURSE

A registered nurse admits a patient into our 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 team.

Some practical areas of involvement may include:

- initiating the patient's plan of care
- monitoring the patient's changing condition, especially in pain management, symptom control, and reporting changes to the physician
- teaching the family to be confident caregivers through education about the disease process and proper use of medications
- coordinating care with the other team members

- supervising hospice aides when assistance is needed for personal care

HOSPICE AIDE

The hospice aides are skilled at assisting with personal care activities. They have been educated in hospice and home health 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
- assistance in maintaining a safe and healthy environment

SOCIAL WORK

A social worker is part of every 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 additional services you may need.

Some practical areas of involvement may include:

- assisting the patient and family with grief issues and 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 us.
- 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 spiritual care counselor is part of every patient's hospice care 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 care counselor is a theologically and clinically trained individual available to the patient and family members. You will find the spiritual care counselor to be accepting and open to all beliefs. They do not displace your own spiritual resources, but they provide complementary support by assuring spirituality has a prominent place among healing resources. 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 our services
- help in finding clergy of a particular denomination, and/or spiritual support within the community, if the patient or family members so choose
- identifying and resolving any spiritual concerns affecting the patient and family
- assistance in reflecting on the mysteries of life, suffering, death and afterlife
- dealing with issues of grief
- identifying ethical dilemmas related to how beliefs affect medical care and decisions
- planning and officiating funerals for those without church involvement

VOLUNTEERS

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. They are a help to us and our families, and an important part of our care team.

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

- stay with the patient to relieve the caregiver
- provide companionship for the patient
- assist with transportation and errands
- read to, or write letters for the patient
- assist the patient with personal care
- assist with light housekeeping
- prepare and feed the patient light meals

- become a friend of the patient and the family

Volunteers are available for in-home visits throughout the day and early evening hours. Families may receive volunteer services up to four (4) hours per weekly visit. Advance notice is preferred for placements. We attempt 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 our services.

If you would like a volunteer, simply ask any staff person, or call the Volunteer Resource Coordinator at one of the following CHAPC offices:

Toll Free - (800) 413-9083, or

South Bend - (574) 243-3100

Plymouth - (574) 935-4511

Elkhart - (574) 264-3321

BEREAVEMENT COUNSELING

Family needs do not end with the death of a patient. The time of bereavement that follows can be very difficult. We want 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 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.

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 and teens
- grief support groups for children and teens

You will regularly receive more information about these services from our 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.

If you are interested in bereavement services, call the CHAPC office:

Life Transition Center, Mishawaka (574) 255-1064

Plymouth (574) 935-4511

Elkhart (574) 264-3321

PHYSICAL CARE

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

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. 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:

Moisturizing Lotion

Extra Pillows

Extra Lift Sheet

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 change positions in bed 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 nurse or hospice aide will demonstrate how to use a lift sheet 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 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 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. The nurse may also suggest the use of an egg-crate mattress or an alternating pressure pad to assist with maintaining good skin care.
6. Despite our best efforts, a bed sore may develop. If this occurs, the hospice nurse

will develop a plan of care to provide comfort.

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)

Body Wash

Lotion

Clean Nightgown or Pajamas

Clean Bed Linen (if linen change is needed)

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 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 cleanser 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.

8. Gently dry the skin with a soft towel.
9. Apply lotion.

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.

The thought of making the bed, with the patient in the bed, can be overwhelming, but a nurse can show you how it is done.

NEEDS:

- Sheets and Pillow Cases
- Lift Sheet
- Incontinent Pads

PROCEDURE:

1. If you have a hospital bed, raise the bed to a height most comfortable for you.
2. 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.
3. Go to the side of the bed with patient's back facing you to loosen all bottom sheets.
4. Roll the bottom sheet(s), along with any incontinent pad, under the patient to the middle of the bed.
5. 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.
6. 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.
7. If the bed has a side rail, put it up and assist the patient to roll towards you over the

rolled linens.

8. Move to the other side of the bed and pull out the soiled sheets.
9. Unroll the clean sheets and incontinent pad. Tuck in the side, top and bottom.
10. 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:

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. Notify the hospice nurse if the pills are too large or become too difficult to swallow, for further instructions.
3. As a patient’s disease progresses and he/she becomes weaker, the 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 his/her 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 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
Cleanser

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, cleanser, 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. 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 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 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.

INFECTION CONTROL

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.

With soap and water:

1. Wet your hands with warm water. Use liquid soap if possible. Apply a nickel- or quarter-sized amount of soap to your hands.
2. Rub your hands together until soap forms a lather and then rub all over the top of your hands, in between your fingers and the area around and under the fingernails.
3. Continue rubbing your hands for 15 seconds. Need a timer? Imagine singing the “Happy Birthday” song twice.
4. Rinse your hands well under running water.
5. Dry your hands using a paper towel if possible. Then use your paper towel to turn off the faucet and to open the door if needed.

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.

SHARP OBJECTS

Place used “sharps” directly into a clean, rigid container with a screw-on or tightly secured lid. Use a hard plastic or metal container. Before discarding a container, reinforce the lid with heavy-duty tape. Never overfill the containers or recap needles once used. DO NOT use glass or clear plastic containers and never put “sharps” in containers that will be recycled or returned to a store. Seal the container with tape and place it in the trash can or dispose of it according to area regulations.

SPIILLS IN THE HOME

Blood/body fluid spills are cleaned by putting on gloves and wiping fluid with paper towels. Use a cleaning solution of household bleach and water (*1 cup of bleach to 10 cups of water*) to wipe the area again. Bag the used paper towels and dispose of them in the trash.

VISITORS

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

SAFETY IN THE HOME

All patients and families need to take special precautions to ensure a safe living environment. Most accidents in the home can be prevented by eliminating hazards.

PREVENTING FALLS

At least half of all falls happen at home. Falls are often due to hazards that are easily overlooked but easy to fix.

Review each of the following safety tips:

- Keep emergency numbers in large print near each phone.
- Wear shoes that give good support and have thin, non-slip soles. Avoid wearing slippers and athletic shoes with deep treads.
- Remove things you can trip over (such as papers, books, clothes and shoes) from stairs and places where you walk.
- Keep outside walks and steps clear of snow and ice in the winter.
- Remove small throw rugs or use double-sided tape to keep them from slipping.
- Ask someone to move any furniture so your path around the house is clear.
- Clean up spills immediately.
- Be aware of where your pets are at all times.
- Do not walk over or around cords or wires (i.e., cords from lamps, extension cords or telephone cords). Coil or tape cords and wires next to the wall so you can't trip over them.
- Keep items used often within easy reach (about waist high) in cabinets.
- Use a steady step stool with a hand bar. Never use a chair as a step stool.
- Improve the lighting in your home. Replaced burned out bulbs. Lamp shades or frosted bulbs can reduce glare.
- Make sure stairways, halls, entrances and outside steps are well lit. Have a light switch at the top and bottom of the stairs.
- Place a lamp, flashlight and extra batteries within easy reach of your bed.
- Place night lights in bathrooms, halls and passageways so you can see where you're walking at night.
- Make sure the carpet is firmly attached to every step.
- Make sure handrails are on both sides of the stairs and are as long as the stairs.
- Install grab bars next to your toilet and in the tub or shower.
- Use non-slip mats in the bathtub and on shower floors.
- Use an elevated toilet seat and/or shower stool, if needed.
- Get up slowly after you sit or lie down.

- Use a cane or assistive device for extra stability, if needed.
- Think about wearing an alarm device that will bring help in case you fall and can't get up.

FIRE SAFETY / BURN PRECAUTIONS

- The fire department number is posted on every telephone. All family members and caregivers are familiar with emergency 911 procedures.
- Notify the fire department if a disabled person is in the home.
- **Do not smoke in bed or where oxygen equipment is being used.** Never leave burning cigarettes unattended. Do not empty smoldering ashes in a trash can. Keep ashtrays away from upholstered furniture and curtains.
- Install smoke alarms on every floor of your home, including the basement. place smoke alarms near rooms where people sleep. Test smoke alarms every month to make sure they are working properly.
- Install new smoke alarm batteries twice a year or when you change your clocks for daylight savings time in the spring and fall.
- Fire extinguishers are checked frequently for stability.
- Make a family fire escape plan and practice it every six months. At least two different escape routes are planned from each room for each family member. If your exit is through a ground floor window, make sure it opens easily.
- If you live in an apartment building, know where the exit stairs are located. Do not use an elevator during a fire emergency.
- Designate a safe place in front of the house or apartment building for family members to meet after escaping a fire.
- If your fire escape is cut off, remain calm, close the door and seal cracks to hold back smoke. Signal for help at the window.
- A **bedbound patient** can be evacuated to a safe area by placing him/her on a sturdy blanket and pulling/dragging them out of the home.
- Remember, life safety is first, but if the fire is contained and small, you may be able to use your fire extinguisher until the fire department arrives.
- Have your heating system checked and cleaned regularly by someone qualified to do maintenance.
- Wood burning stoves are properly installed, chimney is inspected and cleaned by a professional chimney sweep, and trash is not burned in stove because this could overheat the stove. Gasoline or other flammable liquids should never be used to start wood stove fires.
- Portable heaters (electric or kerosene) are placed out of the path of traffic areas. The

heater is operated at least three feet away from upholstered furniture, drapes, bedding and other combustible materials. The heater is used on the floor and is turned off when family members leave the house or are sleeping. A kerosene heater is only used in a well ventilated room. Kerosene is stored outdoors in a tightly sealed, labeled container.

- Make sure electrical appliances and cords are clean, in good condition, and not exposed to liquids.
- Electrical outlets are grounded. “Octopus” outlets with several plugs are not used.
- Keep cooking areas free of flammable objects (potholders, towels, etc.).
- Keep storage area above the stove free of flammable/combustible items.
- Wear short or tight fitting sleeves while cooking; don’t reach over stove burner.
- Do not leave the stove unattended when cooking, especially when the burner is turned to a high setting.
- Turn pan handles away from burners and the edge of the stove.
- Avoid cooking on high heat with oils and fats.
- Puncture plastic wrap before heating foods in the microwave.
- Never place hot liquids/solids at edge of counter.
- Place layered protection between skin and heating pad.
- Keep electrical appliances away from the bathtub or shower area.
- Never leave patient alone in the shower/tub.
- Set water heater thermostat below 120°F to prevent accidental scalding.
- Store flammable liquids in properly labeled, tightly closed, non-glass containers. Store away from heaters, furnaces, water heaters, ranges and other gas appliances. Make sure the garage is adequately ventilated.

MEDICATION SAFETY

- Do not take medications that are prescribed for someone else.
- Know the name of each of your medicines; why you take it; how to take it; potential side-effects; and what foods or other things to avoid while taking it.
- Report medication allergies or side effects to the hospice nurse.
- Take medications exactly as instructed. If the medication looks different than you expected, ask the hospice nurse.
- Drug names can look alike or sound alike. To avoid errors, check with the hospice nurse if you have questions.
- Take your medicine with a light on so you can read the label.
- Store medications safely in a cool, dry place according to instructions on the label of the medication.
- Keep medicines away from children and confused adults.

HAZARDOUS ITEMS AND POISONS

- Know how to contact your poison control team.
- Carefully store hazardous items in their original containers.
- Do not mix products that contain chlorine or bleach with other chemicals.
- Insecticides are only bought for immediate need and excess is stored or disposed of properly.
- Keep hazardous items, cleaners and chemicals out of reach of children and confused or impaired adults.
- Dispose of hazardous items and poisons only as directed.

MEDICAL EQUIPMENT

- Keep manufacturer's instructions for specialized medical equipment with or near the equipment.
- Keep phone numbers available in the home to obtain service in case of equipment problems or equipment failure.
- Use bedside rails only when necessary. Do not use bed rails as a substitute for a physical protective restraint.
- If bed rails are split, remove or leave the foot-end down so the patient is not trapped between the rails.

OXYGEN SAFETY

- Use oxygen only as directed.
- **No smoking around oxygen.** Post “**No Smoking**” signs in the home.
- Store oxygen cylinders away from heat and direct sunlight. Do not allow oxygen to freeze or overheat.
- Keep oil/petroleum products (such as Vaseline, oily lotions, face creams or hair dressings), grease and flammable material away from your oxygen system. Avoid using aerosols (such as room deodorizers) near oxygen.
- Dust the oxygen cylinder with a cotton cloth and avoid draping or covering the system with any material.
- Keep open flames (such as gas stoves and lighted candles) at least 10 feet away from the oxygen source.
- Have electrical equipment properly grounded and avoid operating electrical appliances such as razors and hairdryers while using oxygen. Keep any electrical equipment that may spark at least 10 feet away from the oxygen system.
- Place oxygen cylinders in appropriate stand to prevent tipping, or secured to the wall

or placed on their side on the floor. Store in a well-ventilated area and not under outside porches or decks or in the trunk of a car.

- Have a back-up portable oxygen cylinder in case of a power or oxygen concentrator failure.

POWER OUTAGE

In case of a power outage, if you require assistance contact CHAPC.

If it is not an emergency, call your closest relative or neighbor.

FLOODS

Floods are the most common and widespread of all natural hazards. Some floods can develop over a period of days, but flash floods can result in raging waters in just a few minutes. Be aware of flood hazards, especially if you live in a low-lying area, near water or downstream from a dam.

Assemble a **disaster supplies kit**. Include a battery-operated radio, flashlights and extra batteries, first aid supplies, sleeping supplies and clothing. Keep a stock of food and extra drinking water.

If local authorities issue a flood watch, prepare to evacuate:

- Secure your home. Move essential items to the upper floors of your house.
- If instructed, turn off utilities at the main switches or valves. Do not touch electrical equipment if you are wet or standing in water.
- Fill a clean bathtub with water in case water becomes contaminated or services are cut off.
- Six inches of moving water can knock you off your feet. If you must walk in a flooded area, do not walk through moving water.
- Use a stick to check the firmness of the ground in front of you.

TORNADO

Tornadoes are nature's most violent storms. When a tornado has been sighted, go to your shelter immediately. Stay away from windows, doors and outside walls.

- **In a house or small building:** Go to the basement or storm cellar. If there is no basement, go to an interior room on the lower level (closets, interior hallways). Get under a sturdy table, hold on and protect your head. Stay there until the danger has

passed.

- **If the patient is bedbound**, move the patient's bed as far away from windows as possible. Cover the patient with heavy blankets or pillows being sure to protect the head and face. Then go to a safe area.
- **In a high-rise building**: Go to a small, interior room or hallway on the lowest floor possible.
- **In a vehicle, trailer or mobile home**: Get out immediately and go to a more substantial structure.
- **If there is no shelter nearby**, lie flat in the nearest ditch, ravine or culvert with your hands shielding your head. In a car, get out and take shelter in a nearby building. Do not attempt to out-drive a tornado. They are erratic and move swiftly.

LIGHTNING

Inside a home:

- Avoid bathtubs, water faucets and sinks because metal pipes can conduct electricity.
- Stay away from windows.
- Avoid using the telephone, except for emergencies.

If outside:

- Do not stand underneath a natural lightning rod, such as a tall, isolated tree in an open area.
- Get away from anything metal.

WINTER STORMS

Heavy snowfall and extreme cold can immobilize an entire region. The results can range from isolation due to blocked roads and downed power lines to the havoc of cars and trucks sliding on icy highways.

Gather emergency supplies:

- Battery powered radio, flashlights, battery-powered lamps, extra batteries.
- Food that doesn't require cooking and a manual can opener.
- Your medications.
- Extra blankets.
- Extra water in clean soda bottles or milk containers.
- Rock salt to melt ice on walkways and sand to improve traction.
- Make sure you have enough heating fuel as regular fuel sources may be cut off.

Dress for the season:

- Wear several layers of loose-fitting, light-weight, warm clothing rather than one layer of heavy clothing.
- Outer garments should be tightly woven and water repellent.
- Mittens are warmer than gloves.
- Wear a hat since most body heat is lost through the top of the head.

PHYSICAL CHANGES

NAUSEA

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

- Keep surroundings quiet and have patient rest.
- Use clear liquids only--broth, jello, tea, soda--or try crackers or dry toast.
- Keep mouth fresh and clean at all times.
- Talk to your nurse about medication to lessen nausea and/or the use of other alternative interventions.

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:

- Offer fluids, juices, nectars or jello as tolerated.
- Include fruits and vegetables if patient can tolerate them.
- Encourage mild exercises, such as walking.
- 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:

- Continue to offer clear fluids.
- Keep skin as clean and dry as possible.
- 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:

- Bed pans, adult diapers, and disposable or cloth bed pads.
- Keep the diapers, pads, and linen changed as often as necessary.
- Keep the skin clean and dry to prevent skin breakdown.

- 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:

- Help the patient to stay relaxed. Remain calm and try to calm patient.
- Have patient sit up and lean forward with arms supported on overbed table or other item.
- Raise the head of the bed or elevate patient using pillows.
- Open a window if it is a cool day or use an electric fan to increase air circulation.
- If problem persists, notify your nurse.

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:

- Honor the patient's request for certain types of food and do not be discouraged if they only eat a small portion.
- Serve food in small portions on small plates so as not to overwhelm the patient.
- Frequent small meals and snacks may be tolerated better than the traditional "three meals a day."
- Concentrate on food or liquids higher in calories if less is being eaten.
- Monitor the patient's eating routine to determine if there is a particular time of day when eating is best.

- 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 physical discomfort and distress. This may be evident through signs of the patient coughing, choking, nausea, or vomiting. Notify the hospice nurse to discuss these concerns and for further instructions.

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:

- Less fluid in the throat and lungs to reduce coughing and congestion
- Decreased stomach fluids that may reduce episodes of vomiting
- Less need for urination
- 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.

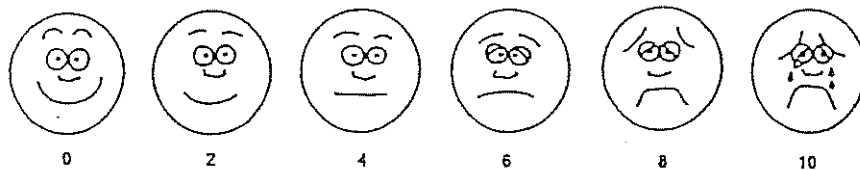
A patient's comfort and dignity will always be our priority. We will consult and work with the physician and family to meet the patient's needs. Staff is always available to talk with you about your feelings, especially regarding difficult issues.

PAIN MANAGEMENT

Good physical pain control is an important element of 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. Most pain, if reported honestly, can be controlled. The 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.



For those patients unable to communicate the hospice nurse is skilled to assess for subtle, non-verbal indications of pain. They will train you in observing for these signs.

PAIN MANAGEMENT

The patient's primary doctor or the hospice medical director will be the person in charge of prescribing all medications. The 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. 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 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 not be a concern for the hospice 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 other alternative techniques and/or a peaceful environment. Companionship can be a positive distraction. Some individuals enjoy being read to or listening to music.

UNDERSTANDING PHYSICAL AND EMOTIONAL CHANGES

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)

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 an incontinent padding under the patient. 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. Medications 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. Avoid saying 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 lighting as the patient wishes. Refrain from asking 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”. 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 CHAPC. We are 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 nurse. Medication or other interventions can possibly be recommended. The best medicine is your presence, or that of a friend or family member.

CONGESTION - Oral secretions may increase 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 pooled secretions that the patient is too weak to clear. 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. Repositioning the patient in bed may be helpful. Contact the hospice nurse with any questions.

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—this is commonly referred to as mottling.

Responses – Continue to provide touch, presence, and messages of your love.

HOW WOULD YOU KNOW DEATH HAS OCCURRED?

Some signs of death may 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 CHAPC 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 3 of this manual.

At the time of death, we will send a team member to assist the family. They 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.

JUST FOR THE CAREGIVERS

It has been our experience that people caring for a loved one often have the tendency to forget about their own needs. We feel 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 our 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. Our 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 staff is also available to listen. This is another way the 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 spiritual counselor is available to assist you as well as your loved one. A volunteer can provide respite for you and companionship for the patient while you renew yourself.

TALKING TO CHILDREN ABOUT ILLNESS

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, impedes learning how to work through their grief from adult role models.

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 and respect what they heard, providing you the opportunity to clarify any 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.

Another good way for a child to express positive feeling is to see if they would like to be involved in planning for the funeral, either prior to the death or after the death. They may want to place a note, toy, or flower in the coffin with the loved one. Some children have helped to pick out pictures for a display of the loved ones life or to read a poem or sing a song at the service. Children can display their own creativity in dealing with a death and saying good-bye.

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 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 social worker or spiritual care counselor in helping you to deal with your child (children).

EASING THE BURDEN

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 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.

IF YOU HAVE A COMPLAINT

Our goal at **The Center for Hospice and Palliative Care, Inc.** 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 a CHAPC administrator at 574-243-3100 or 800-413-9083. 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 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 ours.

State of Indiana Hotline
1-800-227-6334

Monday through Friday
8:00 AM to 4:30 PM

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

ADVANCE DIRECTIVES

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.

THE IMPORTANCE OF ADVANCE DIRECTIVES

Each time you visit your physician, you make decisions regarding your personal health care. You tell your doctor (generally referred to as a "physician") about your medical problems. Your physician makes a diagnosis and informs you about available medical treatment. You then decide what treatment to accept. That process works until you are unable to decide what treatments to accept or become unable to communicate your decisions. Diseases common to aging such as dementia or Alzheimer's disease may take away your ability to decide and communicate your health care wishes. Even young people can have strokes or accidents that may keep them from making their own health care decisions. Advance directives are a way to manage your future health care when you cannot speak for yourself.

WHAT IS AN ADVANCE DIRECTIVE?

"Advance directive" is a term that refers to your spoken and written instructions about your future medical care and treatment. By stating your health care choices in an advance directive, you help your family and physician understand your wishes about your medical care. Indiana law pays special attention to advance directives.

Advance directives are normally one or more documents that list your health care instructions. An advance directive may name a person of your choice to make health care choices for you when you cannot make the choices for yourself. If you want, you may use an advance directive to prevent certain people from making health care decisions on your behalf.

Your advance directives will not take away your right to decide your current health care. As long as you are able to decide and express your own decisions, your advance directives will not be used. This is true even under the most serious medical conditions.

Your advance directive will only be used when you are unable to communicate or when your physician decides that you no longer have the mental competence to make your own choices.

ARE ADVANCE DIRECTIVES REQUIRED?

Advance directives are not required. Your physician or hospital cannot require you to make an advance directive if you do not want one. No one may discriminate against you if you do not sign one. Physicians and hospitals often encourage patients to complete advance directive documents. The purpose of the advance directive is for your physician to gain information about your health care choices so that your wishes can be followed. While completing an advance directive provides guidance to your physician in the event that you are unable to communicate for yourself, you are not required to have an advance directive.

WHAT HAPPENS IF YOU DO NOT HAVE AN ADVANCE DIRECTIVE?

If you do not have an advance directive and are unable to choose medical care or treatment, Indiana law decides who can do this for you. Indiana Code 16-36 allows any member of your immediate family (meaning your spouse, parent, adult child, brother, or sister) or a person appointed by a court to make the choice for you. If you cannot communicate and do not have an advance directive, your physician will try to contact a member of your immediate family. Your health care choices will be made by the family member that your physician is able to contact.

WHAT TYPES OF ADVANCE DIRECTIVE ARE RECOGNIZED IN INDIANA?

- Talking directly to your physician and family
- Organ and tissue donation
- Health care representative
- Living Will Declaration or Life-Prolonging Procedures Declaration
- Psychiatric advance directives
- Out of Hospital Do Not Resuscitate Declaration and Order
- Power of Attorney

TALKING TO YOUR PHYSICIAN AND FAMILY

One of the most important things to do is to talk about your health care wishes with your physician. Your physician can follow your wishes only if he or she knows what your wishes are. You do not have to write down your health care wishes in an advance directive. By discussing your wishes with your physician, your physician will record your choices in your medical chart so that there is a record available for future reference. Your physician will follow your verbal instructions even if you do not complete a written advance directive. Solely discussing your wishes with your physician, however, does not cover all situations. Your physician may not be available when choices need to be made. Other health care providers would not have a copy of the medical records maintained by your physician and therefore would not know about any verbal instructions given by you to your physician. In addition, spoken instructions provide no written evidence and carry less weight than written instructions if there is a disagreement over your care. Writing down your health care choices in an advance directive document makes your wishes clear and may be necessary to fulfill legal requirements.

If you have written advance directives, it is important that you give a copy to your physician. He or she will keep it in your medical chart. If you are admitted to a hospital or health facility, your physician will write orders in your medical chart based on your written advance directives or your spoken instructions. For instance, if you have a fatal disease and do not want cardiopulmonary resuscitation (CPR), your physician will need to write a “do not resuscitate” (DNR) order in your chart. The order makes the hospital staff aware of your wishes. Because most people have several health care providers, you should discuss your wishes with all of your providers and give each provider a copy of your advance directives.

It is difficult to talk with family about dying or being unable to communicate. However, it is important to talk with your family about your wishes and ask them to follow your wishes. You do not always know when or where an illness or accident will occur. It is likely that your family would be the first ones called in an emergency. They are the best source of providing advance directives to a health care provider.

ORGAN AND TISSUE DONATION

Increasing the quality of life for another person is the ultimate gift. Donating your organs is a way to help others. Making your wishes concerning organ donation clear to your physician and family is an important first step. This lets them know that you wish to be an organ donor. Organ donation is controlled by the Indiana Uniform Anatomical Gift Act found in Indiana Code 29-2-16. A person that wants to donate organs may

include their choice in their will, living will, on a card, or other document. If you do not have a written document for organ donation, someone else will make the choice for you. A common method used to show that you are an organ donor is making the choice on your driver's license. When you get a new or renewed license, you can ask the license branch to mark your license showing you are an organ donor.

HEALTH CARE REPRESENTATIVE

A “health care representative” is a person you choose to receive health care information and make health care decisions for you when you cannot. To choose a health care representative, you must fill out an appointment of health care representative document that names the person you choose to act for you. Your health care representative may agree to or refuse medical care and treatments when you are unable to do so. Your representative will make these choices based on your advance directive. If you want, in certain cases and in consultation with your physician, your health care representative may decide if food, water, or respiration should be given artificially as part of your medical treatment.

Choosing a health care representative is part of the Indiana Health Care Consent Act, found at Indiana Code 16-36-1. The advance directive naming a health care representative must be in writing, signed by you, and witnessed by another adult. Because these are serious decisions, your health care representative must make them in your best interest. Indiana courts have made it clear that decisions made for you by your health care representative should be honored.

LIVING WILL

A “living will” is a written document that puts into words your wishes in the event that you become terminally ill and unable to communicate. A living will is an advance directive that lists the specific care or treatment you want or do not want during a terminal illness. A living will often includes directions for CPR, artificial nutrition, maintenance on a respirator, and blood transfusions. The Indiana Living Will Act is found at Indiana Code 16-36-4. This law allows you to write one of two kinds of advance directive.

Living Will Declaration: This document is used to tell your physician and family that life-prolonging treatments should not be used so that you are allowed to die naturally. Your living will does not have to prohibit all life-prolonging treatments. Your living will should list your specific choices. For example, your living will may state that you do not want to be placed on a respirator but that you want a feeding

tube for nutrition. You may even specify that someone else should make the decision for you.

Life-Prolonging Procedures Declaration: This document is the opposite of a living will. You can use this document if you want all life-prolonging medical treatments used to extend your life.

Both of these documents can be canceled orally, in writing, or by destroying the declaration yourself. The cancellation takes effect only when you tell your physician. For either of these documents to be used, there must be two adult witnesses and the document must be in writing and signed by you or someone that has permission to sign your name in your presence.

PSYCHIATRIC ADVANCE DIRECTIVE

Any person may make a psychiatric advance directive if he/she has legal capacity. This written document expresses your preferences and consent to treatment measures for a specific diagnosis. The directive sets forth the care and treatment of a mental illness during periods of incapacity. This directive requires certain items in order for the directive to be valid. Indiana Code 16-36-1.7 provides the requirements for this type of advance directive.

OUT OF HOSPITAL DO NOT RESUSCITATE DECLARATION AND ORDER

In a hospital or health facility setting, if you have a terminal condition and you do not want CPR, your physician will write a “do not resuscitate” order in your medical chart. If you are home when an emergency occurs, there is no medical chart or physician’s order. For situations outside of a hospital or health facility, the “Out of Hospital Do Not Resuscitate Declaration and Order” is used to state your wishes. The Out of Hospital Do Not Resuscitate Declaration and Order is found at Indiana Code 16-36-5. The law allows a qualified person to say they do not want CPR given if the heart or lungs stop working in a location that is not a hospital or health facility. This declaration may override other advance directives. The declaration may be canceled by you at any time by a signed and dated writing, by destroying or canceling the document, or by communicating to health care providers at the scene the desire to cancel the order. Emergency Medical Services (EMS) may have procedures in place for marking your home so they know you have an order. You should contact your local EMS provider to find out their procedures.

POWER OF ATTORNEY

A “power of attorney” (also referred to as a “durable power of attorney”) is another kind of advance directive. This document is used to grant another person say-so over your affairs. Your power of attorney document may cover financial matters, give health care authority, or both. By giving this power to another person, you give this person your power of attorney. The legal term for the person you choose is “attorney in fact.” Your attorney in fact does not have to be an attorney. Your attorney in fact can be any adult you trust. Your attorney in fact is given the power to act for you only in the ways that you list in the document. The document must:

- Name the person you want as your attorney in fact;
- List the situations which give the attorney in fact the power to act;
- List the powers you want to give; and
- List the powers you do not want to give.

The person you name as your power of attorney is not required to accept the responsibility. Prior to executing a power of attorney document, you should talk with the person to ensure that he or she is willing to serve. A power of attorney document may be used to designate a health care representative. Health care powers are granted in the power of attorney document by naming your attorney in fact as your health care representative under the Health Care Consent Act or by referring to the Living Will Act. When a power of attorney document is used to name a health care representative, this person is referred to as your health care power of attorney. A health care power of attorney generally serves the same role as a health care representative in a health care representative advance directive.

Including health care powers could allow your attorney in fact to:

- Make choices about your health care;
- Sign health care contracts for you;
- Admit or release you from hospitals or other health facilities;
- Look at or get copies of your medical records; and
- Do a number of other things in your name.

The Indiana Powers of Attorney Act is found at Indiana Code 30-5. Your power of attorney document must be in writing and signed in the presence of a notary public. You can cancel a power of attorney at any time but only by signing a written cancellation and having the cancellation delivered to your attorney in fact.

WHICH ADVANCE DIRECTIVE OR DIRECTIVES SHOULD BE USED?

The choice of advance directives depends on what you are trying to do. The advance directives listed above may be used alone or together. Although an attorney is not required, you may want to talk with one before you sign an advance directive. The laws are complex and it is always wise to talk to an attorney about questions and your legal choices. An attorney is often helpful in advising you on complex family matters and making sure that your documents are correctly done under Indiana law. An attorney may be helpful if you live in more than one state during the year. An attorney can advise you whether advance directives completed in another state are recognized in Indiana.

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

It is important to discuss your advance directives with your family and health care providers. Your health care wishes cannot be followed unless someone knows your wishes. You may change or cancel your advance directives at any time as long as you are of sound mind. If you change your mind, you need to tell your family, health care representative, power of attorney, and health care providers. You might have to cancel your decision in writing for it to become effective. Always be sure to talk directly with your physician and tell him or her your exact wishes.

ARE THERE FORMS TO HELP IN WRITING THESE DOCUMENTS?

Advance directive forms are available from many sources. Most physicians, hospitals, health facilities, or senior citizen groups can provide you with forms or refer you to a source. These groups often have the information on their web sites. You should be aware that forms may not do everything you want done. Forms may need to be changed to meet your needs. Although advance directives do not require an attorney, you may wish to consult with one before you try to write one of the more complex legal documents listed above.

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

Make sure that your health care representative, immediate family members, physician, attorney, and other health care providers know that you have an advance directive. Be sure to tell them where it is located. You should ask your physician and other health care providers to make your advance directives part of your permanent medical chart. If you have a power of attorney, you should give a copy of your advance directives to your attorney in fact. You may wish to keep a small card in your purse or wallet that states that you have an advance directive, where it is located, and who to contact for your attorney in fact or health care representative, if you have named one.

FINAL THOUGHTS ABOUT ADVANCE DIRECTIVES

- You have the right to choose the medical care and treatment you receive. Advance directives help make sure you have a say in your future health care and treatment if you become unable to communicate.
- Even if you do not have written advance directives, it is important to make sure your physician and family are aware of your health care wishes.
- No one can discriminate against you for signing, or not signing, an advance directive. An advance directive is, however, your way to control your future medical treatment.
- This information was prepared by the Indiana State Department of Health as an overview of advance directives. The Indiana State Department of Health attorneys cannot give you legal advice concerning living wills or advance directives. You should talk with your personal lawyer or representative for advice and assistance in this matter.

MEDICATION DISPOSAL POLICY

Prescription medications no longer needed by the patient will be disposed of and documented in the clinical record by CHAPC staff in compliance with state and federal requirements.

Medications either purchased directly by the patient/family or obtained as the result of a Hospice Benefit program is the property of the patient and is not the property of CHAPC.

1. Upon a change of medication or death/discharge, CHAPC staff will offer to dispose of any unused medications. The patient/family have the right to refuse. The refusal will be reflected in the patient's clinical record, along with the name, strength of the medication, and the remaining. Included in the documentation is the patient/caregiver's name attesting to the refusal, and the date the patient's attending physician was notified of the refusal.
2. No medications, scheduled, unscheduled, or over-the-counter will be removed from the home under any circumstance by CHAPC staff.
3. If medications are disposed of, they will be disposed in the presence of a witness. The name of the medication, the amount and how it was disposed, and the name of the witness will be documented in the patient's clinical record.
4. The U.S. Food and Drug Administration (FDA) and the White House Office of National Drug Control Policy issued the following guidelines in 2007 for the proper disposal of prescription medications:
 - (a) Follow any specific disposal instructions on the drug label or patient information that accompanies the medication. Do not flush prescription drugs down the toilet unless this information specifically instructs you to do so.
 - (b) If no instructions are given, throw the drugs in the household trash, but first: remove the drugs from their original containers and mix them with an undesirable substance, such as used coffee grounds or kitty litter. The medication will be less appealing to children and pets, and unrecognizable to people who intentionally may go through your trash.

- (c) Put the drugs (or the mixture of drugs with an undesirable substance) in a sealable bag, empty can, or other container to prevent the medication from leaking or breaking out of a garbage bag.
- (d) Take advantage of community drug take-back programs that allow the public to bring unused drugs to a central location for proper disposal. Call your city or county government's household trash and recycling service (see the blue pages in a phone book) to determine if a take-back program is available in your community.
- (e) As part of the aforementioned policy, the government recommends the following drugs be flushed down the toilet instead of thrown in the trash. The goal is to reduce the danger of unintentional use or overdose and illegal abuse.
 - Actig (fentanyl citrate)
 - Avinza Capsules (morphine sulfate)
 - Baraclude Tablets (entecavir)
 - Daytrana Transdermal Patch (methlyphenidate)
 - Duragesic Transdermal System (fentanyl)
 - Fentora (fentanyl buccal tablet)
 - Meperidine HCl Tablets
 - OxyContin Tablets (oxycodone)
 - Percocet (Oxycodone and Acetaminophen)
 - Reyataz Capsules (atazanavir sulfate)
 - Tequin Tablets (gatifloxacin)
 - Xyrem (Sodium Oxybate)
 - Zerit for Oral Solution (stavudine)

- 5. Hospice House – When any medications are disposed of in Hospice House, it will be disposed of with the witness of two nurses. The Medication Disposal form will be completed and filed in the patient's chart.
- 6. Long-Term Care / Hospital Setting – When the patient resides in long-term care, or in the in-patient hospital setting, CHAPC staff will follow the policies of the facility for disposing of patient medications.

CHAPC will comply with the Drug Enforcement Administration and adjust the policy as required to assure total compliance with state and federal regulations. Failure to comply with this policy may result in disciplinary action.

UNIVERSAL PRECAUTIONS AND PATIENTS' RIGHTS

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**

PATIENT BILL OF RIGHTS

All patients under the care of **The Center for Hospice and Palliative Care, Inc.** (CHAPC) have a right to be notified verbally and in writing of their rights 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. CHAPC has an obligation to protect and promote these rights and will keep a copy of this signed executed form on file as documentation that these rights have been received, understood and discussed with the patient and/or family. These rights include:

I. DIGNITY AND RESPECT:

1. Patients will receive effective pain management and symptom control regardless of race, age, gender, creed, national origin, handicap, marital status, sexual orientation, source of payment, or ability to pay for services rendered.
2. All CHAPC personnel will treat patient's property with respect.
3. Patients have the right to designate a representative to exercise the patient's rights to the extent allowed by state law should the patient become incompetent.
4. 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 CHAPC. Patients call the CHAPC office and talk with a staff member's supervisor. All alleged violations will be investigated, and immediate action will be taken to prevent further potential violations. Documentation will reflect the existence of the complaint and the resolution.
5. If a complaint has not been resolved by CHAPC, 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 CHAPC. 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.
6. The patient has the right to be treated with dignity and be free from mistreatment,

neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property.

II. DECISION MAKING

1. Patients will be informed about the scope of services CHAPC provides and specific limitations on these services.
2. 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.
3. Patients have the right to participate in developing his/her plan of care, and be advised of changes in that plan prior to making changes, including reasonable discharge notice.
4. Patients have the right to choose his/her attending physician, as well as request a change in a CHAPC caregiver (or health care agencies) without fear of reprisal or discrimination.
5. Patients/families have the right to receive written information in advance regarding their rights to accept or refuse treatment and to make advance directives.
6. Patients have the right to refuse services and/or treatment(s) and be informed of the consequences of refusing care.
7. Patients have the right to be advised that CHAPC 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 CHAPC's commitment to quality care.

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 CHAPC 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 representatives have the right to access their clinical records, unless certain exceptions apply. Patients shall be advised of CHAPC'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 CHAPC may be expected by Medicare, Medicaid, or any other federally funded or aided program to CHAPC.
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 CHAPC 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 CHAPC 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 CHAPC.

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.
2. Patients have a right to be advised to call CHAPC in the event of an emergency seven days a week, 24 hours a day:

Toll Free - 800-413-9083
South Bend - 574-243-3100
Plymouth - 574-935-4511
Elkhart - 574-264-3321

3. Patients have the right to exercise all civil and religious liberties.
4. Patients have the right to be advised that CHAPC 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 our commitment to quality care. Services are never terminated due to an inability to pay for care rendered.
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 CHAPC when they are not able to keep a home care appointment.
5. Patients have the responsibility to ask questions if they do not understand instructions or information given to you.
6. Patients have the responsibility to assist CHAPC 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.

EXPLANATION AND CONSENT

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

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

FINANCIAL EXPLANATION FOR THE HOSPICE MEDICARE BENEFIT

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 us to be related and appropriate for comfort care are paid for by us 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 us**. The patient/family is encouraged to contact us 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 us** under regular Home Health Medicare, if he/she meets those admission requirements. Some medical supplies, which were covered by us 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 we stop care visits due to a patient's inability to pay or qualify for an insurance program.

Should the 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 us anytime, 24 hours per day, 7 days a week to ask questions regarding what expenses are and are not covered under the HMB program.

HOSPICE BENEFITS UNDER MEDICARE

Routine Hospice Home Care

Services are provided on a scheduled basis by the Team, which includes the patient's own physician and/or the Medical Director, nurses, social workers, spiritual care counselors, hospice 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 hospice 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 hospice aide services may supplement the nursing care.

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

HOSPICE DISCLOSURE STATEMENT

The Center for Hospice and Palliative Care, Inc. (CHAPC) 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, CHAPC recognizes that patients and their families have a number of rights. These rights include: participation in the planning of the patient's care, being advised of any change in the plan of care, being advised of the frequency of visits proposed to be furnished, 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, CHAPC provides the following core services:

- Physician services;
- Nursing services;
- Medical Social Work services;
- Counseling services
 - Spiritual Care Counseling
 - Bereavement Counseling
- Volunteer services

Services available during the progressive stages of the terminal illness, as determined by the interdisciplinary team (IDG) include:

- **Routine Home Care** - hospice services are delivered primarily in the home, which may include a nursing home or assisted living facility.

- **General Inpatient Care** - short term stay in an inpatient bed for symptom management and pain control.
- **Inpatient Respite Care** - is available up to five consecutive days to provide a rest for the family or caregiver from the physical and emotional strain of caring for the patient.
- **Continuous Care** - (minimum of 8 hours in a 24 hour period) is designed for short term periods to manage acute medical symptoms with the goal of stabilizing the patient.

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

- Physical therapy;
- Occupational therapy;
- Speech-language pathology;
- Hospice Aide/Homemaker;
- Nutritional counseling;
- Short term inpatient/respite care.

As part of its mandate for patient care, CHAPC 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 CHAPC 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 CHAPC and the patient before the provision of services and supplies begins.

A CHAPC employee may provide supplies to a hospice patient or their family in addition to the supplies provided by the hospice program, but the CHAPC employee may only be reimbursed for the supplies by providing a written receipt to the patient or patient's family. The patient may request CHAPC provide, on a monthly basis, an itemized statement of services and supplies delivered to the patient, as submitted to the patient's payor.

All services and supplies shall be dispensed to the patient based solely on that

individual's needs as determined by the interdisciplinary team and pursuant to a physician's orders. The patient has the right to refuse any component of the hospice's services or supplies.

If a patient, his/her family or his/her legal representative disagrees with a service provided or action taken by CHAPC, 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 CHAPC 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 CHAPC 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 CHAPC 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, CHAPC 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 CHAPC 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.

CHAPC 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 CHAPC may be addressed by calling the Department's toll-free number: 1-800-227-6334.

HOMEBOUND REQUIREMENT

Home Health Program

The Center for Hospice and Palliative Care, Inc. is required to inform you as a recipient of **Medicare Home Health Care** services of the requirement to be “confined to the home.” You may also hear this referred to as being “homebound.”

The Social Security Act of 2003 states: An individual shall be considered to be “confined to his home” if that individual has a condition, due to illness or injury, that restricts the ability of the individual to leave his or her home except with the assistance of another individual or the aid of a supportive device (such as crutches, a cane, a wheelchair, or a walker), or if the individual has a condition such that leaving his or her home is contraindicated. While an individual does not have to be bedridden to be considered “confined to the home,” the condition of the individual should be such that there exists a normal inability to leave the home or the leaving the home requires a considerable and taxing effort.

The staff from our CHAPC will be continually assessing how your condition relates to this regulation. Please ask our staff if you ever have any questions.

HOW CAN YOU HELP?

Many families ask how they can help **The Center for Hospice and Palliative Care, Inc.** (CHAPC). 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 the services offered by our CHAPC to share information regarding our programs. Your testimonial is of great value to The Center for Hospice and Palliative Care—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 our care. If you are not comfortable speaking to groups, we offer a volunteer **Speaker's Bureau** that can deliver your message 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 our care. Share stories of how our service has helped your family. Let them know our service is a gift they can give their terminally ill patients and tell your loved one's physician that you appreciate their support of our care.

BECOME A VOLUNTEER

Many volunteers become involved with CHAPC because a loved one has received our 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 our services 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 CHAPC 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 **The Center for Hospice and Palliative Care, Inc.** 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.

The **Walk For Hospice** takes place on the second Sunday in October. We count on our 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 us, 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 **The Center for Hospice and Palliative Care, Inc.** We would appreciate your support of these events and the businesses that are so generous in giving.

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 **The Center for Hospice and Palliative Care, Inc.** In planned giving, the donor makes a decision to now to make a gift, 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

DONATED SUPPLIES – COMMUNITY RESOURCES

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 CHAPC of some of the agencies and organizations that will accept a variety of items. Although we are always appreciative of donations, we cannot accept these items because we are not licensed as a durable medical equipment supplier or pharmacy. We recommend that you contact CHAPC or organization prior to making the donation.

ST. JOSEPH COUNTY

Disability Rights Commission
3812 York Street
Mishawaka, IN 46544
574-255-1333

bath seats, commodes, crutches, canes,
walkers, toilet side rails, Jevity or food
supplements, insulin, vitamins, syringes.
No narcotics.

Dujarie House
Brothers of Holy Cross
Notre Dame, IN 46556
574-287-1839

walkers, wheelchairs, canes, crutches

Indiana Health Center
1901 W Western Avenue
South Bend, IN 46619
574-234-9033 ext 139

oncology supplies, wheelchairs, crutches,
canes, unopened medications (also accept
open, but will throw away)

Muscular Dystrophy Assoc.
314 W Catalpa Drive
Mishawaka, IN 46545
574-259-9912

walkers, wheelchairs, lifts, DME,
hospital beds

Portage Manor
53308 Portage Road
South Bend, IN 46628
574-272-9100

walkers, canes, commodes, bath seats,
incontinent supplies (will pick up)

Riverbend Cancer Services

wheelchairs, walkers, commodes, canes,

919 E Jefferson, Ste 401
South Bend, IN 46617
574-287-4197
Contact: Judy Cobb

raised toilet seats, crutches, ostomy
supplies, urostomy pouches & wafers,
hearing aids, syringes, lancets, unopened
insulin, Depends, incontinent products,
wound care products, Saline, insulin.
No hospital beds.

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

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

VFW Post 1167
1047 Lincoln Way East
South Bend, IN 46601
574-287-8144

wheelchairs, walkers, canes, crutches,
commodes

VFW Post 360
1307 E Jefferson Blvd
Mishawaka, IN 46545
574-255-4125

canes, walkers, wheelchairs, commodes

ELKHART COUNTY

Diabetic Youth Foundation
c/o The Bookworm
707 Bower Street
Elkhart, IN 46514
574-293-5281

insulin, glucometer test strips

Faith Mission
801 Benham Ave
Elkhart, IN 46516
574-293-3406

Unopened over-the-counter medications,
bandages, diabetic supplies, nebulizer meds,
Depends, nutritional drinks

Maple City Health Care
213 Middlebury St
Goshen, IN 46528
574-534-3300

Medications, with exception of narcotics
as long as they are in original packaging,
including open meds, oxygen tubing

Wheel Chair Help
1201 Richmond St
Elkhart, IN 46516
574-295-2230

All DME including motorized wheelchairs,
elec. scooters, elec. lift chairs, adult diapers,
incontinent supplies

United Cancer Services
2397 US 33 East
Elkhart, IN 46517
574-875-5158

Ensure, Walkers

United Labor Agency for
Community Services
3322 Middlebury Street
Elkhart, IN 46516
574-522-2899

Wheelchairs, large DME
Call ahead prior to dropping off items

Church Services International
574-293-4366

(sends supplies to developing countries)
syringes, gloves, tape, opened diapers, colostomy
supplies, diabetic supplies, vitamins
No medications
Call in evening to arrange pickup

Heart City Health Center
236 Simpson Ave., Elkhart
574-293-0052
Unopened medications

Maple City Health Care Center
213 Middlebury St, Goshen
574-534-3300
Unopened medications

MARSHALL COUNTY

American Legion
1040 E Jefferson St
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,
commodes, shower chairs
lift 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
diapers, Depends

Salvation Army
113 Water Street, Plymouth
574-936-8822
sheets, blankets, wheelchairs,
shower chairs, commodes,
walkers, canes

St. Joseph's Health Care Center
116 E Washington Street
Plymouth, IN 46563
800-854-5312
574-941-2264
wheelchairs, canes, walkers
no medications

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

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

wheelchairs, walkers

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