



Center for
Hospice Care

choices to make the most of life™

Patient/Family Handbook for Hospice Care

Toll Free: 1-800-HOSPICE
(1-800-467-7423) Only in
CHC's servicearea

- Elkhart Office
Phone: (574) 264-3321
- Plymouth Office
Phone: (574) 935-4511
- South Bend Office
Phone: (574) 243-3100
- La Porte Office
Phone: (219) 575-7930
- Life Transition Center
Phone: (574) 255-1064

STATEMENT OF CONFIDENTIALITY

This booklet may contain protected health information.
Persons other than you and your health care providers
must have your permission to view this booklet.

Revision Date March 2018

OFFICE HOURS

Our office hours are Monday through Friday from 8:00 a.m. to 5:00 p.m. You may reach us by calling **the number checked on the front or back cover of this booklet.**

Issues that are handled during regular office hours:

- Medication refills
- Messages for the primary nurse:
 - You need the nurse to bring or order supplies (adult diapers, Chux, etc.)
 - Questions about your visit schedule
- Calls for social worker, spiritual counselor or other hospice staff
- Lab or bloodwork results
- Questions about the hospice aide or volunteer

SERVICE AREA

Center for Hospice Care's service area includes the counties of Elkhart, Fulton, Kosciusko, LaPorte, LaGrange, Marshall, Porter, St. Joseph, and Starke.

ON-CALL GUIDELINE

Center for Hospice Care (CHC) wants you to know that you are never alone with your concerns. Because a patient's condition may change at any time and you may have important caregiving questions, we have nurses on call 24 hours a day, seven (7) days a week. After 5:00 p.m. or on weekends and holidays, your call will be answered by our Triage Nurse. The Triage Nurse is available to answer questions, assist with symptom management, or have one of our on-call staff come visit you at your home. Please do not hesitate to call at any time.

Calling the Physician

- Patients and families are asked to call the CHC nurse before calling the physician. In most situations nurses will be able to answer your question, help you decide whether to call the physician, or can call the physician 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 deciding if you need to go to the hospital. It's likely our nurse will 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 you need to go to the hospital, the nurse can assist you to make sure the transition is as smooth as possible. Staff can also advise you on insurance requirements so that insurance coverage is not interrupted.

Examples of after hour situations:

- Pain that does not respond to pain medication on hand
- Difficulty breathing
- New onset of agitation or restlessness
- Falls where possible injury has occurred
- No urine in eight (8) hours associated with discomfort
- Uncontrolled nausea, vomiting or diarrhea
- Uncontrolled bleeding
- Temperature above **101°F** that does not respond to Tylenol®. **Note:** Patients on chemotherapy may be instructed to call before taking Tylenol®.
- Unable to awaken patient (new problem)
- Catheter leaking
- Chest pain
- Patient taken to the hospital
- Patient death

If the Triage Nurse is on another call, please leave your NAME and PHONE NUMBER on our voicemail and we will return your phone call as soon as possible.

The Triage Nurse has access to your information in our electronic medical record. He/she receives daily updates on all patients we serve, and will help answer your questions and concerns.

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SECTION 1 – Welcome, Mission and Philosophy

Center for Hospice Care (CHC) 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, CHC:

- 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 insurance and commercial insurance payments. No eligible 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.
- Places focus on comfort care for those who are no longer seeking curative treatment.

CHC is licensed in the state of Indiana. We are committed to ensuring your rights and privileges as a hospice patient. We have written this booklet to help you better understand hospice care. If you have additional questions, please do not hesitate to ask us.

Respectfully,
The Management and Staff of Center for Hospice Care



OUR MISSION

To improve the quality of living

OUR VALUES

Compassion

Dignity

Innovation

Integrity

Quality

Service

Stewardship

OUR VISION

To be the premiere hospice and palliative care organization for all end-of-life issues.

LANGUAGE ASSISTANCE SERVICES

Attention: Language assistance services are available free of charge. Please call your nurse or social worker at (574) 243-3100.

Spanish

Atención: si habla español, dispone de servicios gratuitos de asistencia de idiomas. Por favor, llame a su enfermero o trabajador social al (574) 243-3100.

Chinese

注意：如果您講中文，可免費為您提供語言協助服務。請致電(574) 243-3100 聯絡您的護士或社工。

German

Hinweis: Wenn Sie Deutsch sprechen, können Sie unser kostenloses Angebot zur fremdsprachlichen Unterstützung nutzen. Rufen Sie dazu Ihre Pflegekraft oder Ihren Betreuer an unter (574) 243-3100.

Pennsylvania Dutch

Gebt Acht: Wann du Pennsylvaniaisch Deitsch schwetzscht, Schprooch Hilfe, mitaus Koscht, kannscht du griege. Sei so gut un ruff dei Nurse odder Social Worker uff (574) 243-3100.

Burmese

သတိပြုရန် - အကယ်၍ သင့်သည် ဗမာစကားပြောတတ်ဆိုင်သူများအတွက် သဘောအတိုင်း တာဝန်ယူပေးသည့် အကူအညီအဖွဲ့အစည်းများအား အခမဲ့ ရရှိစေရန်အတွက် ပေးပါသည်။ သင့်၏ သူနာပြု သို့မဟုတ် လူမှုရေး လုပ်ငန်းစဉ် (574) 243-3100 သို့ ကော်ဖီးပေးသည့်အားဖြင့် ဆက်သွယ်ပါ။

Arabic

تنبه: إذا كنت تتحدث اللغة العربية، يمكنك الاستفادة من خدمات المساعدة اللغوية مجاناً. يرجى الاتصال بـ (574) 243 3100 مرقاً على عكس الخاصات ماعية الـ ج ي صائ الأ أو (574) 574 243 3100

Korean

알림: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 담당 간호사나 사회복지사에게 (574) 243-3100 번으로 전화해 주십시오.

Vietnamese

Lưu ý: Nếu bạn nói tiếng Việt, chúng tôi sẽ cung cấp dịch vụ hỗ trợ ngôn ngữ miễn phí cho bạn. Vui lòng gọi cho nhân viên công tác xã hội hoặc y tá của bạn theo số (574) 243-3100.

French

Attention : si vous parlez français, vous pouvez bénéficier de services d'aide linguistique gratuits. Veuillez contacter votre infirmier/infirmière ou votre assistant(e) social(e) au numéro suivant : (574) 243-3100.

Japanese

注意: 日本語の通訳サービスを無償でご利用いただけます。看護師またはソーシャルワーカーと日本語でご相談される場合は、(574) 243-3100までお電話ください。

Dutch

Let op: Als u Nederlands spreekt, is er gratis taalassistentie voor u beschikbaar. Bel uw verpleegster of sociaal werker op

(574) 243-3100.

Tagalog

Atensyon: Kung nagsasalita ka ng Tagalog, ang serbisyong tulong para sa wika, walang bayad, ay maaari para sa iyo. Mangyaring tawagan ang iyong nurse o social worker sa (574) 243-3100.

Russian

Внимание! Если Вы говорите на русском языке, Вам могут быть бесплатно предоставлены услуги переводчика. Позвоните своей медсестре или закрепленному за Вами социальному работнику по телефону (574) 243-3100.

Punjabi

ਠਿ ਧਆਨ ਠਿ ਦਓ: ਜੇ ਤੁਸ ਪੰਜਾਬੀ ਬੋਲਦੇ ਹੋ ਤ ਤੁਹਾਡੇ ਲਈ ਮੁਫਤ ਭਾਸ਼ਾ ਸਹਾਇਤਾ ਸੇਵਾਵ ਉਪਲੱਬਧ ਹਨ। ਠਿ ਕਰਪਾ ਕਰਕੇ (574) 243-3100

'ਤੇ ਆਪਣੇ ਨਰਸ ਜ ਸਮਾਠਿ ਜਕ ਕਾਰਜਕਰਤਾ ਨ ਠਿ ਕਾਲ ਕਰੋ।

Hindi

ध्यान दः यद आप हंद बोलते ह तओ आप के लए नःशुल्क भाषा सहायता सेवाएं उपलब्ध ह। कृपया (574) 243-3100 पर

अपने नर्स या सामाठि जक कायककतार् को फोन कर।

SECTION 2 – Hospice Overview

POLICIES

This book contains general information regarding your rights and responsibilities as a patient. As state and federal regulations change there may be additions or changes to this book as necessary.

CRITERIA FOR ADMISSION

Admission to our hospice program may be made upon the recommendation of your physician and is based upon your needs. Normally, appropriate candidates for hospice are patients:

- With a life expectancy of six (6) months or less if the illness runs its normal course;
- Who desire palliative treatment (comfort care);
- Who want to stay at home as long as possible; and
- Who have a primary care person.

On admission, our nurse will visit you or your family to discuss hospice services, assess your immediate needs and recommend a plan of care.

If we cannot meet your needs, either directly by our hospice or indirectly through service agreements with other providers, we will not admit you or will not continue to provide services to you.

HOSPICE CONCEPT

What is Hospice?

Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

Why Hospice?

- Hospice treats you, not the disease. The focus is on care, not cure. You and your family's medical, social, emotional and spiritual needs are addressed by a team of hospice professionals and volunteers.
- Hospice considers your entire family, not just you, as the "unit of care." You and your family are included in the decision-making process. Hospice will help you and your family make choices about end-of-life issues and enable you to have greater control over these choices. Bereavement counseling is provided to your family for up to 13 months after your death.
- Hospice offers palliative (comfort care), rather than curative treatment. Hospice will provide care and comfort when cure is no longer an option. Through ever advancing technology, pain and symptom control will enable you to live as fully and comfortably as possible.
- Hospice emphasizes quality, rather than length of life. Hospice neither hastens nor postpones your death. It affirms life and regards dying as a normal process.

SERVICES

Hospice services include **Nursing, Social Services, Physician Services, Hospice Aide, Physical, Occupational and Speech Therapy, Volunteer Services and Spiritual and Bereavement Counseling**. All services are provided under the direction of your attending physician and/or the Hospice Physician.

Arrangements will be made for hospice approved medications, medical supplies and equipment, as appropriate.

THE CHC TEAM

CHC works together as a team to meet the physical, emotional and spiritual needs of the patients and families in our care. You, your caregiver and your 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 and your family. The following are the primary team members and how they can assist with your care and concerns.

Hospice Physician

The Hospice Physician 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 your own physician, but works as a member of the hospice team in overseeing the delivery of quality care to all hospice patients.

The Hospice Physician's services and responsibilities may include:

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

Nurse

A Registered Nurse will admit you into our hospice services. They will make sure that you understand the hospice philosophy, how hospice functions and how the on-call system works, as well as answer any other questions that you have. They will assess for symptoms and help manage them, document your medications and complete a physical assessment. A case manager who is a Registered Nurse will be assigned following the first home visit. Your case manager will coordinate your care, along with other nurses participating in your care, family and/or significant other, your physician and the team.

Some practical areas of involvement may include:

- Initiating your plan of care.
- Monitoring your changing condition, especially in pain management, symptom control and reporting changes to the physician.

- Teaching your 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/home health aides when assistance is needed for personal care.

Social Work

A social worker is part of every team and will meet with you and your family to assess your non-medical needs. The social worker is directly linked not only with you, but with all of your family members. This effort is to maximize the quality of life for you 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 you and your caregiver recognize your abilities, despite increased limitations.
- Discussing ways for caregivers to care for themselves.
- Utilizing community resources that provide helpful services not provided by CHC.
- 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.
- Assisting with setting up a Health Care Representative and a Power of Attorney.

Hospice/Home Health Aide

The hospice/home health 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.
- Assisting with mouth care.
- Providing skin care.
- Changing bed linens.
- Assisting in maintaining a safe and healthy environment.

Physical, Occupational and Speech Therapists

Services are provided by a licensed therapist or licensed therapy assistant under the direction of the therapist. Therapy services may be provided only as reasonable and necessary for symptom control or to enable you to maintain activities of daily living and basic functional skills in accordance with the hospice philosophy. These services must be approved by the Hospice Interdisciplinary Group (IDG), and may not be appropriate for all hospice patients.

Volunteers

Volunteers are a valuable resource to you and your family. Volunteers come from diverse backgrounds and lifestyle situations, and have a common thread of caring and compassion. They are an important part of our CHCteam.

Our volunteers complete a comprehensive patient care training program to assist them in providing quality care for you.

Some of the services our patient care volunteers provide are:

- Respite care for your caregiver by staying with you, which provides relief for your family/caregiver.
- Companionship.
- Assisting with transportation and errands.
- Reading to, or writing letters for you.
- Assisting with personal care.
- Assisting with light housekeeping.
- Preparing and feeding you light meals in your home, as needed.

Volunteers are available for visits in the home 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. Ideally, the same volunteer(s) will remain with your family for as long as you and your family require our services. If you would like a volunteer, simply ask any staff person, or call the Volunteer Coordinator at the **phone number checked on the front or back cover of this booklet.**

Tuck-In Program

CHC provides a supportive service in which volunteers contact you and/or your caregivers every Thursday, on behalf of our nursing staff, to learn if there are any needs to be met in order for you to get through the upcoming weekend. Volunteers will let staff know if medical equipment, supplies and/or medications are needed. All requests will be taken care of, so you are "tucked-in" and have everything you need to get through the weekend.

Please contact your Case Manager if you have any questions about our Tuck-In Program.

Spiritual Care

The chaplain is part of every hospice care team. As we all work together to ensure the quality of your life, spiritual care touches your innermost spirit, assisting you to find the freedom to accept all phases of your life - the past, the present and the future.

A chaplain is a theologically and clinically trained individual available to you and your family members. You will find the chaplain to be accepting and open to all beliefs. Services are offered in addition to your own clergy or spiritual resources. Spiritual care is focused on you as an individual and 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 your illness.

Some spiritual areas of involvement may include:

- Notifying your clergy of your involvement with our services.
- Helping find clergy of a particular denomination, and/or spiritual support within the community, if you or your family members so choose.
- Identifying and resolving any spiritual concerns affecting you and your family.
- Assisting 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.

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 innerhealing.

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 Life Transition Center at (574) 255-1064.

LEVELS OF HOSPICE CARE

Routine Home Care: Care is provided intermittently by hospice team members in the patient's or family's home or in a nursing care facility.

General Inpatient Care: Care is provided at one of our inpatient units, a hospital or skilled nursing facility contracted by CHC for patients who need pain control or acute/chronic symptom management which cannot be managed in other settings. The necessity for inpatient care and paid length of stay will be determined by the hospice interdisciplinary team. If a hospice patient needs hospitalization for any reason unrelated to the terminal diagnosis, traditional Medicare Part A will be utilized.

Inpatient Respite Care: Up to five (5) days of respite care at one of our inpatient units, a hospital, or nursing care facility contracted by CHC will be paid by hospice, if approved by the hospice interdisciplinary team. This benefit may be used to give the family/caregiver a rest and the patient does not need to meet acute care standards.

Continuous Home Care: A minimum of eight (8) hours of care per day may be provided during periods of crisis to maintain the patient at home. Criteria for continuous home care are the same as general inpatient care and consist predominantly of nursing care; however, hospice aides may also supplement nursing care.

How is the Hospice Care Program different from the Home Health Care Program?

- The Hospice Care Program offers comfort care for patients with a terminal diagnosis, that have stopped life-prolonging treatment and that may have a life expectancy of six months or less.
- Medications, supplies and durable medical equipment related to the terminal diagnosis will be ordered and paid for by CHC.
- The patient's personal physician will be a part of the care team, along with the CHC Hospice Physician.
- There is no homebound condition.
- CHC offers four different levels of care for patients and caregivers.

All of our patients, in either program, have access to our team, which includes the patient's own physician and/or the CHC Hospice Physician (hospice only), nurses, hospice/home health aides, social workers, and Chaplains (hospice only).

Emergency care is available 24 hours a day, seven (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 CHC are always just a phone call away.

MEDICARE HOSPICE BENEFIT

Medicare will reimburse the cost of hospice care under your Medicare Hospital Insurance (Part A). When all requirements are met Medicare will cover the following:

Services Covered Under the Medicare Hospice Benefit (if included in the plan of care)	Services Not Covered Under the Medicare Hospice Benefit
<ul style="list-style-type: none"> • Physician services • Nursing care • Medical appliances and supplies • Medications for symptom management and pain relief of the terminal illness and related conditions (must be pre-approved by hospice) • Short-term inpatient care for pain and symptom control • Hospice Aide • Spiritual counseling • Bereavement counseling • Physical therapy, occupational therapy, speech therapy • Medical social services • Dietary counseling • Volunteer services • Short-term respite care 	<ul style="list-style-type: none"> • Treatment for the terminal illness which is not for palliative symptom management and <u>is not within</u> the hospice plan of care • Care provided by another hospice that was not arranged by the patient's hospice • Ambulance transportation not included in the plan of care • Medications that are not related to the terminal illness • Visits to the emergency department without the prior approval or arrangements by hospice • Inpatient care at non-contracted facilities • Sitter services/hired caregivers • Admission to the hospital without the prior approval or arrangements by hospice • Lab studies, medical testing and/or any treatments not indicated

If you are receiving care under the Medicare Hospice Benefit, Medicare requires that no more than 30 days prior to the beginning of the third benefit period (180 days) and prior to each subsequent benefit period, a hospice physician or nurse practitioner must conduct a face-to-face visit with you to determine continued eligibility for hospice care. If you refuse to allow the face-to-face visit, you will no longer be eligible to receive hospice care under the Medicare Hospice Benefit.

If you have Medicare Part D coverage, we will work with your physician and pharmacy to determine which medications we will cover under the Medicare Hospice Benefit, which medications will be covered under your Part D plan and which medications are determined to be no longer medically necessary and if continued, would become your financial responsibility. If you disagree with any drug coverage determination, you may appeal the decision through the Medicare fee-for-service appeals process, Part D appeals process or submit a complaint with a Medicare-contracted Quality Improvement Organization (QIO). Please ask your hospice representative if you need assistance with any of these steps.

CHARGES

In most cases, your insurance company will pay hospice directly; however, not all insurance plans provide full coverage for hospice care and some hospice services may not be covered under your plan. We receive our reimbursement from Medicare, Medicaid and private health insurance for services. All third party payers are billed for hospice services as appropriate.

All patients, who meet the requirements, are accepted regardless of ability to pay. Medicare or Medicaid patients will not be refused care or have their hospice care discontinued or reduced due to their inability to pay for that care. Our social worker will meet with the patient/family to determine concerns and needs.

Should any change be made in this policy regarding services or charges, you or your responsible party will be advised. Please call our office if you have questions about charges or insurance billing.

PLAN FOR CARE, TREATMENTS AND SERVICES

Our hospice involves key professionals and other staff members in developing your individual plan of care, which is based upon identified problems, needs and goals, physician orders for medications, treatments and care, your environment and your personal wishes whenever possible. Effective pain management is an important part of your treatment plan.

The plan includes five basic areas:

- Physical care
- Spiritual needs
- Bereavement care
- Personal care and comfort
- Psychosocial needs

The plan is reviewed and updated as needed, based on your changing needs. We encourage your participation and will provide necessary medical information to assist you. You have the right to refuse any medication or treatment procedure; however, such refusal may require us to obtain a written statement releasing the agency from all responsibility resulting from such action. Should this happen, we would encourage you to discuss the matter with your physician for advice and guidance.

On admission, you and a nurse will create a list of your current medications (including any over-the-counter medications, herbal remedies, and vitamins). We will compare this list to the medications ordered by your physician. Our staff will continue to compare the list to the medications that are ordered, administered or dispensed to you while under our care. This will be done to resolve any discrepancies (such as omissions, duplications, contraindications, unclear information, potential interactions and changes).

We fully recognize your right to dignity and individuality, including privacy in treatment and in the care of your personal needs. We will always notify you if an additional individual needs to be present for your visit for reasons of safety, education, or supervision. Prior to anyone visiting your home, we **will ask your permission. You have the right to refuse any visitors and this** will not compromise your care in any way.

We do not participate in any experimental research connected with patient care except under the direction of your physician and with your written consent.

There must be a willing, able and available caregiver to be responsible for your care between hospice visits. This person can be you, a family member, a friend, or a paid caregiver.

MEDICAL RECORDS

Your medical record is maintained by our staff to document physician orders, assessments, progress notes and treatments. Your records are kept strictly confidential by our staff and are protected against loss, destruction, tampering or unauthorized use. Our Notice of Privacy Practices describes how your protected health information may be used by us or disclosed to others, as well as how you may have access to this information.

DISCHARGE, TRANSFER AND REFERRAL

Discharge, transfer and referral from hospice may result from several types of situations including the following:

- The hospice determines that you are no longer terminally ill;
- You move out of the hospice's service area;
- You are receiving treatment for a medical condition unrelated to the terminal illness or related conditions in a facility with which the hospice does not have a contract and is unable to access you to provide hospice services;
- You transfer to another hospice;
- Your behavior (or situation) is disruptive, abusive or uncooperative to the extent that delivery of your care or the ability of the hospice to operate effectively is seriously impaired;
- Issues of patient or staff safety cannot be resolved; and/or
- You or a family member request to end (revoke) the services of the hospice.

You will be given a timely advance notice of a transfer to another agency or discharge, except in case of emergency. If you are referred, transferred or discharged to another organization, we will provide them with a list of your current medications and information necessary for your continued care, including pain management.

If you are discharged because you are no longer considered to be terminally ill, we will provide any necessary family counseling, patient education or other services as needed.

All transfers or discharges will be documented in the medical chart on a discharge summary. When a discharge occurs, an assessment will be completed and instructions will be provided for any needed ongoing care or treatment. We will coordinate your referral to available community resources as needed.

Notice of Medicare Non-Coverage: You or your authorized representative will be asked to sign and date a Notice of Medicare Non-Coverage at least two days before your covered Medicare services will end. If you or your authorized representative is not available, we will make contact by phone, and then mail the notice. If you do not agree that your covered services should end, you must contact the Quality Improvement Organization (QIO) at the phone number listed on the form no later than noon of the day before your services are to end and ask for an immediate appeal.

EXPERIENCE OF CARE/PATIENTS SATISFACTION SURVEYS

Our hospice has contracted with Press Ganey Associates, a vendor approved by the Centers for Medicare and Medicaid Services (CMS) to perform mandatory Consumer Assessment of Health Care Providers and Systems (CAHPS) surveys. The survey considers you and your primary caregiver as a unit of care. Press Ganey Associates may contact your caregiver or family member by mail or telephone after your death to evaluate the experience of care and services you and your loved ones received from our hospice agency.

Our patients are very important to us. Please ask questions if something is unclear regarding our services or the care you receive or fail to receive. Our hospice agency may also contact you, your caregiver or family at intervals to assess your satisfaction with the care and services we are providing. We will not ask the same questions included in the CAHPS survey. Your answers will help us to improve our services and ensure that we meet the needs and expectations of our patients and families.

PROBLEM SOLVING PROCEDURE

We are committed to ensuring that your rights are protected. If you feel that our staff has failed to follow our policies or has in any way denied you your rights, please follow these steps without fear of discrimination or reprisal:

1. If a patient, his/her family or his/her legal representative disagrees with a service provided or action taken by CHC, 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 CHC staff member. This form should be completed and returned directly to the President/CEO in the self-addressed stamped envelope provided, or, a patient and/or his/her family may call the CHC office at **(574) 243-3100 or toll-free at 1-800-413-9083**, 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 CHC administration receives the formal complaint, it will initiate an internal investigation. Based on that investigation, a brief report of the allegations will be written, whether those allegations were substantiated, and what action, if any, CHC 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 CHC 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.

2. CHC 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 CHC may be addressed by calling the Department's toll-free hotline number at **1-800-227-6334**. The state's home care hotline operates from 8:00 a.m. to 4:30 p.m. If voicemail answers, please leave a message and your call will be returned. The purpose of the hotline is to receive complaints or questions about local home health/hospice agencies and to lodge complaints concerning the implementation of advance directive requirements.

NOTICE OF NON-DISCRIMINATION / FILING A GRIEVANCE

CHC complies with applicable federal civil rights laws and does not discriminate, exclude or treat people differently on the basis of race, color, religion, sexual orientation, gender identity, national origin, age, or disability with regard to admission, access to treatment or employment.

CHC provides free aids and services to people with disabilities to communicate effectively with us, including free language services to people whose primary language is not English. If you need these services, please contact the nurse or social worker on your hospice team.

If you believe that CHC has failed to provide these services or discriminated in any other way, you may file a grievance in person or by mail or email by using the contact information listed below. Please contact our Chief Operating Officer at: Chief Operating Office, 111 Sunnybrook Court, South Bend IN 46637 or email nondiscrimination@cfhcare.org.

It is the law for CHC not to retaliate against anyone who opposes discrimination, files a grievance, or participates in the investigation of a grievance.

Grievances must be submitted to CHC within 60 days of the date you become aware of the possible discriminatory action, and must state the problem and the solution sought. We will issue a written decision on the grievance based on preponderance of evidence no later than 60 days after its filing, including a notice of your right to pursue further administrative or legal action. You may also file an appeal of our decision in writing to our President/CEO within 15 days. Our CEO will issue a written response within 30 days after its filing. Contact: President/CEO, 501 Comfort Place, Mishawaka IN 46545.

Additionally, you may file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at:

<https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, or by mail or phone at: U.S. Department of Health and Human Services, 200 Independence Avenue, SW, Room 509F, HHH Building, Washington, DC 20201. 1-800-368-1019, 1-800-537-7697 (TDD). Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.

SECTION 3 – Patient Rights and Responsibilities

All patients under the care of CHC 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. CHC 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.

YOUR RIGHTS

DIGNITY AND RESPECT - YOU HAVE THE RIGHT TO:

- Receive effective pain management and symptom control from CHC for conditions related to your terminal illness(es) regardless of race, age, gender, creed, national origin, disability, marital status, sexual orientation, source of payment or ability to pay for services rendered.
- Receive training about your role and your family's role in managing pain when appropriate, as well as potential limitations and side effects of pain treatments.
- CHC personnel treat your property with respect.
- Designate a representative to exercise your rights to the extent allowed by state law should you become incompetent.
- Be free from mistreatment, neglect, verbal, mental, sexual and physical abuse, injuries of unknown source and misappropriation of your property. All mistreatment, abuse, neglect, injury and exploitation complaints by anyone furnishing service on behalf of hospice are reported immediately by our staff to the hospice administrator. All reports will be promptly investigated and immediate action taken to prevent potential violations during our investigation. Hospice will take appropriate corrective action in accordance with state law. All verified violations will be reported to the appropriate state/local authorities, including the state survey and certification agency, within five (5) working days of becoming aware of the violation.
- Be free from physical and mental abuse, corporal punishment, restraint or seclusion of any form imposed as a means of coercion, discipline, convenience or retaliation by staff while receiving care in a hospice-operated inpatient facility.
- Voice grievances regarding treatment or care that is (or fail to be) furnished, and regarding the lack of respect for your property by anyone furnishing services on behalf of CHC. You may call the CHC 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. If you feel that you

have been the victim of discrimination, you have the right to file a grievance without retaliation for doing so.

- 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 advance directives requirements for Medicare home health/hospice agencies such as CHC. The hotline operates during the hours of 8:00 a.m. to 4:30 p.m., Monday through Friday and can be reached at **1-800-227-6334** (toll-free). Voicemail is used to record calls after office hours (i.e., evenings, weekends, holidays). All complaints will be investigated.

DECISION MAKING - YOU HAVE THE RIGHT TO:

- Be informed about the services CHC provides and specific limitations of these services.
- 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.
- Participate in developing your plan of care, and be advised of changes in that plan prior to making changes, including reasonable discharge notice.
- Choose your attending physician, as well as request a change in a CHC caregiver (or health care agencies) without fear of reprisal or discrimination.
- Receive written information by you and/or your family in advance regarding your rights to accept or refuse treatment and to make advance directives.
- Have your wishes concerning end of life decisions addressed and to have health care providers comply with your advance directives in accordance with state laws.
- Refuse or discontinue services and/or treatment(s) and be informed of the consequences of refusing or discontinuing care.
- Be advised that CHC or your physician (with reasonable notice) may be forced to refer you to another source of care if your refusal to comply with the plan of care threatens to compromise CHC's commitment to quality care. Services are never terminated due to a person's inability to pay for care rendered.

PRIVACY - YOU HAVE THE RIGHT TO:

- Confidentiality with regard to information about your health status, social or financial circumstances, and about what takes place in the home setting.
- Be advised that CHC 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 your prior consent.
- Right to access your clinical records, unless certain exceptions apply by you or your legal representative. You shall be advised of CHC's policies and procedures regarding the accessibility of clinical records.
- Restrict visitors or have unlimited contact with visitors and others and to communicate privately with these persons if you are residing in an inpatient hospice facility.
- Request us to release information written about you only as required by law or with your written authorization.

FINANCIAL - YOU HAVE THE RIGHT TO:

- Be advised before care is initiated of the extent to which payment for services rendered by CHC may be expected by Medicare, Medicaid or any other federally funded or aided program to CHC.
- Be informed of any charges that will not be covered by Medicare or other sources.
- Be informed of any charges for which you may be liable.
- 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 CHC becomes aware of a change.
- Access, upon request, all bills for services the patient has received, regardless of whether they are paid out-of-pocket or by another party.
- Be informed of the ownership status of CHC and its affiliation with any entities to whom the patient is referred.
- 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 that have an ownership or control interest in CHC.

PATIENT CARE - YOU HAVE THE RIGHT TO:

- Appropriate and compassionate care regardless of race, age, gender, creed, national origin, disability, marital status, sexual orientation, source of payment or the ability to pay for services rendered.
- Be advised to call CHC in the event of an emergency seven days a week, 24 hours a day **by calling the phone number checked on the front or back cover of this booklet.**
- Have an environment within the Inpatient unit that preserves dignity and contributes to a positive self-image.
- Exercise all civil and religious liberties.

PATIENT RESPONSIBILITIES - YOU HAVE THE RESPONSIBILITY TO:

- Provide complete and accurate information about all matters pertaining to your health.
- Treat staff with respect.
- Provide a safe environment for which care is to be given.
- Inform CHC when you are not able to keep a home care appointment.
- Ask questions if you do not understand instructions or information given.
- Assist CHC with billing and/or payment issues to help process third party payments.
- Identify a medical Power of Attorney, Health Care Representative or another individual authorized to make medical determinations on your behalf in the event you are unable to do so.

NOTICE OF PRIVACY PRACTICES

This notice describes how medical information about you may be used and disclosed and how you can get access to this information. Please review it carefully.

I. Our Pledge to You.

Your health information -- which means any written or oral information that we create or receive that describes your health condition, treatment or payments - is personal. Therefore, the Practice pledges to protect your health information as required by law. We give you this Privacy Notice to tell you (1) how we will use and disclose your "protected" health information, or "PHI" and (2) how you can exercise certain individual rights related to your PHI as a Patient of our practice. Please note that if any of your PHI qualifies as mental health records, alcohol and drug treatment records, communicable disease records or genetic test records, we will safeguard these records as "Special PHI" which will be disclosed only with your prior express written authorization, pursuant to a valid court order or as otherwise required by law. We are required by law to maintain the privacy of your PHI and to provide you with this notice of our legal duties and privacy practices.

II. How We Will Use and Disclose Your PHI

- A. To Provide Treatment.** We may use and disclose your PHI to provide, coordinate or manage your health care and any related services. This includes the management or coordination of your health status and care with another health care Provider. For example, we may disclose your PHI to a pharmacy to fill a prescription or to a laboratory to order a blood test. We may also disclose your PHI to another physician who may be treating you or consulting with us regarding your care.
- B. To Obtain Payment.** We may also use and disclose your PHI, as needed, to obtain payment for services that we provide to you. This may include certain communications to your health insurer or health plan to confirm (1) your eligibility for health benefits; (2) the medical necessity of a particular service or procedure; or (3) any prior authorization or utilization review requirements. We may also disclose your PHI to another Provider involved in your care for the other Provider's payment activities. For example, this may include disclosure of demographic information to another physician practice that is involved in your care, or to a hospital where you were recently hospitalized, for payment purposes.
- C. To Perform Health Care Operations.** We may also use or disclose your PHI, as necessary, to carry on our day-to-day health care operations, and to provide quality care to all of our Patients, but only on a "need to know" basis. These health care operations may include such activities as: quality improvement; physician and employee reviews; health professional training programs, including those in which students, trainees, or practitioners in health care learn under supervision; accreditation; certification; licensing or credentialing activities; compliance reviews and audits; defending a legal or administrative claim; business management development; and other administrative activities. In certain situations, we may also disclose your PHI to another health care provider or health plan to conduct their own particular health care operation requirements.

- D. To Contact You.** To support our treatment, payment and health care operations, we may also contact you at home, either by telephone or mail, from time to time (1) to remind you of an upcoming appointment date, or (2) to ask you to return a call to the Practice unless you ask us, in writing, to use alternative means to communicate with you regarding these matters. We may also contact you by telephone to inform you of specific test results or treatment plans, but only with your prior written authorization.
- E. To Be in Contact with Your Family or Friends.** Additionally, we may also disclose certain of your PHI to your family member or other relative, a close personal friend, or any other person specified by you from time to time, but only if the PHI is directly related (1) to the person's involvement in your treatment or related payments; or (2) to notify the person of your physical location or a sudden change in your condition, while receiving treatment at our facility. Although you have a right to request reasonable restrictions on these disclosures, we will only be able to grant those restrictions that are reasonable and not too difficult to administer, none of which would apply in the case of an emergency.
- F. To Conduct Research.** Under certain circumstances, we may use and disclose certain of your PHI for research purposes, but only if the research is subject to special approval procedures and the necessary rules governing uses and disclosures are agreed to by the researchers. For example, a research project may compare two different medications used to treat a particular condition in two different groups of Patients by comparing the Patients' health and recovery in one group with the second group. Any other research will require your written authorization.
- G. According to Laws that Require or Permit Disclosure.** We may disclose your PHI when we are required or permitted to do so by any federal, state or local law, as follows:
- 1. When there are Risks to Public Health.** We may disclose your PHI to (1) report disease, injury or disability; (2) report vital events such as births and deaths; (3) conduct public health activities; (4) collect and track FDA-related events and defects; (5) notify appropriate persons regarding communicable disease concerns; or (6) inform employers about particular workforce issues.
 - 2. To Report Suspected Abuse, Neglect or Domestic Violence.** We may notify government authorities if we believe that a Patient is the victim of abuse, neglect or domestic violence, but only when specifically required or authorized by law or when the Patient agrees to the disclosure.
 - 3. To Conduct Health Oversight Activities.** We may disclose your PHI to a health oversight agency for activities including audits; civil, administrative, or criminal investigations, proceedings, or actions; inspections; licensure or disciplinary actions; or other activities necessary for appropriate oversight, but we will not disclose your PHI if you are the subject of an investigation and your PHI is not directly related to your receipt of health care or public benefits.

4. **In Connection with Judicial and Administrative Proceedings.** We may disclose your PHI in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal. In certain circumstances, we may disclose your PHI in response to a subpoena if we receive satisfactory assurances that you have been notified of the request or that an effort was made to secure a protective order.
 5. **For Law Enforcement Purposes.** We may disclose your PHI to a law enforcement official to, among other things, (1) report certain types of wounds or physical injuries; (2) identify or locate certain individuals; and (3) report limited information if you are the victim of a crime or if your health care was the result of criminal activity, but only to the extent required or permitted by law.
 6. **To Coroners, Funeral Directors, and for Organ Donation.** We may disclose PHI to a coroner or medical examiner for identification purposes, to determine cause of death or for the coroner or medical examiner to perform other duties. We may also disclose PHI to a funeral director in order to permit the funeral director to carry out their duties. PHI may also be disclosed for organ, eye or tissue donation purposes.
 7. **In the Event of a Serious Threat to Health or Safety, or for Specific Government Functions.** We may, consistent with applicable law and ethical standards of conduct, use or disclose your PHI if we believe, in good faith, that such use or disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety or to the health and safety of the public, or for certain other specified government functions permitted by law.
 8. **For Workers' Compensation.** We may disclose your PHI to comply with workers' compensation laws or similar programs.
 9. **To Conduct Fundraising.** Under certain circumstances, we may use and disclose certain of your PHI to communicate with you and conduct fundraising activities on our behalf, but only when permitted by HIPAA. Please note that you always have the right to "opt out" of receiving any future fund raising communications and any such decision will have no impact on your treatment or payment for services.
 10. **To Communicate with You Regarding Your Treatment.** We may also communicate information to you, from time to time, that may encourage you to use or purchase a particular product or services, but only as it relates to your treatment and only when permitted by HIPAA.
- H. With Your Prior Express Written Authorization.** Other than as stated above, we will not disclose your PHI, or more importantly, your Special PHI, without first obtaining your express written authorization. Please note that you may revoke your authorization in writing at any time except to the extent that we have taken action in reliance upon the authorization.

1. Uses and disclosures of Special PHI (if recorded by us in the medical record) except to carry out your treatment, payment or health care operations, to the extent permitted or required by law;
2. Uses and disclosures of PHI to conduct certain marketing activities that may encourage you to use or purchase a particular product or services for which HIPAA requires your prior express written authorization;
3. Disclosures of PHI that constitutes a sale of your PHI under HIPAA;
4. Uses and disclosures of certain PHI for fundraising purposes that are not otherwise permitted by HIPAA;
5. Psychotherapy notes; and
6. Other uses and disclosures not described in this Notice.

III. Your Individual Rights Concerning Your PHI

- A. The Right to Inspect and Copy Your PHI.** You may inspect and obtain a copy of your PHI that we have created or received as we provide your treatment or obtain payment for your treatment. A copy may be made available to you either in paper or electronic format if we use an electronic health format. Under federal law, however, you may not inspect or copy the following records: psychotherapy notes; information compiled in reasonable anticipation of, or for use in, a civil, criminal, or administrative action or proceeding; and PHI that is subject to a law prohibiting access. Depending on the circumstances, you may have the right to request a second review if our Privacy Officer denies your request to access your PHI. Please note that you may not inspect or copy your PHI if your physician believes that the access requested is likely to endanger your life or safety or that of another person, or if it is likely to cause substantial harm to another person referenced within the information. As before, you have the right to request a second review of this decision. To inspect and copy your PHI, you must submit a written request to the Privacy Officer. We may charge you a fee for the reasonable costs that we incur in processing your request.
- B. The Right to Opt Out of Fundraising.** We may use or disclose your name, address, telephone number or email information, age, date of birth, gender, health insurance status, dates of service, department of service information, treating physician information, or outcome information, to a business associate or institutionally related foundation, for the purpose of raising money for our benefit. Although we may contact you to raise funds for us, you have the right to opt out of receiving future fundraising communications and your decision will have no impact on your treatment or payment for services by us.

- C. The Right to Receive Confidential Communications of PHI.** You may request to receive communications of PHI from us by alternative means or at alternative locations, and we will work with you to reasonably accommodate your request. For example, if you prefer to receive communications of PHI from us only at a certain address, phone number or other method, you may request such a method.
- D. The Right to Request Restrictions on How We Use and Disclose Your PHI.** You may ask us not to use or disclose certain parts of your PHI, but only if the request is reasonable. For example, if you pay for a particular service in full, out-of-pocket, on the date of service, you may ask us not to disclose any related PHI to your health plan. You may also ask us not to disclose your PHI to certain family members or friends who may be involved in your care or for other notification purposes described in this Privacy Notice, or how you would like us to communicate with you regarding upcoming appointments, treatment alternatives and the like by contacting you at a telephone number or address other than at home. Please note that we are only required to agree to those restrictions that are reasonable and which are not too difficult for us to administer. We will notify you if we deny any part of your request, but if we are able to agree to a particular restriction, we will communicate and comply with your request, except in the case of an emergency. Under certain circumstances, we may choose to terminate our agreement to a restriction if it becomes too burdensome to carry out. Finally, please note that it is your obligation to notify us if you wish to change or update these restrictions after your visit by contacting the Privacy Officer directly.
- E. The Right to Request Amendments to Your PHI.** You may request that your PHI be amended so long as it is a part of our official Patient Record. All such requests must be in writing and directed to our Privacy Officer. In certain cases, we may deny your request for an amendment. If we deny your request for amendment, you have the right to file a statement of disagreement with us and we may respond to your statement in writing and provide you with a copy.

The Right to Receive an Accounting of Disclosures of PHI. You have the right to request an accounting of those disclosures of your PHI that we have made for reasons other than those for treatment, payment and health care operations, which are specified in Section II (A-C) above. The accounting is not required to report PHI disclosures to those family, friends and other persons involved in your treatment or payment; (2) that you otherwise requested in writing; (3) that you agreed to by signing an authorization form; or (4) that we are otherwise required or permitted to make by law. As before, your request must be made in writing to our Privacy Officer. The request should specify the time period, but please note that we are not required to provide an accounting for disclosures that take place prior to April 14, 2003. Accounting requests may not be made for periods of time in excess of six years. We will provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

- F. The Right to Receive Notice of a Breach.** You have the right to receive written notice in the event we learn of any unauthorized acquisition, use or disclosure of your PHI that was not otherwise properly secured as required by HIPAA. We will notify you of the breach as soon as possible but no later than sixty (60) days after the breach has been discovered.
- G. The Right to File a Complaint.** You have the right to contact our Privacy Officer at any time if you have questions, comments or complaints about our privacy practices or if you believe we have violated your privacy rights. You also have the right to contact our Privacy Officer or the Department of Health and Human Services' Office for Civil Rights in Baltimore, Maryland regarding these privacy matters, particularly if you do not believe that we have been responsive to your concerns. We urge you to contact our Privacy Officer if you have any questions, comments or complaints, either in writing or by telephone as follows:

Center for Hospice Care
111 Sunnybrook Court
South Bend, IN 46637
Attn: Privacy Officer
Phone: (574) 243-3100

Please note that we will not take any action, or otherwise retaliate, against you in any way as a result of your communications to the Practice or to the Department of Health and Human Services' Office for Civil Rights. As always, please feel free contact us. We look forward to serving you as a Patient.

- H. Your Right to Revoke Authorization.** Any other uses and disclosures not described in this Notice will be made only with your written authorization. Please note that you may revoke your authorization in writing at any time except to the extent that we have taken action in reliance upon the authorization.

Revised September, 2013

SECTION 4 – Advance Directives



Indiana State
Department of Health

YOUR RIGHT TO DECIDE
2 North Meridian Street • Indianapolis, Indiana 46204
March 1999; Revised July 2013

The purpose of this information is to inform you of ways that you can direct your medical care and treatment in the event that you are unable to communicate for yourself. This information covers:

- What is an advance directive?
- Are advance directives required?
- What happens if you do not have an advance directive?
- What are the different types of advance directive?

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 DIRECTIVES ARE RECOGNIZED IN INDIANA?

- Talking directly to your physician and family
- Health care representative
- Tissue and eye donation
- Psychiatric advance directives
- Living Will Declaration or Life-Prolonging Procedures Declaration
- Power of Attorney
- Out of Hospital Do Not Resuscitate Declaration and Order
- Physician Orders for Scope of Treatment (POST)

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.

TISSUE AND EYE DONATION: Increasing the quality of life for another person is the ultimate gift. Donating your tissue/eyes is a way to help others. Making your wishes concerning tissue/eye donation clear to your physician and family is an important first step. This lets them know that you wish to be a tissue/eye donor. Tissue/eye donation is controlled by the Indiana Uniform Anatomical Gift Act found at Indiana Code § 29-2-16. A person that wants to donate their tissue/eyes may include their choice in their will, living will, on a card, or other document. If you do not have a written document for tissue/eye donation, someone else will make the choice for you. A common method used to show that you are a tissue/eye 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 a tissue/eye 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, 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 not in a hospital when an emergency occurs, the emergency personnel or the hospital where you are sent likely would not have a physician's order to implement your directives. For situations outside of a hospital, 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. 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.

PHYSICIAN ORDERS FOR SCOPE OF TREATMENT (POST): A "Physician Orders for Scope of Treatment" (also referred to as a POST form) is a direct physician order for a person with at least one of the following:

1. An advanced chronic progressive illness.
2. An advanced chronic progressive frailty.
3. A condition caused by injury, disease or illness from which, to a reasonable degree of medical certainty there can be no recovery and death will occur from the condition within a short period without the provision of life-prolonging procedures.
4. A medical condition that, if the person were to suffer cardiac or pulmonary failure, resuscitation would be unsuccessful or within a short period the person would experience repeated cardiac or pulmonary failure resulting in death.

In consultation with you or your legal representative, your physician will write orders that reflect your wishes with regards to cardiopulmonary resuscitation (CPR), medical interventions (comfort measures, limited additional interventions or full treatment), antibiotics and artificially administered nutrition. You additionally have the option on the POST form to designate a "Health Care Representative" (see the section "Health Care Representative" above for additional information). Note that if you have previously designated a health care representative and you name a different person on your POST form, the person designated on the POST form replaces (revokes) the person named in the previous health care representative advance directive. The Indiana POST form is available on the Indiana State Department of Health website at www.in.gov/isdh/25880.htm.

The POST form must be signed and dated by you (or your legal representative) and your physician to be valid. The original form is your personal property and you should keep it. Paper, facsimile (fax) or electronic copies of a valid POST form are as valid as the original. Your physician is required to keep a copy of your POST form in your medical record or; if the POST form is executed in a health facility, the facility must maintain a copy of the form in the medical record. The POST form may be used in any health care setting. The Physician Orders for Scope of Treatment statute is found at Indiana Code § 16-36-6.

Executed POST forms may be revoked at any time by any of the following:

1. A signed and dated writing by you or your legal representative.
2. Physical cancellation or destruction of the POST form by you or your legal representative.
3. Another individual at the direction of you or your legal representative.
4. An oral expression by you or your legal representative of intent to revoke the POST form.

The revocation is effective upon communication of the revocation to a health care provider.

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:

1. Name the person you want as your attorney in fact;
2. List the situations which give the attorney in fact the power to act;
3. List the powers you want to give; and
4. 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:

1. Make choices about your health care;
2. Sign health care contracts for you;
3. Admit or release you from hospitals or other health facilities;
4. Look at or get copies of your medical records; and
5. 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/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. Several of the forms are specified by statute. Those forms may be found on the Indiana State Department of Health (ISDH) Advance Directives Resource Center at www.in.gov/isdh/25880.htm. The following forms are available on that web site: Living Will Proclamation, Life-Prolonging Procedures Declaration, Out of Hospital Do Not Resuscitate Declaration and Order and Physician Orders for Scope of Treatment (POST).

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.

ADDITIONAL INFORMATION: For additional information on advance directives, visit the Indiana State Department of Health Advance Directives Resource Center located at www.in.gov/isdh/25880.htm. The site includes links to state forms, *Your Right to Decide* brochure, links to Indiana statutes and links to other websites. The ISDH website contains a wealth of information about public health. Visit ISDH Home Page at www.in.gov/isdh.

SUMMARY OF 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.

AGENCY POLICY ON ADVANCE DIRECTIVES

Our agency complies with the Patient Self-Determination Act of 1990, which requires us to:

- Provide you with written information describing your rights to make decisions about your medical care;
- Document advance directives prominently in your medical record and inform all staff;
- Comply with requirements of state law and court decisions with respect to advance directives; and
- Provide care to you regardless of whether or not you have executed an advance directive.

An ethics committee is available to serve in an advisory capacity when ethical issues, such as the withdrawal or withholding of life-sustaining treatments arise during the care of patients with or without an advance directive. Discussion shall involve the patient and/or designated representatives, the home care staff involved in the patient's care and the patient's physician.

Unless the physician has written a specific **Do Not Resuscitate (DNR)** order, it is our policy that every patient will receive cardiopulmonary resuscitation (CPR). If you do not wish to be resuscitated, you, your family or your Health Care Representative or Power of Attorney must request DNR orders from your physician. These orders are documented in your medical record and routinely reviewed; however, **you may revoke your consent to such an order at any time.**

SECTION 5 – Emergency Preparedness

EMERGENCY PREPAREDNESS PLAN

In the event of a natural disaster, inclement weather or emergency, we have an emergency operations plan to continue necessary patient services. We will make every effort to continue home care visits; however, the safety of our staff must be considered. When roads are too dangerous to travel, our staff will contact you by phone, if possible, to let you know that they are unable to make your visit that day. Every possible effort will be made to ensure that your medical needs are met.

All patients are assigned a priority level code that is updated as needed. The code assignment determines agency response priority in case of a disaster or emergency. These codes are maintained in the agency office, along with information which may be helpful to Emergency Management Services in case of an area disaster or emergency. You will be contacted for medical attention:

- **Level I** – Within 24 hours
- **Level II** – Within 24-48 hours
- **Level III** – Within 48-72 hours

In case of bad weather or other situations that might prevent our staff from reaching you, turn to your local radio and/or TV station(s). Please notify our office if you evacuate to another location or emergency shelter.

In the event of evacuation, have a plan for your pets. Will they evacuate with you? Do you have a carrier to put them in for evacuation?

POWER OUTAGE

If you need help in a power outage and our phone lines are down:

- Call 911 or go to the emergency room if you have an emergency.
- Call your closest relative or neighbor if it is not an emergency.

LIGHTNING

If you are inside:

- Avoid tubs, faucets and sinks because metal pipes conduct electricity.
- Stay away from windows.
- Avoid using phones with cords except for emergencies.

If you are outside:

- Avoid natural lightning rods such as tall trees in open areas.
- Get away from anything metal.

FLOOD

Be aware of flood hazards, especially if you live in a low-lying area, near water or downstream from a dam. Flooding can take days to happen, but flash floods produce raging waters in minutes. Six inches of moving water can knock you off your feet. Avoid moving water if you must walk in a flooded area. Use a stick to test if the ground is firm enough to walk on.

Be ready to evacuate if a flood watch is issued. Move important items upstairs. Fill a clean bathtub with water in case water becomes contaminated or is shut off. Turn off your utilities at the main valves if you are instructed to do so. Do not touch electrical equipment if you are wet or standing in water.

TORNADO

As soon as a tornado is sighted, go to the lowest floor and find an interior room. Good shelters are basements, rooms and halls with no outside walls, bathtubs and spaces under the stairs. Many public buildings have designated shelter areas. Stay away from windows, doors and outside walls. Get under a sturdy item, such as a table, and protect your head. Stay until the danger passes.

If **the patient is bedbound**, move the bed as far from windows as you can. Use heavy blankets or pillows to protect the head and face.

If you are in a vehicle, trailer or mobile home, get out immediately and go to a sturdy structure. If there is not one close by, lie flat in the nearest ditch and cover your head. Do not try to out-drive a tornado. They are erratic and move swiftly.

HOT WEATHER

There is a higher risk for heat-related illness in the summer. When it is hot outside:

- Never leave anyone sitting in a closed, parked car.
- Drink lots of water even if you are not thirsty. Avoid alcohol and caffeine.
- Eat small, frequent meals.
- Stay inside and out of the sun. Stay on the lowest floor, pull shades over the windows and use fans if you do not have air conditioning.
- Mist or sponge yourself frequently with cool water.
- Use sunscreen.
- Wear hats and clothes that are loose and lightweight. Clothes with light colors will deflect the sun's energy.
- Talk to your doctor about how sun and heat exposure will affect you if you take drugs such as diuretics or antihistamines.
- Move to a cool place at the first sign of heat illness (dizziness, nausea, headache, cramps). Rest and slowly drink a cool beverage. Seek medical attention immediately if you do not feel better.

WINTER STORM

Heavy snowfall and extreme cold can immobilize a region, resulting in isolation. Icy and/or blocked roads and downed power lines can happen any time it is cold or snowy. Wear layers of loose, lightweight, warm clothes, rather than one heavy layer. Wear hats and outer layers that are tightly woven and water repellent. Mittens will keep your hands warmer than gloves.

EMERGENCY KIT FOR THE HOME

Bad weather can be dangerous, so be prepared. Keep a kit with these items in case you have a weather emergency:

- Battery-powered radio
- Lamps and flashlights
- Extra batteries
- Food that you don't have to cook
- Manual can opener
- Utensils, cups and plates
- Medications
- Extra Blankets
- Water in clean milk or soda bottles
- Rock salt or sand for walkways
- Extra Fuel
- Cash in case of power outage

SHELTER SUPPLIES

The following is a list of what to bring to a shelter during an evacuation:

- Two-week supply of medication
- Medical supplies and oxygen
- Wheelchair, walker, cane, etc.
- Special dietary foods/can opener
- Air mattress/cot and bedding
- Lightweight folding chair
- Extra clothing, hygiene items, glasses
- Important papers
- Valid ID with current name & address
- Hospice folder

Most shelters have electric power from a generator. If you evacuate to a shelter, bring your electrical devices (such as an oxygen concentrator).

Note: Pets are usually allowed in shelters.

SECTION 6 – Home Safety

All patients need to take special precautions to ensure a safe living environment. Most accidents in the home can be prevented by eliminating hazards. This list will help you find potential hazards in your home. Take note of each statement that you need to work on to make your home a safer place. **Please speak with your case manager or call the agency at any time if you have any concerns or questions about patient safety.**

PREVENTING FALLS

At least half of all falls happen at home. Each year, thousands of older Americans experience falls that result in serious injuries, disability and even death. Falls are often due to hazards that are easily overlooked but easy to fix. Use the following **SELF ASSESSMENT**. Check all of the risk factors below that apply to you and your home. The more factors checked, the higher your risk for falling.

- History of Falling** - Two (2) or more falls in last six (6) months.
- Vision Loss** - changes in ability to detect and discriminate objects; decline in depth perception; decreased ability to recover from a sudden exposure to bright light or glare.
- Hearing Loss** - may not be as quickly aware of a potentially hazardous situation.
- Foot Pain/Shoe Problems** - foot pain; decreased sensation/feeling; skin breakdown; ill-fitting or badly worn footwear.
- Medications** - taking four or more medications; single or multiple medications that may cause drowsiness, dizziness or low blood pressure.
- Balance and Gait Problems** - decline in balance; decline in speed of walking; weakness of lower extremities.
- High or Low Blood Pressure** that causes unsteadiness.
- Hazards Inside Your Home** - tripping and slipping hazards; poor lighting; bathroom safety; spills; stairs; reaching; pets that get under foot.
- Hazards Outside Your Home** - uneven walkways; poor lighting; gravel or debris on sidewalks; no handrails; pets that get under foot; hazardous materials (snow, ice, water, oil) that need periodic removal and clean up.

WALKING SAFETY

- Wear shoes that are flat, preferably low-heeled with non-skid soles.
- Keep shoes in good repair.
- Tack down carpeting. Do not use throw rugs unless non-skid backing is applied.
- Keep furniture, clothing and electrical cords out of walkways.
- Keep walkways clear and well lit. Lamps and light switches should be conveniently located.
- Stairs should have non-slip treads and a securely mounted hand rail.
- Wipe up spills. Make sure floors are dry before walking, and avoid highly polished floors.
- Keep sidewalks and outdoor stairs shoveled, sanded and/or salted during cold, wet weather.

STAIRWAY SAFETY

- Remove loose rugs around the entry or exit to a stairway.
- Storage of loose items such as newspapers, boxes or tools on stairways can cause you to trip or fall.
- Use a handrail and adequate lighting.
- Use non-slip strips securely fastened to the steps.
- Keep outdoor steps dry and free from ice and snow.

ELECTRICAL SAFETY

- Use only three-pronged extension cords for equipment requiring electricity.
- Use a three-pronged adapter when required.
- Do not plug equipment into an electrical outlet that is already being used.
- Be sure electrical outlets have the required amperage and are appropriately grounded.
- Frequently check for exposed or faulty cords or wiring.
- Do not expose electrical equipment to water or other liquids.
- Be sure electrical cords do not interfere with walkways.

FIRE SAFETY

- Never smoke in bed or near oxygen equipment.
- Have a fire extinguisher within easy reach where fires may occur (fireplace, kitchen stove, furnace area, etc.).
- Install smoke detectors on ceilings or high on walls and check them frequently. Place one on at least every floor of your home. If the detector starts to beep intermittently, replace battery immediately.
- Have a plan for evacuating the home in case of fire and have an alternate route available. Do not take anything with you - just leave the house immediately.
- Keep the bedroom doors closed at night to delay the spread of fire and deadly gases.
- Place an incapacitated patient in a room with multiple escape routes if at all possible. Prior to any emergency need, discuss a plan for assisting him or her out of the house.
- If you are unable to exit, stuff wet towels or clothing into door cracks. Stay near a slightly opened window. If the room is covered with smoke, cover your nose and mouth with a damp towel and get as low to the floor as possible.

BATHROOM SAFETY

- Consider securely installing grab bars around the shower or tub to assist in entering and departing these areas.
- Utilize a tub or shower chair to increase stability.
- Attach a toilet safety to frame your toilet seat so use and transfer will be easier.
- Keep floors dry to prevent slippery conditions.
- Install non-slip carpeting to prevent slippery conditions.

MEDICATION SAFETY

- Do not take medications that are prescribed for someone else.
- Create a complete list of current medications (including prescription and over-the-counter medications, herbal remedies and vitamins), and keep this list with you at all times in the event of emergency situations. Review the list for discrepancies and make changes immediately as they occur. Show the list to your doctor or pharmacist to keep from combining drugs inappropriately.
- 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 your health care provider.
- Take medications exactly as instructed. If the medication looks different than you expected, ask your health care provider or pharmacist about it.
- Drug names can look alike or sound alike. To avoid errors, check with your health care provider if you have questions.
- Do not use alcohol when you are taking medicine.
- Do not stop or change medicines without your doctor's approval, even if you are feeling better. If you miss a dose, do not double the next dose later.
- Use a chart or container system (washed egg carton or med-planner) to help you remember what kind, how much and when to take medicine.
- Take your medicine with a light on so you can read the label.
- Read medicine labels (including warnings) carefully and keep medicines in their original containers.
- 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.

DISPOSAL OF CONTROLLED DRUGS

Prescription medications no longer needed by the patient should be properly disposed of in accordance with state and federal drug disposal guidelines. Medications are the property of the patient and are not the property of the Agency. Agency nurse may only educate the POA/Responsible party on proper handling and disposal of medications. Agency staff shall not perform destruction and disposal.

Medication disposal will be documented in the clinical record by Agency staff, utilizing the Agency Medication Disposal form, in compliance with state and federal requirements.

Medications remaining in the patient's home after the death/discharge of the patient will be documented in the patient's medical record.

1. Upon a change of medication or death/discharge, the Agency staff will educate and offer guidance to the family members on the appropriate disposal methods of remaining medications. The patient/family has the right to refuse.
2. No medications, scheduled, unscheduled or over the counter, will be removed from the home under any circumstance by the Agency staff.

3. 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:
- Follow any specific disposal instructions on the drug label or patient information that accompanies the medication. Do not flush prescription drugs down the toilet
 - If no instructions are given, throw the drugs in the household trash, but first remove the drugs from the original containers and mix them with water and 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.
 - 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.
 - Remove any patient identification labels, or completely mark through patient identification information.
 - 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 the phone book) to determine if a take-back program is available in your community.
4. **Inpatient unit:** When any medications are disposed of in Inpatient unit, they will be disposed of with the witness of two staff members. The Medication/Disposal form will be completed and filed in the patient's chart.
5. **Long Term Care/Hospital Setting:** When the patient resides in long term care, or in the inpatient hospital setting, Agency staff will follow the policies of the facility for disposing of patient medications.
- The Agency will comply with the Drug Enforcement Administration and adjust the policy as required to ensure total compliance with state and federal regulations. Failure to comply with this policy may result in disciplinary action.

Patients and families may locate an authorized collection receptacle by calling the DEA Office of Diversion Control's Registration Call Center at 1-800-882-9539

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.
- Purchase insecticides for immediate need only and store excess 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 SAFETY

- Keep manufacturer's instructions with or near specialized medical equipment. Perform routine and preventive maintenance according to the instructions.
- Keep phone numbers available in the home to obtain service in case of equipment problems or equipment failure.
- Have backup equipment available, if indicated.
- Provide adequate electrical power for medical equipment such as ventilators, oxygen concentrators and other equipment.
- Test equipment alarms periodically to make sure that you can hear them.
- Have equipment batteries checked regularly by a qualified service person.
- Have bedside rails properly installed and use 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.
- The mattress must fit the bed. Add stuffers in gaps between the rail and mattress or between the head and foot board and mattress to reduce gaps.
- Register with your local utility company if you have electrically powered equipment such as oxygen or ventilator.

OXYGEN SAFETY

- Use oxygen only as directed.
- Oxygen creates a high risk for fire because it causes an acceleration of flame in the presence of flammable substances and open flames.
- **Do not smoke around oxygen.** Post "**No Smoking**" signs inside and outside 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 burning candles) at least 10 feet away from the oxygen source.
- Keep at least 6 inches of clearance around an oxygen concentrator at all times. Plug it directly into a wall outlet, and limit the use of extension cords.
- Have electrical equipment properly grounded and avoid operating electrical appliances such as razors and hairdryers while using oxygen. Keep any electrical equipment (including e-cigarettes) that may spark at least 10 feet from the oxygen system.
- Use 100% cotton bed linens and clothing to prevent sparks and static electricity.
- 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 backup portable oxygen cylinder in case of a power or oxygen concentrator failure.
- Alert property management of oxygen use when living in a multi-dwelling residence.

SECTION 7 - Facility

CARING FOR NURSING FACILITY PATIENTS

Not all persons who could benefit from hospice care have available caregivers or reside in the typical "home" setting. Medicare and Medicaid also recognize this limitation by expanding the definition of home to include health care facilities. This allows patients who are paying for their room and board privately or through Medicaid the opportunity to utilize the Hospice Medicare Benefit, with the health care facility staff in the role of primary caregiver. Similarly, Medicaid patients may access services through the Medicaid Hospice Benefit. It is important to note that hospice care is available to any patient who meets our admission criteria.

CHC has established a partnership with health care facilities that wish to offer hospice care to their residents. This partnership promotes optimal end-of-life care as CHC provides the same level of services for patients living in a nursing facility as those patients living in their homes. This is accomplished by a coordinated effort of the CHC team and the nursing facility team. Patients and their families can contact directly members of either team to express questions or concerns.

ELIGIBILITY

A representative from CHC will meet with a patient, family member and/or other significant individuals to explain CHC's services when a person is referred to the hospice program. Payment for services through a patient's Medicare or Medicaid insurance is explained at the initial visit, prior to initiation of care. To be eligible for services, a patient must meet the following requirements:

- Patient is certified as terminally ill by a physician.
- Patient's diagnosis meets appropriate guidelines.
- Patient's care is managed by a physician. This can be either the patient's attending physician or our Hospice Physician.
- Patient is no longer receiving curative or aggressive treatment for his or her terminal illness.
- Patient resides in a nursing facility that maintains a written agreement with CHC.
- Patient chooses our hospice services.
- Patient is not on a Medicare A Bed.

SECTION 8 – Infection Control at Home

Stay clean and use good hygiene to help stop the spread of infection. Items used in health care, such as bandages or gloves, can spread infection and harm the environment. They can harm trash handlers, family members and others who touch them if they are not disposed of properly. Be careful when you handle them.

Some illnesses and treatments (such as chemotherapy, dialysis, AIDS, diabetes and burns) can make people more at risk for infection. Your nurse will tell you how to use protective clothing (such as gowns or gloves) if you need it.

Please tell your doctor or a hospice staff member if you notice any of the following signs and symptoms of infection:

- Pain, tenderness, redness or swelling
- Inflamed skin, rash, sores or ulcers
- Fever or chills
- Sore throat or cough
- Pain when urinating
- Increased tiredness or weakness
- Confusion
- Green or yellow pus
- Nausea, vomiting or diarrhea

WASH YOUR HANDS

Wash your hands frequently and correctly, even if you wear gloves. It is the single most important step in controlling the spread of infection. Always wash hands before:

Always wash hands before:

- Tending to a sick person
- Treating a cut or wound
- Touching or eating food

Always wash hands after:

- Tending to a sick person
- Treating a cut or wound
- Using the bathroom
- Touching animals or their waste
- Touching soiled linens
- Touching garbage
- Changingdiapers
- Coughing, sneezing or blowing tour nose

If you have visibly dirty hands, or they are contaminated or soiled in any way, wash them with soap (liquid soap is best) and warm running water. Remove jewelry, apply soap, wet your hands and rub them together for at least 20 seconds. Wash all surfaces, including wrists, palms, back of hands, between fingers and under nails. Rinse off the soap and dry your hands with a clean towel that has not been shared. If one is not available, air-dry your hands. Use a towel to turn off the faucet. If you used paper towels, throw them in the trash. To avoid dry or chapped hands, pat them dry and use lotion after washing.

If you do not have visibly dirty hands, use an alcohol-based hand rub to clean them. Use a rub with 60-90% ethyl or isopropyl alcohol. Open the cap or spout and apply a dime-size amount (or the amount recommended on the label) in one palm, then rub hands vigorously, covering all surfaces of hands and fingers, until they are dry.

COVER YOUR COUGH

Cover your mouth and nose with a tissue when you cough or sneeze. If you do not have a tissue, cover your mouth with your upper sleeve, not your hands. Throw your used tissue in the trash. You may be asked to wear a mask to protect others.

DISPOSABLE ITEMS AND EQUIPMENT

Some items that are not sharp: *paper cups, tissues, dressings, bandages, plastic equipment, catheters, diapers, Chux, plastic tubing, gloves, etc.*

Store these in a clean, dry area. Throw away used items in waterproof (plastic) bags. Fasten the bags securely and throw them in the trash.

NON-DISPOSABLE ITEMS AND EQUIPMENT

Some items that are not thrown away: *dirty laundry, dishes, thermometers, toilets, walkers, wheelchairs, bath seats, suction machines, oxygen equipment, mattresses, etc.*

Wash dirty laundry separately in hot, soapy water. Handle it as little as possible so you don't spread germs. If the patient has a virus, add a mix of one (1) part bleach and ten (10) parts water to the load.

Clean equipment as soon as you use it. Wash small items (not thermometers) in hot, soapy water, then rinse and dry them with clean towels. Wipe thermometers with alcohol before and after each use. Store them in a clean, dry place. Wipe off equipment with a normal disinfectant or bleach mix. Follow the cleaning instructions that came with the item and ask your nurse or therapist if you have questions.

Pour liquids in the toilet. Clean their containers with hot, soapy water, then rinse them with boiling water and let them dry.

SHARP OBJECTS

Some sharp items: *needles, syringes, lancets, scissors, knives, staples, glass tubes and bottles, IV catheters, razors, etc.*

Put used **sharps** in a clean, hard plastic or metal container with a screw-on or tight lid. Seal it with heavy-duty tape and dispose of it in the trash or according to area regulations. Do not overfill sharps containers or re-cap used needles. **DO NOT use glass** or clear plastic containers. **Never** put sharps in containers that will be recycled or returned to a store.

BODY FLUIDSPILLS

Put on gloves and wipe the fluid with paper towels. Use a solution of one (1) part bleach and ten (10) parts water to wipe the area again. Double bag used paper towels and throw them in the trash.

UNIVERSAL PRECAUTIONS AND PATIENT'S 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.

CHC complies with the infection control practices required by 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, nondisposable 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, 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 receives 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 CHC staff. 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 Exposure Control Coordinator
2 North Meridian St.
Indianapolis, IN46204
(317) 234-2804

SECTION 9 – Symptom Management

Perhaps the greatest fear a person can have is to experience unbearable pain. Few realize that pain can be controlled and that many patients do not experience pain. The aim of CHC is to provide pain control and to allow you to live as comfortably and fully as possible. CHC nurses are highly skilled in assessment and management of pain, as well as many other symptoms that may arise.

PAIN CONTROL

Pain Control

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 your maximum comfort.

Describing Pain

We rely on you to communicate your pain or discomfort as clearly as possible. The nurse will ask about the location, duration, onset and severity of the pain. The intensity of your pain is typically described on a scale ranging from 0 to 10. A rating of 0 means no pain, 1-3 is a range of mild pain, 4-6 is moderate pain, and 7-10 describes severe pain.

Pain Management

Your attending doctor/CHC Hospice Physician will be the person in charge of prescribing all medications. The nurse will keep the doctor informed of your pain, symptoms and changing condition. Together we will work to keep you as comfortable as possible to enhance your quality of life.

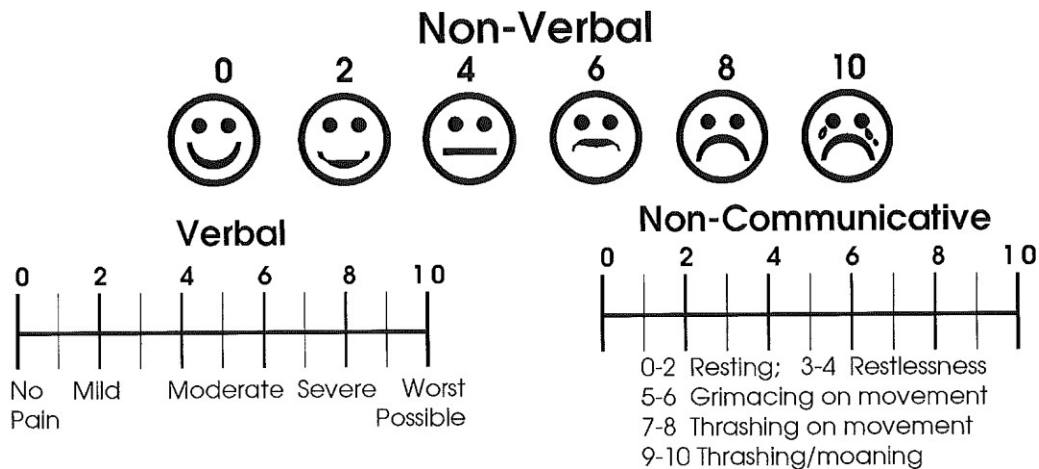
In many instances, a non-prescription medication is used effectively for mild pain.

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. The nurse will instruct you in the proper use and respond to your questions and concerns. Here are a few suggestions to keep in mind:

- Communicate your pain goal to your team. The team will initiate treatment and follow up until your goal is reached.
- Allow time for your 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. Most patients find that the best pain control occurs when pain medications are taken on a regular schedule to stay "on top" of the pain. Do not wait until the pain becomes severe before administering another dose of pain medicine. If doses are skipped, maximum comfort cannot be maintained.
- Addiction from prescription medications should never be a problem for the patient. This medication is being given for pain control, not for an emotional high. Comfort is the primary concern.
- Narcotic medicine is very constipating. It is important to follow a bowel regime as outlined by your nurse and doctor.

- Pain control is often helped by a pleasant and peaceful environment. Companionship can be a positive distraction. Some individuals enjoy being read to or listening to music.
- When pain is managed, patients feel more alive and less "sick." CHC has many experts in the area of pain management. Our goal is your comfort.
- Contact CHC 24 hours a day, seven (7) days a week with new or unresolved pain. We have staff available to assist and make a home visit.

Pain Scales:



NUTRITION

Whenever anyone is ill, it is common for his or her appetite to decrease. The body's need for calories and other nutrients is altered because of the change in activity and the change in metabolic rate, due to the disease process.

Many hospice patients experience one or more of the following problems that interfere with nutrient intake: decrease or loss in appetite, nausea, vomiting, chronic pain, diarrhea and constipation. This makes it difficult to find the right kind of foods that are well tolerated and accepted by the patient. Too often this challenge can turn into friction between the patient and the caregiver and interfere with open communication. To keep communication open it is best to allow the patient to eat what and when he/she desires. When a person is facing the end of their life their priorities change and eating is often not important to them. Furthermore, the disease process and medication can cause taste aversions and specific foods may taste bland, salty, sour or too sweet.

The following are some frequent eating problems and suggestions for overcoming them. Remember that these are just suggestions. Each person has individual needs and preferences. For increased nutritional needs such as added calories, protein, fluids, vitamins and/or minerals contact the hospice nurse.

When it is difficult to swallow liquids or solids:

- Thin liquids are usually the most difficult to swallow, softer blended foods are sometimes easier to swallow. There is also commercial thickener available.
- If mucus is a problem, then cranberry, pineapple or citrus juice may be helpful in cutting or thinning the mucus. If milk products increase mucus production, a dairy-free nutritional supplement can be used.

- For further information on swallowing difficulties or for special products contact your case manager.

When you are just not hungry:

- Keep snacks handy and in sight for nibbling.
- Drinks made with ice cream or frozen yogurt (such as milk shakes and smoothies) provide a large number of calories within a small volume. Also supplemental drinks such as Carnation® Breakfast Essentials provide nutrients.
- Breakfast foods are often well tolerated. Do not feel that a particular food should be eaten at a particular time. Eat whatever you like, whenever you like.
- Try eating small meals with snacks in between. Small meals may even be just one item.

When you are nauseated:

- Eat frequent small meals.
- Choose bland foods that are not greasy or too sweet, such as chicken noodle soup with saltine crackers, gelatin with fruit and apple juice.
- Drink liquids between meals rather than at meal times. Clear, cool beverages are usually better tolerated. Popsicles® and flavored ice cubes are good choices.
- Dry foods such as toast and crackers are usually well tolerated.
- Do not lie down for at least two hours after eating. Sit up or recline with your head at least four inches above your feet.

When your mouth or throat is sore or dry:

- Take small bites of food and take a swallow of beverage with each bite.
- Try cold foods such as Popsicles®, sherbet, ice cream, fruit ices, milk shakes and ice chips. Sometimes eating ice-cold foods first may make eating other foods more tolerable.
- Sometimes using a straw can make swallowing more comfortable.
- Smooth foods such as whipped cream, pudding cream pies, canned fruits or gelatins are usually less irritating to the mouth or throat.
- Creamed soups and other creamed foods are often well tolerated. Keep temperatures warm rather than piping hot.
- Drink soothing beverages such as apple juice, peach or pear nectar and milk (if tolerated). Carbonated beverages, salty liquids (such as broth or vegetable juices), citrus juices (containing acid) and spicy foods may irritate a sore mouth or throat.

BOWEL MANAGEMENT INSTRUCTIONS

Most hospice patients have some difficulty with their bowel movements. There are several reasons why you may be constipated. Changes in your diet decreased fluid intake or decreased activity may contribute to constipation; however, the use of pain medications (narcotic analgesics) is usually the major cause of constipation.

Untreated constipation can lead to a more serious condition (impaction or bowel obstruction) and a daily bowel program can help to prevent such problems. The overall goal is to have a bowel movement approximately every three (3) days. The following guidelines should help you maintain normal bowel function.

- Drink plenty of liquids, especially in combination with high-fiber foods. Tea, hot lemon water and juices, such as prune juice, may be effective.
- Try to have a bowel movement at the same time of the day. Be sure to allow adequate time on the toilet or bedpan.
- Keep a record of your bowel movements and note whether they are hard or soft.
- Take your stool softener/laxative pill *as prescribed*. The dose can range from two to eight (2-8) pills per day or more if needed. Examples of such preparations are Peri-Colace®, Senokot S® or Doxidan®.
- Other laxative preparations can be added if the stool softener/laxative pill alone does not work. Examples of these are Dulcolax®, milk of magnesia, Phillips' M-O or lactulose.
- Call the nurse if you do not have a bowel movement in three (3) days. It might be necessary for you to have a rectal suppository, an enema, or be checked for a stool impaction.
- Call the nurse if you have any of the following symptoms:
 - Abdominal distention or bloating
 - Rectal pain with your bowel movement
 - The urge but inability to pass stool
 - Oozing of liquid stool after no bowel movement for several days
 - Rectal fullness and pressure

SECTION 10–Primary Caregiver Guidelines

We thank you for the privilege of assisting you with the care of your loved one. We salute you for all you have done to surround your loved one with understanding care, to provide your loved one with comfort and calm, and to enable your loved one to leave this world with a sense of peace and love. You have given your loved one the most wonderful, beautiful and sensitive gifts we humans are capable of, and, in giving that gift, have given yourself a wonderful gift as well.

Caring in the home for a loved one who has a limited life expectancy and who is undergoing many physical, emotional, mental and spiritual changes, can be a challenging and fulfilling experience. It can also be confusing and tiring.

CHC supports your willingness to undertake the role of primary caregiver for your loved one. In this way you permit him or her to be maintained in comfortable and familiar surroundings at this vulnerable time in his or her life's journey. We will do everything possible to help you do this effectively and appropriately. We see ourselves as a team with each of us having differing roles and responsibilities which, taken together, achieve maximum benefit for your loved one and for you.

Primary care refers to the basic physical and emotional activities involved in meeting the ongoing daily living needs of your loved one at home. This may involve doing such things as maintaining the person's hygiene, nourishment and use of medications. It may involve such comfort measures as preventing constipation, nausea or other symptoms, turning, skin care, oral care, bathing and grooming. It may include learning such skills as ostomy care and utilizing special equipment. It may include filling prescriptions, communicating with the physician, communicating with community resources, utilizing printed materials and making final arrangements. Generally, it means being available to your loved one to listen, to touch, to share, to be present and to care.

Your hospice team is pledged to support you in every possible way as you undertake this role. It will help you deal with your limitations and frustrations. It will help you arrange for all supportive services that are needed in the home. It will help facilitate utilization of respite care and inpatient care as needed. It will help you deal with your own feelings and how this situation is affecting your life, your needs and your hopes. It will help you clarify your choices, your available alternatives and resources, and your values, priorities and beliefs, and implement them in the most helpful manner.

The team will explain the progression of the illness, how the needs of your loved one will change and how to respond as these changes take place. It will seek to help you anticipate these changes and implement procedures so that they do not become big problems or out-of-control situations. In all that the team says, does and offers you, it is the team's deepest commitment to enable you to maximize your involvement of time, energy and love with your loved one.

TO BE ABLE TO TAKE CARE OF ANOTHER, YOU MUST FIRST TAKE CARE OF YOURSELF.

Tips on taking care of yourself:

- Love yourself at least as much as you love the one you are caring for.
- Get enough rest, perhaps naps during the day. Conserve your energy.
- Exercise. Even a short walk helps sleep and gives energy.
- Eat well. Choose a variety of foods from the five basic food groups. Drink plenty of water.
- Reduce stress. Think about what has helped in the past.
- Take breaks. Relax and think of other things.
- Pay attention to what your body is telling you. Is it tired, stressed, tense?
- Nurture your spiritual side. Pursue those things that are uplifting to you.
- Pamper yourself, especially on difficult days. Be patient and considerate of yourself.
- Avoid unrealistic expectations of yourself.
- Allow others to help you.
- Set limits. It's OK to say "no" sometimes.
- Recognize your needs and limitations.

Tips on helping loved ones:

- Allow them to talk. Listen without judgment. Only occasionally comment.
- Acknowledge and validate their feelings and let them express their feelings in many ways.
- Avoid taking any negative feelings personally.
- Let them have control over their situation as much as possible.
- Include them in decision making and discussions.
- Let them do as much as they want to and have the energy for, no matter how slow, painful or difficult it seems to you.
- Don't underestimate their pains, symptoms and fear. These are real and valid.
- Talk about subjects you used to discuss together, the times you shared.
- Laugh together.

Experience has shown that often the best patient care is provided by family and friends. Regardless of how capable and efficient a professional's care may be, the presence and touch of a person who has a close relationship with the patient will provide the greatest gift.

SECTION 11-Understanding the Physical and Emotional Changes at the End of Life

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 allalong.

ONE TO THREE MONTHS PRIOR TO DEATH

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

Responses - Continue to keep your loved one well informed, especially of family matters and former areas of interests. Your loved one may not respond, but that does not mean he/she is not hearing the information. If your loved one does appreciate visitors, shorter contacts (10-15 minutes) will be less tiring. It is good to allow your loved one to make his/her 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" his/her life, sort things out, and hopefully come to peace with the life lived. With this comes increased sleep (or the appearance that the person is sleeping). A morning nap is added to the afternoon nap. Your loved one may spend more time in bed or all day in bed.

Responses - We want to encourage you to allow your loved one to sleep more and respect his/her need to be alone. The times that your loved one is awake will be more beneficial and meaningful to you and to him/her.

LESS COMMUNICATION - Don't take it personally if your loved one does not want to talk. He/she may 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 your loved one during these times. Hold your loved one's hand or lie beside him/her, 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 a 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 your loved one.

Responses - Offer suggestions of small food or snacks at intervals throughout the day. Don't force food. Let your loved one is in control.

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. Your loved one may often talk to people and about places and events that are of the past or unknown to others. Your loved one may be disturbed by dreams or see and converse with loved ones who have died.

Responses - You may want to listen closely to your loved one, because he or she may say a word or phrase that contains significant information or requests. Remind your loved one of where he/she are, the day and time, who is present in the home and who is talking to him/her. 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, your loved one may become restless and/or agitated. You will notice your loved one possibly picking or pulling at the blankets or bedclothes, and demonstrating random arm movements.

Responses - You may want to talk calmly and assuredly with your loved one so as not to startle or frighten him or her. Reassure your loved one of your presence. Soft music or a backrub may be helpful.

INCONTINENCE - Your loved one's body becomes relaxed, sometimes due to the dying process, sometimes due to comfort medications. It is not uncommon for your loved one to lose control of bowel and bladder function.

Responses - It is important to explain to your loved one that what has occurred is a result of medications being taken or of his/her weakened condition. This is an embarrassment to patients and they should never be blamed. Keep incontinent padding under your loved one. Adult diapers can also be used (always refer to them as "adult"). These protective pads should be changed when soiled to keep your loved one 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 your loved one.

Responses - If your loved one is resting comfortably, allow him/her to continue to rest. You can raise the head of the bed if he/she breathe more easily this way, or offer to change his/her position.

BODY TEMPERATURE AND PULSE - As your loved one'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 nailbeds.

Responses - Blankets can be provided or removed as needed for your loved one's comfort. Never use an electric blanket at this time. Sponge your loved one with a cool washcloth if this promotes comfort. Change perspiration-soaked garments and bed linens. Medications may be ordered if your loved one's temperature rises to a level of discomfort.

SPEECH, VISION AND HEARING - As your loved one makes efforts to communicate with you, you may experience a sense of frustration as his/her speech may become difficult to understand. The lack of understanding may make you feel as though you are not "pleasing" your loved one. 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 your loved one's presence that would make him or her feel uncomfortable or uneasy.

Responses - If you have difficulty understanding your loved one'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 your loved one can respond to with "yes" or "no." Reassure your loved one that someone will always be around to provide his/her care. If it is apparent that vision is failing, keep your loved one 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 your loved one wishes. Refrain from asking unnecessary questions of your loved one 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 your loved one by giving a gentle massage or simply holding your loved one's hand.

DAYS OR HOURS PRIOR TO DEATH

The last few days of a person'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 your loved one know you will miss him/her, 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 your loved one. If you have questions, you are encouraged to contact CHC. We are available to you, as well as your loved one.

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. The patient may 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. Your loved one 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 your loved one's wishes. He or she will know what they can or cannot do. Treasure the moments and be reassuring of your loved one.

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 your loved one, 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 your loved one 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 your loved one in bed may be helpful. Contact the CHC nurse with any questions.

BODY CIRCULATION - As your loved one'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 TO KNOW WHEN 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

FAMILY GUIDELINES WHEN DEATH OCCURS

Please call CHC at the number checked on the front or back cover of this booklet if you feel death has occurred or have questions/concerns about any changes. **DO NOT** call the police or an ambulance.

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.

SECTION 12 – Giving Opportunities

Many families ask how they can help the **Center for Hospice Care (CHC)**. 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; BECOME A HOSPICE ADVOCATE

We count on those who have experienced the services offered by our CHC to share information regarding our programs. Your testimonial is of great value to CHC - you can educate your friends, co-workers, fellow club members, etc. Some family members even write **letters to the editor** of their local newspaper regarding the benefits of our care. Let us know of speaking opportunities, health fairs or other ways we might educate your community.

CHC is Social! Follow CHC on Facebook and Twitter at Center4Hospice.

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 CHC 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 volunteers.

In addition to providing patient care in homes and at Inpatient unit, we offer opportunities to volunteer in our 11th Hour Program, We Honor Veterans Program, pet visitation, tuck-in callers, barbers, hair stylists, bereavement callers, office support, and many other areas.

MEMORIAL DONATIONS

Throughout the year, many members of the community make donations to CHC 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 *Crossroads*, our Foundation's publication.

DIRECT MAIL CAMPAIGNS

Two times each year The Hospice Foundation mails a letter to our friends and family members asking for financial support of our program. In May, 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 focuses on one area of need.

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 CHC. In planned giving, the donor makes a decision 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
- Donors can possibly save on income, estate and capital gains taxes.

Center for Hospice Care has established funds through community foundations to provide permanent annual support. If you would like additional information on planned giving, please contact the **Hospice Foundation for the Center for Hospice Care** at (574) 243-3100 or visit FoundationForHospice.org.

PATIENT NAME: _____

DOB: _____

INSTRUCTIONS: This form is used to acknowledge receipt of the Patient/Family Handbook for Hospice Care and confirm your understanding and agreement with its contents. Your signature below indicates your approval.

ACKNOWLEDGEMENT OF RECEIPT

The Center for Hospice Care (CHC) representative:

- Explained and gave me a Patient/Family Handbook for Hospice Care which contains the Notice of Privacy Practices.
- Discussed the agency may release information or receive protected health information about me to carry out treatment plan, payment, or health care services.
- Informed me that a copy of my rights and responsibilities as a patient is in the Patient/Family Handbook for Hospice Care.

I authorize release of information to the following persons (if no one, mark none):

Name: _____	Relationship: _____
Name: _____	Relationship: _____
Name: _____	Relationship: _____
Name: _____	Relationship: _____

CONSENT FOR TREATMENT

Initials

_____ **Hospice Care** - I hereby give my permission for authorized personnel of CHC to perform all necessary procedures and treatments as prescribed by my physician for the delivery of **Hospice** care. I understand the following hospice care and services may be provided to me during the course of illness: physician, nursing, social V/vOrk, therapy services, counseling services (bereavement and spiritual), hospice aide, volunteers, durable medical equipment, pharmaceuticals, medical supplies, respite care, short term inpatient care and continuous care. The extent of services and supplies provided are based on the patient's needs and determined by the hospice interdisciplinary team.

_____ **Home Health Care** - I hereby give my permission for authorized personnel of CHC to perform all necessary procedures and treatments as prescribed by my physician for the delivery of **Home Health** care. I understand that durable medical equipment, pharmaceuticals, and certain medical supplies are not covered by CHC.

_____ I understand that I may refuse treatment or terminate services at any time and CHC may terminate their services to me as explained during my orientation.

_____ I understand I have a right to participate in planning my care and agree and consent to the care plan.

_____ I give my permission to have my blood tested for Hepatitis B, C, and HIV should an employee inadvertently come in contact with my blood or body fluids.

ADVANCE DIRECTIVES

I understand that the Federal Patient Self-Determination Act of 1990 requires that I be made aware of my right to make health care decisions for myself. I understand that I may express my wishes in a document called an Advance Directive so that my wishes may be known when I am unable to speak for myself.

If you have any of the below Advance Directives, please give a copy to a CHC representative or social V/vOrker.

- | | |
|---|-------------------|
| • I have made a Living Will | D No D Yes |
| • I have made a Health Care Representative/Power of Attorney for Medical Care | D No D Yes |
| • I have an Out of Hospital Do Not Resuscitate Order | D No D Yes |
| • I have a Physician Order for Scope of Treatment (POST) form | D No D Yes |

I understand a copy of this consent form shall be as valid as the original and shall remain in effect until I am discharged from the agency. I also understand that I may revoke this consent in writing at any time.

Patient Signature	Date	Responsible Person or Legal Guardian Signature
-------------------	------	--

CHC Representative Signature	Date	Printed Name and Relationship of Person Above
------------------------------	------	---

D Patient unable to sign due to: _____

Do Not Resuscitate Order

Patient: _____ DOB: _____

Physician: _____

I have thoroughly discussed my disease process with my physician and am aware that I have a terminal illness, so it is my wish that in the event that my heart would cease to function, I would not want to be resuscitated.

Patient / Patient Representative Signature

Date

Physician Signature

Date

*Revised 02/17
Clinical/DNR Order*

NOTICE OF ELECTION OF HOSPICE BENEFIT

I (*patient name*), _____ **DOB:** _____

choose to elect the Medicare, Commercial, Self pay hospice benefit from Center for Hospice Care

I understand the purpose of hospice care and that the treatment is primarily palliative rather than curative. I understand that the goal of hospice care is not to cure my terminal illness, but to maintain my quality of life through palliative and supportive care and management of symptoms. Medicare patients: Certain Medicare services are waived when the Medicare Hospice benefit is elected and this has been fully explained to me.

Initial:

_____ I understand that I and/or my caregiver will participate in developing the plan of care along with the hospice team composed of a physician, nurse, medical social worker, spiritual counselor, volunteer and other disciplines that may be necessary.

_____ I understand that I can revoke this benefit at any time and resume regular **Medicare** coverage. I know I will lose any hospice days remaining in the benefit period in which I revoke.

_____ I understand that I may transfer my **Medicare** hospice care to another hospice program once during each election period.

Initial:

_____ I understand I have the right to choose an attending physician, who may be a physician or nurse practitioner. I understand I am not required to have an attending to elect my benefit and Center for Hospice Care Hospice Physicians/Nurse Practitioners (NP) will serve as my attending. I also understand in the event my elected physician is unable or chooses not to attend, Center for Hospice Care Hospice Physicians/Nurse Practitioners can serve as my attending or I can choose another physician. I understand I have the right to change my attending at any time by completing a form provided by Center for Hospice Care.

I do have an Attending Physician/Nurse Practitioner (*print full name*): _____

If my attending physician is unavailable or I do not have a physician, I choose the CHC Hospice Physician/NP (*print full name*): _____

Beneficiary or Representative Signature _____
Date

Relationship of Legal Representative to Beneficiary

Agency Representative Signature _____
Date

CHC Use Only

Benefit Period: First 90 Second 90 Unlimited 60

Attending NPI: _____ Address: _____

CHC MD/ DO/NP NPI# _____

Effective Date of Hospice Election: _____ **ICD-10:** _____

Your Professional Hospice Staff

Nurse: _____

Hospice Physician: _____

Hospice Aide: _____

Social Worker: _____

Spiritual Counselor: _____

Volunteer: _____



Center for
Hospice Care

choices to make the most of life™

Toll Free: 1-800-HOSPICE (1-800-467-7423)
Only within CHC's service area.

Elkhart Office
22579 Old US 20 East
Elkhart, IN 46516
Phone: (574) 264-3321

Plymouth Office
112 S Center Street
Suite C
Plymouth, IN 46563
Phone: (574) 935-4511

South Bend Office
111 Sunnybrook Court
South Bend, IN 46637
Phone: (574) 243-3100

Life Transition Center
501 Comfort Place
Mishawaka, IN 46545
Phone: (574) 255-1064

La Porte Office
286 W Johnson Road
Suite B
La Porte, IN 46350
Phone: (219) 575-7930