



IOWA CITY
HOSPICE

Iowa City Hospice

Care Manual

800-897-3052

www.iowacityhospice.org

Iowa City Hospice is honored to be part of your team.

Below are the names of your Iowa City Hospice Team Members:

Primary Nurse Case Manager:

Medical Social Worker:

Spiritual Counselor:

Hospice Aide:

Music Therapist:

A Message from Iowa City Hospice

Thank you for allowing Iowa City Hospice to be part of your care. At one of the most intimate transitions of your life, our compassionate staff and volunteers will be here to walk beside you—respecting your choices, and empowering you to retain control of your end-of-life care.

For the past 30 years, Iowa City Hospice has remained a not for profit hospice provider, meaning that we can bring our compassionate care to all in need without regard for ability to pay. With our unparalleled experience and focus on quality, this care is extraordinary - fully 100 per cent of our families report patient pain relief through the right amount of medication.

We remain focused on the care that is needed, not the care that is covered providing a personalized approach to each patient and their loved ones. Customizing your care plan from the most comprehensive scope of hospice services available, will ensure the respect, comfort, and peace of mind that patients and families need most.

I can say with confidence that Iowa City Hospice will add life to each day not only through our extraordinary care for the person facing a terminal illness but through support and information for the caregivers and counseling as needed.

If you have any questions or suggestions at any time, I encourage you to contact me at 319-351-5665, 800-897-3052 or maggie.elliott@iowacityhospice.org. We are honored to serve you.

Sincerely,

A handwritten signature in blue ink that reads "Maggie Elliott". The signature is written in a cursive, flowing style.

Maggie Elliott
Executive Director

Iowa City Hospice Care Manual

Table of Contents

SECTION 1: Iowa City Hospice’s Care	1
Iowa City Hospice’s Notice of Patient’s Rights and Responsibilities.....	1
How to Voice a Complaint or Concern About Care.....	3
What Kind of Care Does Iowa City Hospice Provide?	4
The Scope of Iowa City Hospice’s Services.....	5
Where Is Iowa City Hospice’s Care Provided?	6
The Medicare Hospice Benefit.....	6
How Services Are Paid	7
Iowa City Hospice’s Caregiver & Emergency Assistance Funds	7
Iowa City Hospice Care for Residents of Long-Term Care & Assisted Living Facilities.....	8
Why have Iowa City Hospice and nursing home services?	8
Iowa City Hospice Inpatient Options.....	9
 SECTION 2: The Iowa City Hospice Interdisciplinary Team	 10
The Iowa City Hospice Medical Director	11
The Iowa City Hospice Nurse	12
The Iowa City Hospice Social Worker.....	13
The Iowa City Hospice Spiritual Counselor.....	14
The Iowa City Hospice Aide	15
The Iowa City Hospice Music Therapist.....	16
The Iowa City Hospice Bereavement Counselor	17
The Iowa City Hospice Patient and Family Support Volunteers	18
 SECTION 3: Decisions to Discuss	 19
Fluids Decisions.....	19
Nutritional Decisions	20
Sedation Decisions	20
Resuscitation Decisions.....	21
Calling 9-1-1.....	22
 SECTION 4: For a Safe, Manageable Home	 23
Staying Safe.....	23
Fire Safety	23
Storm Safety.....	24
Equipment Safety	24
Medication Safety	24
Managing Trash And Waste.....	25
Hand Washing.....	26
Guidelines for Medication Disposal.....	27

SECTION 5: Caregiver Resources	28
A Caregiver Resource: seriousillness.org/iowacity	29
Information & Ideas for Hands-on Care at Home.....	30
Bathing	31
Bowel Function	32
Breathing	33
Confusion, Disorientation, Hallucination.....	34
Cough.....	34
Emotions.....	35
Fatigue and Sleepiness.....	36
Immobility	36
Mouth Care.....	37
Nausea And Vomiting.....	38
Pain	39
Narcotics Facts	41
Poor Appetite.....	43
Restlessness, Agitation, Anxiety	44
Skin Care.....	45
Swallowing.....	47
Urinary Function	47
Weakness.....	47
SECTION 6: Final Days.....	48
Easing the Last Days	48
Nearing the End of Life	49
Signs of Decline: The Dying Process	49
Signs Death Has Occurred	50
What to Do When Death Occurs.....	50
Frequently Asked Questions at the Time of Death	51
SECTION 7: Grief Support Services	52
SECTION 8: The Iowa City Hospice Organization	53
Iowa City Hospice History	53
Supporting Iowa City Hospice.....	53

Iowa City Hospice's Notice of Patient's Rights and Responsibilities

As a patient at Iowa City Hospice, you have the right:

- To exercise your rights as a patient of this hospice.
- To have your property and person treated with respect.
- To voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of the hospice.
- To not be subjected to discrimination or reprisal for exercising your rights.
- To receive effective pain management and symptom control from us for conditions related to your hospice diagnosis.
- To participate in all decisions regarding care and services and to be involved in the development or revision of your hospice plan of care so that it reflects the patient's priorities and preferences.
- To refuse treatment to the extent permitted by law, and be informed of the medical consequences of such refusal.
- To choose your attending physician.
- To be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of your property.
- To receive information about the services covered under the Medicare hospice benefit or by other payer sources, the services the hospice will provide and any specific limitation(s) on those services, and to be informed of any charges/services not covered by insurance.
- To be provided with information and the opportunity or assistance needed to formulate advance directives and to receive care and services whether or not advance directives have been executed.
- To make decisions whether to withhold resuscitation and/or to forgo or withdraw life-sustaining care.
- To choose whether or not to participate in research, investigational or experimental studies, or clinical trials.
- To have your communication needs met.

- To withdraw from Iowa City Hospice or transfer to a different hospice program or health care provider at any time.
- To unlimited contact with visitors and others regardless of the setting in which care and services are provided.
- To a timely response to concerns and questions and to have concerns and complaints heard without fear of negative repercussions.
- To have a confidential clinical record and your health information protected in accordance with Federal HIPAA privacy and security regulations with the following specific privacy rights:
 - *To receive a paper copy of the hospice's Notice of Privacy Practices;*
 - *To request restrictions on the uses and disclosures of health information;*
 - *To request to receive confidential communication;*
 - *To access your protected health information for inspection and/or copying;*
 - *To amend your health care information; and*
 - *To request an accounting of disclosures of health information.*

As a patient of Iowa City Hospice, you have the responsibility:

- To participate in developing and implementing your plan of care and revising it as necessary.
- To provide Iowa City Hospice with complete and accurate information about your health status and symptoms.
- To ask for pain relief, help your nurse assess your pain, and report if your pain is not relieved.
- To promptly report any changes in your condition, level of pain, or adverse reaction to medication or other treatments.
- To assist Iowa City Hospice's staff in providing and maintaining a safe environment in which care can be provided.
- To inform Iowa City Hospice's staff of the existence of any advance directives and any changes made to them.
- To advise Iowa City Hospice's staff of any problems or dissatisfaction with the care / services provided.

How to Voice a Complaint or Concern About Care

Iowa City Hospice is committed to the highest standards of quality care. Every patient, family and caregiver has the right to problem resolution with respect to treatment or care that is (or fails to be) provided.

If you have questions and/or concerns, Contact

Iowa City Hospice toll free at 800-897-3052

Ask to speak to a care team leader.

We can also be reached by visiting www.iowacityhospice.org and clicking “Contact Us.”

If questions or concerns are not fully addressed, please ask to speak with the Iowa City Hospice Executive Director.

All complaints will be handled confidentially and in a timely manner. A patient, family or caregiver will not be discriminated or retaliated against, or in any way penalized, for requesting problem resolution.

Complaints may also be filed or questions asked about any home health or hospice agency in the State of Iowa by contacting:

Iowa Department of Inspections and Appeals
Lucas State Office Building
321 East 12th Street
Des Moines, Iowa 50319-0083

Toll-Free Home Health Hotline: 800-383-4920

Calls are answered Monday through Friday, 8 am to 4 pm. During other hours, leave a message with name and phone number for a return call.

What Kind of Care Does Iowa City Hospice Provide?

Iowa City Hospice provides four levels of care appropriate to the needs of the hospice patient.

1. **Routine Care** is provided in the patient's own home or the facility in which he or she resides. Routine care includes assessments, hands-on care, support, teaching, and other assistance. Our goal is relief of physical, psychosocial, and spiritual symptoms. The Iowa City Hospice team adjusts the frequency of visits to meet the goals of the plan of care as symptoms and situations change. We do not provide a full-time in-home caregiver.
2. **General Inpatient Acute Care** is provided in a contracted facility for the management of pain or symptoms that cannot be managed in the patient's home. Iowa City Hospice continues to provide care during short inpatient stays in the hospital or a care facility.
3. **Inpatient Respite Care** is provided in a contracted facility when necessary to provide respite when a family member or caregiver needs relief and rest from caregiving duties. The Iowa City Hospice patient can spend up to five consecutive days in a hospital or long-term care facility. The family member or caregiver resumes care after the stay. This is a short-term, temporary stay, not a long-term solution.
4. **Continuous (Crisis) Care for Symptom Management** is provided when a hospice patient is experiencing an acute crisis. Patients sometimes experience difficult or severe symptoms that might require longer or more frequent professional staff visits. If symptoms cannot be relieved in a timely manner, inpatient care will be considered.

Care During Final Days. It is common that the last few days of life are peaceful and quiet, but if problems occur, a more intensive effort may be needed. Visits may be longer or more frequent. More family and caregiver support may be provided. Specialized volunteers may be offered. This is true wherever the patient is -- in the home, a long-term care facility, an assisted living facility, or a hospital.

The Scope of Iowa City Hospice's Services

Iowa City Hospice patients and their families receive the services of Iowa City Hospice's Interdisciplinary Team, which includes:

- nursing services
- medical social services
- physician services (from the Iowa City Hospice Medical Director and/or the patient's attending physician)
- counseling services (including spiritual counseling; dietary counseling; and bereavement counseling for adults, children and youth)
- hospice aide services
- other therapies, including physical therapy, occupational therapy, speech-language pathology services, and music therapy
- pharmacist services

In addition to the services of the Interdisciplinary Team, Iowa City Hospice provides medical supplies, medical equipment, and drugs that are used for the management of pain and symptom control related to the patient's terminal illness.

Iowa City Hospice's care covers palliative symptom control measures such as chemotherapy, radiation and blood transfusions. Our goal is to provide care that is effective: the benefit of treatment outweighs the burden. As the benefit and burden of treatment may change over time, our interdisciplinary team will continually monitor and assess the goals of care with the patient. In cases where the outcome may not be clear, we will work with the patient and the attending physician to develop a timeframe for a trial and evaluation.

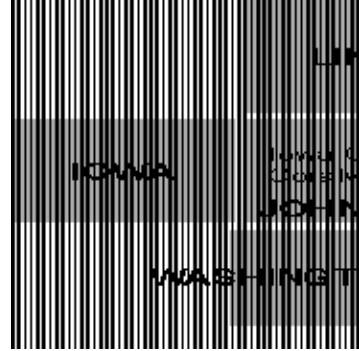
The scope and frequency of services provided by Iowa City Hospice are in accordance with each patient's needs as identified in his or her plan of care.

Nursing services, physician services, and drugs and biologicals are routinely available on a 24-hour basis 7 days a week. Other services are available on a 24-hour basis when reasonable and necessary to meet the needs of the patient and family.

Where Is Iowa City Hospice's Care Provided?

Iowa City Hospice provides care to individuals within our seven-county service area of Cedar, Iowa, Johnson, Linn, Louisa, Muscatine and Washington Counties. Our staff goes wherever the patient is.

Iowa City Hospice has contracts with most of the hospitals and care facilities throughout the area we serve. A list of area hospitals long-term care and assisted living facilities is available from any Iowa City Team member.



The Medicare Hospice Benefit

To be eligible for the Medicare Hospice Benefit, a patient must be entitled to Medicare Part A benefits and must be certified as terminally ill, defined by the Medicare Regulations as “a medical prognosis with a life expectancy of 6 months or less if the disease runs its normal course, as certified by a physician.”

The patient must also elect the Medicare Hospice Benefit, and be certified as appropriate by the Iowa City Hospice Medical Director or the Iowa City Hospice Interdisciplinary Team physician and the patient’s attending physician (if the individual has an attending physician).

If the patient should improve or become stable and the prognosis is no longer appropriate for hospice services, the patient can be discharged from hospice care with proper notice, returning to regular insurance coverage.

Patients can be readmitted at any time their condition is appropriate.

HOW SERVICES ARE PAID

As a community-oriented, not for profit organization, Iowa City Hospice is dedicated to offering services to everyone regardless of an individual's ability to pay.

Medicare, Medicaid and most private insurance companies cover the cost of hospice services. Community contributions assure the **hospice care and services for those who cannot pay** and for **care not covered by insurance**.

Iowa City Hospice covers the services of the interdisciplinary team and volunteers, palliative interventions, treatments, medications, supplies and equipment for symptom management related to the patient's hospice diagnosis and secondary conditions. Interventions covered by Iowa City Hospice are used for palliation and control of symptoms.

IOWA CITY HOSPICE DOES NOT CHARGE FOR OUR SERVICES.

However you may receive a bill from other providers for services related to the hospice diagnosis and secondary conditions.

- If you have **Medicare and/or Medicaid**, you will not be responsible for co-pays, deductibles.
- If you have **private insurance**, you will continue to be responsible for co-pays and deductibles.
- For those **without hospice coverage**, Iowa City Hospice will seek reimbursement from any outside funding source for which the patient is eligible before accessing Iowa City Hospice funds.
- Treatments or services not approved by the Iowa City Hospice Team as part of the hospice care plan and/or with providers not contracted by Iowa City Hospice are the responsibility of the patient.

Iowa City Hospice staff will work with you to help you cover the cost of services that you may be responsible for. In addition, Iowa City Hospice has **Caregiver and Emergency Funds** to provide limited funds on a need-based basis.

Iowa City Hospice Care for Residents of Long-Term Care & Assisted Living Facilities

Iowa City Hospice cares for many people who live in long-term care (nursing homes) and assisted living facilities.

Why have Iowa City Hospice and nursing home services?

Sometimes people ask why a person in a nursing home or assisted living facility would also need Iowa City Hospice's care. In fact, Iowa City Hospice, nursing homes and assisted living facilities make excellent partners.

Nursing homes and assisted living facilities provide professional care and security. Iowa City Hospice adds expertise in symptom management and issues important to those facing a terminal illness.

A facility staff member caring for multiple patients at night can call the on-call Iowa City Hospice nurse if an Iowa City Hospice patient develops pain, just as a family member or caregiver would call from home.

Iowa City Hospice aides are specially trained in end-of-life personal care needs, which provides additional cares to the patient, in coordination with the care facility.

The counseling and support of Iowa City Hospice social workers, spiritual counselors, and bereavement counselors are available to patients, families and caregivers, as well as to facility staff. Iowa City Hospice and facility staff have regular care conferences to coordinate and update care.

Choosing a facility

Choosing a long-term care or assisted living facility may be a difficult decision. Iowa City Hospice cannot recommend a particular facility because each patient, family and caregiver has different needs and preferences. We can help identify the features of a facility that might be most important.

We have contracts with many facilities throughout the area we serve. Talk with the Iowa City Hospice social worker for more information. A list of area long-term care and assisted living facilities is available.

Iowa City Hospice Inpatient Options

Patients of Iowa City Hospice can also receive care as an inpatient in the hospital or Medicare-approved care facility. For patients on Medicare, Medicaid and some Commercial Insurances, there are two levels of inpatient care available, inpatient respite care for the relief of the patient's caregivers and general inpatient care for pain control or symptom management.

Your insurance policy may have limits on the use of these benefits.

These inpatient services are designed to provide short-term inpatient care for the purposes of pain control and other symptom management; evaluation in changes in condition; and respite care.

The intent of these inpatient services is to offer Iowa City Hospice's care in an environment that is as home-like and conducive to the normalization of living as possible.

Inpatient Respite Care

Inpatient respite care is intended to give family caregivers a brief break, or "respite" from the demands of caregiving.

Respite care does not require that a worsening of the patient's condition precede the respite stay.

Inpatient respite care is a short-term, temporary stay, rather than a long-term solution for care.

General Inpatient Care

Iowa City Hospice patients may be admitted for short-term general inpatient care when the physician, Iowa City Hospice team and the patient believes symptom management cannot feasibly be provided in the home setting.

Although the length of stay for general inpatient level of care is based on the patient's condition and acute need, not any specific numbers of days, **patients are not usually in the hospital setting for longer than a week.** The patient returns or transitions to home hospice care once daily interventions have ceased and symptoms abate.

SECTION 2: The Iowa City Hospice Interdisciplinary Team

Iowa City Hospice designates an Interdisciplinary Team composed of qualified individuals who assess, plan, provide and evaluate the care and services provided to Iowa City Hospice patients and caregivers.

The Interdisciplinary Team at Iowa City Hospice includes, at a minimum, the following individuals:

- a doctor of medicine or osteopathy
- a registered nurse
- a social worker
- a spiritual or other counselor

In addition, our Interdisciplinary Team may include:

- the patient's attending physician (if any)
- trained volunteers under the supervision of the volunteer coordinator
- Iowa City Hospice aides
- bereavement counselors
- music therapists
- Pharmacist
- Advance Practice Nurse
- Others with appropriate clinical and educational experience

Iowa City Hospice care and services provided to patients and their caregivers are in accordance with an individualized, written plan of care established by the Iowa City Hospice's Interdisciplinary Team in collaboration with the patient's attending physician (if any) and, if appropriate, the patient or representative and the primary caregiver.

A nurse member our Interdisciplinary Team is designated as the Nurse Case Manager for each patient. The Nurse Case Manager is responsible for coordinating the care and services provided by the Interdisciplinary Team, ensuring continuous assessment of patient needs, and implementing the interdisciplinary plan of care.

The Nurse Case Manager coordinates the patient's plan of care and facilitates the ongoing sharing of information with the attending physician, contracted facilities, vendors, other members of the Interdisciplinary Team, and non-hospice healthcare providers furnishing services unrelated to the terminal illness.

The Iowa City Hospice Medical Director

Iowa City Hospice designates an individual who is a doctor of medicine or osteopathy to serve as Iowa City Hospice's Medical Director. The Iowa City Hospice Medical Director assumes the overall responsibility for the medical component of the patient care program.

What does the Iowa City Hospice Medical Director Do?

- The Iowa City Hospice Medical Director reviews clinical information to assess and certify the patient's initial eligibility for hospice care.
- The Iowa City Hospice Medical Director reviews clinical information and consults with members of the Interdisciplinary Team and the patient's attending physician (if there is one) regarding the patient's continued eligibility and appropriateness for recertification into subsequent benefit periods.
- The Iowa City Hospice Medical Director consults with the patient's attending physician (if there is one) as needed and appropriate.
- The Iowa City Hospice Medical Director serves as a medical resource for members of the Interdisciplinary Team.
- The Iowa City Hospice Medical Director attends and participates in Interdisciplinary Team meetings.
- The Iowa City Hospice Medical Director oversees the services of the Iowa City Hospice Advance Practice Nurse who may be seeing and serving as Iowa City Hospice's health provider.
- The Iowa City Hospice Medical Director serves as a liaison to other physicians in the community.
- The Iowa City Hospice Medical Director participates in Iowa City Hospice's quality assessment and performance improvement program.

The Iowa City Hospice Nurse

Iowa City Hospice nurses specialize in pain and symptom management. The patient's nurse case manager is the nurse the patient will see the most and is responsible for planning and coordinating care. What is happening to the patient physically cannot be separated from the emotional or spiritual, so Iowa City Hospice nurses use a holistic approach. This means they provide nursing care with awareness of the patient's, family's and caregiver's wishes, reactions, and feelings.

What does the Iowa City Hospice nurse do?

- Iowa City Hospice nurses monitor symptoms (such as pain, nausea, skin problems) and the success of symptom relief measures.
- Iowa City Hospice nurses watch for complications and problems that might be prevented or kept to a minimum.
- Iowa City Hospice nurses coordinate care at home, helping to manage medications, supplies, and equipment, and arranging and supervising hospice aides.
- Iowa City Hospice nurses provide hands-on care, such as wound management, giving medications, managing medication or nutritional pumps and teaching family members or caregivers to do some of these cares.
- Iowa City Hospice nurses keep the patient and caregiver updated on the status of the disease and condition and communicates with the patient's physician.

Advanced Registered Nurse Practitioner

- Iowa City Advanced Registered Nurse Practitioners are responsible for patient care activities involving symptom management, wound care, and face-to-face visits required by Medicare.
- The Iowa City Hospice Medical Director oversees the services of the Iowa City Hospice Advance Practice Nurse who may be seeing and serving as Iowa City Hospice's health provider.

The Iowa City Hospice Social Worker

Iowa City Hospice social workers are experts in the social and emotional issues that confront those with a terminal illness and their families. They provide support and information for the best quality of life possible.

What does the Iowa City Hospice social worker do?

- Iowa City Hospice social workers are experts in difficult emotional issues and how to cope with them. Not only patients, but also family members, caregivers and friends often need support and counseling.
- Iowa City Hospice social workers can arrange and facilitate family meetings. Many families and caregivers find these conferences helpful for improving communication, working out problems, expressing concerns, and finding ways of supporting one another.
- Iowa City Hospice social workers are familiar with resources available in the community, such as Meals on Wheels, legal assistance, Social Security benefits, in-home care, Lifeline[®] medical alert, or transportation services. They can help interpret and connect patients, families and caregivers to these community resources.
- Iowa City Hospice social workers can help find resources for legal and financial needs.
- Iowa City Hospice social workers can help explore choices and make arrangements for those who need care in a long-term care facility (nursing home) or assisted living facility.
- Iowa City Hospice social workers also help patients think through decisions about health care and help make their wishes known. This may include creating a healthcare directive. It may include discussing wishes regarding Cardiopulmonary Resuscitation (CPR), feeding tubes and other types of medical interventions. This is a medical order known as IPOST (Iowa Physician Orders for Scope of Treatment).

The Iowa City Hospice Spiritual Counselor

Iowa City Hospice spiritual counselors are experts in the spiritual issues that many individuals and families face. They provide support and information to help the patient reach the best quality of life possible, but do not represent a particular religion or belief.

What does the Iowa City Hospice spiritual counselor do?

- Iowa City Hospice spiritual counselors support each patient, family and caregiver in their own beliefs and practices. For those who have a spiritual leader/supporter in place, Iowa City Hospice spiritual counselors may act as additional support for the family and coordinate services with their spiritual leader.
- Iowa City Hospice spiritual counselors listen without judgment and coach individuals as they explore concerns, struggles, fears, and questions. Some people find it comforting to discuss their life experiences, relationships with family and friends, struggles, accomplishments, and desires for spiritual support.
- Iowa City Hospice spiritual counselors can provide comfort through prayer, readings, sacraments, or other meaningful rituals.
- Iowa City Hospice spiritual counselors can assist people in planning their own memorial service or funeral. Choices such as burial or cremation, organ donation, clergy, flowers, memorials, music, and speakers can be made in advance. This can help the family by assuring them they are following their loved one's wishes and by reducing the details they must handle at the time of death. Iowa City Hospice spiritual counselors can assist with funeral or memorial planning and sometimes lead the service when requested.

The Iowa City Hospice Aide

Iowa City Hospice aides work under the supervision of the Iowa City Hospice nurse case manager, providing help with the patient's personal care, such as bathing and getting dressed. Their assistance saves energy for the patient, family and caregiver. Iowa City Hospice aides are specially trained and certified to work with hospice patients.

What does the Iowa City Hospice aide do?

- Iowa City Hospice aides give baths (tub or bed) and assist with showers. They can do shampoos, give massages, do basic nail care, apply skin lotions, and assist with getting dressed.
- Iowa City Hospice aides help transfer the patient from bed to chair or wheelchair.
- Iowa City Hospice aides can do range-of-motion exercises under the direction of the nurse.
- Iowa City Hospice aides sometimes do basic wound care and other cares under the nurse's supervision.
- Iowa City Hospice aides provide light housekeeping such as dusting or vacuuming.
- Iowa City Hospice aides teach caregivers how to provide personal care to patients.

The Iowa City Hospice Music Therapist

Iowa City Hospice's Music Therapy program is provided to enhance patients', families' and caregivers' quality of life through music. Our music therapists are specially trained in both music and therapy skills. Emotional, cognitive, spiritual, social, and physical issues are explored and expressed through music. For example, patients experiencing pain, insomnia, agitation, and stress have benefited from music therapy services.

Note: A person needs no musical experience, skills, or talent to enjoy and benefit from Iowa City Hospice's Music Therapy services.

What does the Iowa City Hospice music therapist do?

- Iowa City Hospice music therapists use music in a variety of ways, depending on a patient's, family's or caregiver's needs.
- Iowa City Hospice music therapists may sing, play instruments, provide recordings, or teach new skills. Through music and support, they help patients, families, caregivers and friends express and explore thoughts and feelings.
- Iowa City Hospice music therapists work with music that is meaningful for each individual person.
- Iowa City Hospice music therapists help patients, family members or caregivers use or create music to express feelings and thoughts.
- Iowa City Hospice also has a music program that includes a music lending library and equipment.

The Iowa City Hospice Bereavement Counselor

Iowa City Hospice's services do not end with the death of the patient. Bereavement counselors offer ongoing emotional support and education about grief, loss and life adjustments following the death of a loved one. Iowa City Hospice bereavement counselors have social work or counseling backgrounds and are specialists in loss and grief.

What Does the Iowa City Hospice Bereavement Counselor Do?

- Iowa City Hospice bereavement counselors can help a person who has experienced a loss understand thoughts and feelings that are normal during grieving.
- Iowa City Hospice bereavement counselors can meet one-on-one or with several family members and caregivers, providing a safe setting to express thoughts and feelings, helping to reconcile differences and difficulties.
- Iowa City Hospice recognizes that the grieving process is very different for children and teens. A variety of bereavement services specially designed for children and youth are offered, including one-on-one grief counseling and support groups.
- Because family members and caregivers with children may need additional support, Iowa City Hospice offers a support group for the parents/guardians of children and teens.
- Iowa City Hospice bereavement counselors help with special dates that may be difficult, such as birthdays, anniversaries, and holidays.
- Iowa City Hospice bereavement counselors provide support groups, educational programs, and periodic mailings with information on grief and loss. Other mailings announce special events available to those experiencing grief and loss.

Patient and Family Support Volunteers

Patient and Family Support volunteers provide companionship and assistance to terminally ill patients and their loved ones. They may be regular visitors, or visit just once or twice when special help is needed. Many have had personal experience with hospice care, and are inspired to help others going through the crisis of serious illness. Iowa City Hospice volunteers provide support in a variety of ways, including:

Legacy Project Volunteers

Legacy volunteers record patient's stories, images, and wisdom in a variety of forms. Interviews are transcribed into a captivating narrative; photographic portraits create an "occasion"; or memory books can include memorabilia, photos, or important documents bound in a book or on a CD.

We Honor Veterans

Volunteers support our veteran patients by providing informed, nonjudgmental companionship to veterans and their families, creating opportunities to share military experiences. Iowa City Hospice patients who are veterans receive a Certificate of Appreciation for Military Service.

Compassionate Touch Volunteers

Compassionate Touch is a light massage that can be given in a wheelchair, in a hospital bed, a regular bed, in a recliner or in a chair. It is patient-centered, providing comfort and connection, relaxation and pain relief.

Pet Therapy Volunteers

Pet therapy visits promote loving connection, relaxation, decreased anxiety, and even lowered blood pressure.

Pet Peace of Mind Volunteers

The daily responsibilities of pet care may become overwhelming when a family is coping with a terminal illness. The Pet Peace of Mind volunteers provide support services that include walks and exercise, stimulation, grooming and clean up.

11th Hour Volunteers

When it is anticipated that a patient is within 24-48 hours of death, Iowa City volunteers can provide support with their presence.

SECTION 3: Decisions to Discuss

Individuals experiencing a terminal illness handle tough situations every day, but some decisions are especially hard. The following are some considerations to discuss.

For All of These Difficult Decisions

- Ask questions. Find out what various options actually mean for the patient, family and caregiver. Ask the patient's attending physician or Iowa City Hospice Interdisciplinary Team for information until all the options are understood.
- Discuss options with family members and caregivers.
- Put decisions *in writing*. Share them with the patient's attending physician and a member of the Iowa City Hospice Interdisciplinary Team.
- The patient's wishes or directives should be *easy to find* in the home. It is recommended that the document be placed in a clear plastic sleeve on the refrigerator.
- These decisions can be changed at any time. The changes need to be rewritten and communicated to the attending physician and Iowa City Hospice Interdisciplinary Team.

Fluids Decisions

When it becomes difficult or impossible to drink fluids, several problems occur. Forcing fluids can cause choking or inhaling fluid into the lungs. For most people at the end of life, IV fluids cause increased lung congestion and swelling or edema (fluid in the tissues).

There are a few conditions in which IV fluids may add to comfort and better balance in the body. In most cases, at the end of life, the individual wants and needs less fluid and is more comfortable if not forced.

IMPORTANT: When people cannot eat or drink, mouth care is important for comfort. The nurse can teach family members and caregivers how to use swabs to clean the mouth and teeth. Do not use mouth rinses or swabs with alcohol or lemon juice; they will dry out the mouth and may cause pain if there are open areas.

Nutritional Decisions

At some point, almost everyone with a terminal illness eats less food and eventually no food. For some people, physical problems interfere with eating. In that case, the Iowa City Hospice nurse can help find alternative ways of getting nutrition. But for many others, it's a matter of losing their appetite.

- The Iowa City Hospice Interdisciplinary Team can provide support when difficult feelings are experienced related to food issues. When someone cannot eat, it often means the disease is progressing and days are growing short. It may be helpful to find other ways of providing comfort at this time.
- The Iowa City Hospice Interdisciplinary Team can provide support when someone cannot eat or can eat only a little. Family members and caregivers worry about starvation, about weight loss, about whether they are doing all they can. For the person who has traditionally prepared meals, providing pleasure and comfort, it can be stressful to give up that role.
- The Iowa City Hospice Interdisciplinary Team can help find ways of including everyone at mealtime, even if eating is not possible. Meals often are a social time as well, and many holidays and celebrations center on a festive meal. For these reasons, giving up meals can be very stressful. The Iowa City Hospice Interdisciplinary Team also can suggest alternate ways of socializing and celebrating when big meals are no longer appropriate.

Sedation Decisions

In most cases, pain and other symptoms can be managed so that the end of life is comfortable. In some *rare* cases, even aggressive efforts to make a patient comfortable do not work. It may be possible to offer drugs that induce sedation in such cases so that intolerable symptoms are not experienced at the very end of life.

If a patient is sedated, he or she may be brought out of sedation periodically to determine if symptoms might have lessened or stopped. (Please note that at the end of life, it is not uncommon for people to slip into a coma, so they may not awaken even if sedation is stopped.)

When a person is sedated, all comfort and hygiene measures continue.

Resuscitation Decisions

Iowa City Hospice **does NOT require that a patient have a Do Not Resuscitate (DNR) order** in place before admission to Iowa City Hospice.

Cardiopulmonary resuscitation (CPR) was developed to restart breathing and heartbeats in a person who has *suddenly* lost breathing and circulation, such as when a heart attack, drowning, or electrocution has occurred. The person is otherwise in relatively good health, but an accident caused the problem. CPR works in some of the cases, but is much less successful in a diseased body.

Even in healthy people, CPR can cause harm (broken ribs, lacerated liver, etc.). At the end of life, CPR could be painful for the patient, and traumatic for the family and caregiver.

It is very important for every patient, family and caregiver to discuss their feelings and intentions related to resuscitation.

- The Iowa City Hospice Interdisciplinary Team and the patient's physician can help talk through special situations so the best decision can be reached.
- The Iowa City Hospice social worker can help prepare Advance Directive documents. For the convenience of patients, families and caregivers, Iowa City Hospice social workers are Notary Publics. They can come to the patient's home or facility to notarize important documents such as the Durable Power of Attorney for Health Care or Financial Durable Power of Attorney.
- The Iowa City Hospice team can work with the patient's physician to write an IPOST (Iowa Physician Orders for Scope of Treatment) order, if so desired.

Calling 9-1-1

Call Iowa City Hospice at **800-897-3052** if the patient's breathing has stopped.

It is not necessary to call 9-1-1 or an ambulance for the normal expected death of an Iowa City Hospice patient.

Although it is always the family's or caregiver's right to call 9-1-1, please keep in mind that, unless a Do Not Resuscitate (DNR) order is executed, Emergency Medical Treatment staff must start resuscitation efforts if the patient is not breathing.

Please note that you may be responsible for the cost of transportation and related medical/hospital charges.

How to Call Iowa City Hospice

1-800-897-3052

During office hours, you will be connected to the Iowa City Hospice office Nurse.

After hours press "1" to be connected to the on call operator.

Ask them to: **"Call the Iowa City Hospice nurse on-call."**

The operator will ask for information and the Iowa City Hospice Nurse will return your call immediately.

If you do not hear back within 15 minutes, call again and ask to be connected directly to the Iowa City Hospice Nurse.

SECTION 4: For a Safe, Manageable Home

Staying Safe

- **Bathroom hazards.** Many bathrooms need some safety features added when someone is being cared for at home:

Tub/shower hand rails	Toilet handrails & seat riser
Non-slip tub strips	Non-skid bath mats
Lower water temperature	Bath supplies within reach

- **Electrical hazards.** Check for these possible problems:

Frayed cords	Overloaded outlets
Extension cords	Cords or appliances near water

Note: Do not alter 3-prong (grounded) plugs. Hospital beds and oxygen concentrators require 3-prong grounded outlets.

- **Falls.** Look around each room. What might cause someone to trip or slip? Think about the following hazards:

Rugs and carpets	Cords and cables	Furniture corners
Stairs	Uneven surfaces	Clutter
Dark areas	Wet spots/leaks	

- **Weapons.** Iowa City Hospice asks that any weapons be secured and stored for the safety of everyone.

Fire Safety

- Check for smoke detectors with good batteries, and extinguishers that are up to date, and ensure the family and caregiver knows how to use them.
- A patient can be moved by placing them on a rug or blanket and dragging them from a dangerous situation.
- Have a plan to move the patient out of the house.
- Never smoke when sleepy or groggy from drugs or when oxygen is in the home.

Storm Safety

- **Dangerous weather.** If there is danger of a tornado, move the patient to a room without windows if possible. Pull the patient on a blanket if necessary. If the patient cannot be moved, close the curtains, move away from windows, and cover the person with blankets and pillows.
- **Power outages.** In the event of electrical failure, an oxygen tank can be used. Spare tanks can be kept for this purpose. Never use candles or gas/kerosene heaters around oxygen.

Equipment Safety

- **Practice with the nurse.** The Iowa City Hospice nurse will make sure the patient, family and caregiver are comfortable and knowledgeable about new equipment (such as walkers, wheelchairs, canes, hospital beds, oxygen tanks and concentrators, suction).
- **Oxygen.** Iowa City Hospice will arrange for oxygen when needed. The oxygen company will check for hazards, such as smoking, pilot lights, and candles. Oxygen can saturate cloth much like water can, so after the oxygen is turned off, it is still dangerous to have an open flame.

Medication Safety

- **Storage.** Each medication needs to be stored according to directions. If they are not, they may not be effective; their chemical nature might be changed. Some medications must be kept in the dark, so they have dark bottles. Do not move them to other containers. Some drugs must be kept cold.
- **Access.** Keep medications from pets and children. Use safety caps. Iowa City Hospice has lock boxes available when needed.
- **Avoid drug errors.** It's not unusual for Iowa City Hospice patients to take many drugs. And it's not unusual for drugs to be changed frequently.
 - Never place one drug in the bottle from another drug.
 - Many drugs look alike. Double-check in good lighting.

- **Safe disposal.** If there are medications in the home that are not being used, the Iowa City Hospice nurse can advise on safe disposal.
- **Avoid drug interactions.** Sometimes people think over-the-counter drugs are harmless or less potent than prescription drugs. It is important that the patient's physician and Iowa City Hospice nurse know *all* the drugs being taken, even medicines for colds, headaches, constipation, and herbal and nutritional supplements.
- **Never use someone else's drugs.** Sometimes two drugs can be very dangerous when taken together. Sometimes they simply make one another less effective.
- **Keep an up-to-date list of drugs** for use in the home and to take to medical appointments.

If there is a problem: If the wrong drug is taken, taken at the wrong time, too much or too little, or a dose has been missed, call and tell the Iowa City Hospice nurse.

Managing Trash and Waste

In most cases, trash can be handled as any household trash is handled. Iowa City Hospice can help with disposal of the following:

- **Needles.** To protect family members, caregivers and trash collectors, needles should never be placed in the trash. Iowa City Hospice will provide a heavy plastic bottle that has a cap for disposal of used needles. Return the container to Iowa City Hospice when full. Never stuff needles into a full container, as a needle stick may occur, and cause an infection. If there is a needle stick, call the Iowa City Hospice nurse or personal physician.
- **Soiled laundry.** In most cases, laundry can be done at home as always, though it may be preferable to do heavily soiled laundry separately. Because some patients are sensitive to odors, unscented laundry products may be helpful.
- **Dressings/pads.** Soiled dressings and pads should be handled with gloves. Many can be placed in the regular trash. Wash hands after handling pads or dressings.

- **Body fluids.** Urine, stool, suctioned liquids and other fluids usually can be flushed.
- **Spills.** If body waste spills, gloves can be used to clean up, and hand washing should follow. If there are any liquids or materials of concern, contact the Iowa City Hospice nurse to discuss cleanup techniques.
- **Universal Precautions.** For the safety of patients, family members, caregivers, and Iowa City Hospice team members, a Universal Precautions kit, including hand sanitizer, CPR mask, cat litter (see Guidelines for Medication Disposal on the next page), goggles, gown, shoe covers, antiseptic wipes, paper towels, cap, face mask, alcohol pads, trash bags, biohazard bags, disposable aprons, sharps container, antibacterial soap and gloves, is provided.

Hand Washing

In a world of high-tech solutions, nothing beats hand-washing for preventing infections. Infected fluids and solids get onto skin, clothing, bedding, and dressings. It is very easy to transfer infection to eyes, mouth, food, or a crack in the skin. Hands should be washed before and after caring for a patient.

Hand washing dries skin and causes cracks too small to see. Use hand lotion after washing. If a family member's or caregiver's hands do have cracks, gloves should be used to handle potentially infectious materials.

Patients, family members and caregivers do not need a cold or cough. Again, careful hand washing can help stop the spread of illness. Masks are available for people who have coughs.

Iowa City Hospice can help family members and caregivers avoid uncomfortable situations by making a sign announcing that *Iowa City Hospice* requests that ill visitors postpone their visit.

Guidelines for Medication Disposal

Once a common practice, the disposal of unused medication in sinks and toilets is no longer recommended. Sewage treatment plants are not designed to remove these chemicals, and current studies reveal the presence of pharmaceuticals in our lakes, rivers, and drinking water. Iowa City Hospice has implemented a method of disposal that helps prevent unused medications from contaminating water supplies.

After a death, the task of disposing of what is often a large amount of unused medications can be daunting. The following guidelines are suggested for the disposal of unused medications:

- To safeguard private health information, cross out personal information on the medication containers. A black, permanent marker is helpful.
- Keep medications in the original containers when feasible. If not, a plastic container such as a beverage container with a screw-top lid may be used. Multiple medications may be placed together in a single, large container that can accommodate larger volumes of waste.
- Render the drugs unusable and prevent the unintended ingestion of discarded medication with these techniques:
 - **Liquids and IV medications:** Add cat litter or flour to the container and recap. A funnel may be helpful.
 - **Tablets and capsules:** Add rubbing alcohol or water to the container, followed by cat litter or flour. Recap the container.
 - **Suppositories:** Add cat litter or flour to the container and recap.
- Place all medication containers in a plain paper bag to discourage identification and tampering. Dispose of the bag in the trash bin.

SECTION 5: Caregiver Resources

The caregiver for an Iowa City Hospice patient may have many questions and concerns. Daily tasks may seem endless and, at times, the challenges are overwhelming. A caregiver gives the gift of being with a loved one even when that is very difficult. The Iowa City Hospice Interdisciplinary Team provides support, teaches the caregiver (how to lift, move a person in bed, give medications, support emotional responses) and is a resource to make the job easier. The Iowa City Hospice Interdisciplinary Team supports caregivers through the stress, fatigue, and ups and downs of the caregiving experience.

- **Take care of the caregiver.** Sometimes caregivers think worrying about themselves is selfish. In fact, there is no way to provide such demanding care for a loved one if the caregiver does not take good care of himself or herself.

Each caregiver's experience is unique, but here are a few principles that are useful for most caregivers:

- **Be flexible.** Just when everything is figured out, it will change. When medications are set up, a new one will be ordered. When the patient finds something he or she will eat, the next day it won't sound so good. Change happens.
- **Use the help that is available.** Many times, when a suggestion is made, such as to try a hospital bed or to start hospice aides for baths, people resist change—they've had about all the change they can stand. It may help to accept a trial period. The end result might be, "Why didn't we do this earlier?"
- **Let friends pitch in.** Accepting help may be uncomfortable, but most people are grateful for a chance to help. Letting friends help is actually a gift to them.
- **No one is alone under Iowa City Hospice's care.** Ask for help.

A Caregiver Resource

Go to www.seriousillness.org/iowacity

Yours is an important job!

You shoulder many responsibilities caring for a friend or relative who is seriously ill. You may also have strong feelings arise as you watch your loved one coping with the difficulties of poor health. Iowa City Hospice proudly offers this educational resource to support you, your friends and family who so tenderly care for your frail or ill loved ones. **You are not alone.**

Educational Articles

Whether you are concerned about your loved one's eating habits, or are coping with feelings of grief or hopelessness, you can get sound advice regarding a wide array of topics:

- Medical Concerns
- Emotional-Spiritual Issues
- Important Decisions

Caregiving Tips

Managing pain, easing fatigue, helping with bathing...these are just some of the many ways that family members support an ailing loved one. You can learn simple tips for making daily life more comfortable for you and the person you care for. Print out these articles, or email them to a friend or family member.

Directory of Community Programs

You are not alone. There are programs available to help. We have an extensive list of national, state and local services geared to assist you in your current situation.

Links to National Resources

The Internet has so much information to offer, it can be overwhelming. We assist you by providing links to credible websites with information based on current research.

Monthly E-Newsletter for Families

Once a month, we bring you topical articles with information that will make your life easier. >From tax tips for family caregivers to coping with depression, we give you up-to-date advice from national experts. Subscribe today and tell a friend. It's free!

Information & Ideas for Hands-on Care at Home

Iowa City Hospice strives to:

- Provide the patient, family and caregiver exceptional care.
- *Prevent* problems.
- Treat problems with the best methods available.
- Address related emotional and spiritual issues.
- Teach and support the family and caregiver.
- Provide appropriate supplies and equipment.
- Keep communication open among the patient, family, caregiver and the Iowa City Hospice Interdisciplinary Team.

Patients, families and caregivers can help by:

- Reporting any problems right away.
- Writing down concerns to discuss with the Iowa City Hospice Interdisciplinary Team.
- Being open with the Iowa City Hospice Interdisciplinary Team when not happy with services.
- Letting a member of Iowa City Hospice's Interdisciplinary Team know when instructions are not understood.

There is no one plan that fits every caregiving situation, but there are some **general principles** for caregiving at home.

The Iowa City Hospice nurse will teach caregivers how to do the care that is needed in each particular case, and will bring the necessary equipment and supplies.

The following pages contain suggestions, and they are just that—suggestions.

Bathing

Bathing another person is more than washing skin. It is a delicate balance of cleansing the body, preserving dignity, promoting independence, and acknowledging loss of independence.

Some people are very modest, and it is stressful to be bathed by another person. For some people, a bath given by a hospice aide may be easier than one given by a family member. For others, having a family member is more comfortable.

Modesty/privacy

- Try to keep everything covered with a sheet or towel except the area being washed.
- Make sure there will be no interruptions during the bath. Place a sign on the door, if necessary.
- If the patient is able, offer him or her the washcloth to clean private areas by him or herself.

Equipment

The Iowa City Hospice nurse or hospice aide can teach how to give a tub or bed bath or assist with a shower. They will help teach the use of equipment such as tub rails, shower chairs, and shampoo trays.

Soap

Talk with the Iowa City Hospice nurse about soaps and lotions that are best for skin care.

Safety

Tubs and wet floors always pose a safety problem, and when someone is weaker than usual, there is increased risk. Install non-skid strips in the tub, use a tub/shower chair and rails, and make sure floors are dry.

Bowel Function

It is never easy for people to discuss personal issues such as bowel function with family members, caregivers, doctors or nurses. Unfortunately, bowels are affected by most diseases, by many drugs, by radiation and chemotherapy, by diet changes, and by immobility. It is likely anyone with a terminal illness will run into constipation, diarrhea, gas, and/or incontinence problems at some point.

- Bowel problems are part of nearly every hospice patient's life at some time. The Iowa City Hospice nurse is used to talking about bowels, sometimes at every visit.
- If problems occur between visits, it is important to call and report them.
- Since there are different causes for bowel problems, it is very important to find out what is causing the problem so the correct treatment can be used.
- Bowel problems are much easier to solve if they are caught early.
- It is important to work with a physician or the Iowa City Hospice nurse before trying to solve bowel problems. The wrong method may postpone relief and may even make the problem worse.

Breathing

Breathing problems can be caused by disease, drugs, pain, immobility, or weakness. The Iowa City Hospice Interdisciplinary Team will try to determine the cause so that the best treatment can be chosen. (If the cause is unknown, symptoms still will be treated.)

If oxygen is needed, the Iowa City Hospice nurse will review how to use it effectively and safely. Smoking and other open flames must be eliminated. Spare oxygen tanks will be available to use in case of power failure. Portable tanks may be useful for use outside of the home.

For the family and caregiver, breathing problems may be difficult to watch. The Iowa City Hospice Interdisciplinary Team will provide information and support.

Treatments for Shortness of Breath:

- Raise the head of the bed. Move arms away from the body. This gives lungs more room to expand. Use pillows to support the head and arms.
- Try a fan. Moving air feels refreshing and can ease breathing.
- Calm the environment to reduce stress.
- Report any pain as it can keep the patient from taking a deep breath.
- Talk with the Iowa City Hospice social worker about relaxation methods.
- Save energy by letting others help.

Treatments for Lung Congestion:

- A cool mist humidifier may help.
- Coughing may help loosen secretions.
- Inhaled medications may help clear the lungs.

Treatments for Mucous:

- Try bubbly soda, especially colas, if tolerated.
- Cough and breathe deeply.
- Clean the mouth with sponge swabs.
- Talk with the Iowa City Hospice nurse—some medications may help.

Confusion, Disorientation, Hallucination

Few things are more worrisome to patients than the possibility they may become confused or disoriented. They are concerned about what they might say or do if this happens. And few things are as difficult for family members and caregivers as a confused, disoriented, or hallucinating patient. Again, both disease and medications can cause these problems.

- Make sure the patient is safe.
- Orient the patient to the people, the time, and the place.
- Speak slowly and calmly.
- Do not argue with confused statements.
- Ask for support from the Iowa City Hospice Interdisciplinary Team.
- Take a break. Let other family members or caregivers provide respite.
- Know that the patient is still present despite temporary physical changes that are causing the behavior.

Cough

Coughing can be related to disease, to something in the environment, or to a simple cold or allergy. No matter the cause, it can prevent sleep and cause pain. The Iowa City Hospice nurse and the patient's physician will try to determine the cause so they can target the best treatment.

- Medications may help thin mucous and quiet the cough.
- A cool (not hot) mist humidifier may help.
- Over-the-counter cough syrups, drops and lozenges may help, but check with the nurse to make sure they don't interact with other drugs.
- Try removing flowers, pets, etc. from the room to see if it reduces coughing.
- Make sure no one smokes in the room with the patient.
- Drinking non-dairy beverages may help thin secretions.

Emotions

Under the best of circumstances, we have our own unique emotional lives, so it's not easy to generalize how an individual will react to a terminal illness. It is normal and common to experience many different emotions related to loss.

- **Anger** can occur in the most even-tempered people. Stress, fear, and discomfort contribute to anger. Thoughts of multiple losses and unfinished business also can cause resentment and anger. Anger burns energy and interferes with relationships if it persists. Talking it out can be difficult, but it may provide relief.
- **Guilt** is also a common response to illness. Some people think they have caused the illness or should have prevented it or caught it earlier. Again, sharing these feelings—letting them out—is important.
- **Depression** about the illness and losses is common. It may feel as though depression will never end but it usually does. If depression does not lift or if it grows worse, counseling and medication are often effective treatments.
- **Anxiety** is understandable when the future is uncertain. People worry about how they might feel, how they will handle themselves, how their family will fare. Iowa City Hospice social workers and spiritual counselors are trained to help talk out fear and uncertainty that underlies anxiety. In some cases, medication may also help.
- **Intimacy and sexuality** are affected by serious illness, but few people talk about this. Being touched, feeling attractive, and being close are important to most people. Changing bodies, weakness, and discomfort interfere with closeness. Family members and caregivers may fear hurting their loved one by touching or holding them. Talking openly about feelings of loss, and about what is desired and tolerated by each person can help nourish intimacy and relationships. The Iowa City Hospice social worker can assist in finding satisfying and comfortable ways of maintaining intimacy.
- **Sadness and grief** are common reactions to illness and loss. The Iowa City Hospice social worker can help with these feelings.

Fatigue and Sleepiness

Fatigue often increases slowly throughout an illness and treatment. It is difficult to treat and can be one of the most distressing symptoms for patients and families.

- Limit daytime naps to improve sleep at night.
- Let someone else do tasks that are less important to save energy.
- Cut down light, noise, and interruptions during sleep.
- Stick to the same routine before sleep.
- Talk with the Iowa City Hospice social worker or spiritual counselor about concerns or anxieties that are interrupting sleep.
- Talk with the Iowa City nurse about checking medication schedules for drugs that might sedate or stimulate the patient at the wrong time of day.

Immobility

When it is difficult to walk, there are several major concerns.

- Weakness, unfamiliar devices such as canes or walkers, and fatigue all increase the risk of falls.
- Wait a minute for the body to adjust to each new position. Move slowly to prevent dizziness. Look ahead, not down at the floor, to prevent dizziness.
- Losing the ability to get around by oneself is very difficult. Talk it over with family members, caregivers and the Iowa City Hospice Interdisciplinary Team. Allow and hear expressions of loss.
- Taking care of someone who cannot move is tiring. It means more time spent, more strain on the back, more equipment around the house.
- The Iowa City Hospice nurse can teach ways of moving and lifting and how to use equipment such as wheelchairs, gait belts, mechanical lifts, walkers, or draw sheets.

Mouth Care

Illness, diet changes, decreased fluids, and some medical treatments can cause mouth problems, including dryness and sores. As with any skin, it is important to check the mouth for problems and call the Iowa City Hospice nurse if there are red areas, bleeding, cracks, swelling, or if there is pain. A sore mouth affects nutrition, mood, and socializing. It is important to prevent problems and treat any that occur.

- **Brushing.** If the mouth is dry or sore or the patient cannot tolerate normal brushing, a very soft toothbrush or sponge mouth swab may be used. Clean gently.
- **Dentures.** Many times, after a long illness, dentures no longer fit. Poorly fitting dentures can cause sores. Talk with the Iowa City Hospice nurse. Keep dentures clean by brushing and using cleansing tablets.
- **Rinses.** Many mouth rinses contain alcohol or lemon that can dry the mouth and cause pain. Use plain water or very diluted rinses.
- **Moisture.** A dry mouth is vulnerable to cracking and pain. Keep clean water and gentle swabs handy. Keep lips moist with balms or lip creams. Oral gels and artificial saliva may help if dryness is a problem. Keep water at the bedside. Frequent sips may help. A straw or syringe may be used to give sips of water if choking is not a problem.
- **Food.** If the mouth is sore, eat soft, bland, and moist food.
- **Medications.** There are pain medications for sore mouths. The timing of these medications is important, because fluids can rinse them away before they ease the pain.

Nausea And Vomiting

Nausea and vomiting are problems that can have many causes: disease, drugs, treatments, constipation, or a combination. Sometimes the cause cannot be determined, but the symptoms will be treated.

- Bland foods may be more appealing than spicier dishes.
- Moderate temperatures may go down better than hot or cold.
- Smaller, more frequent meals may put less stress on the stomach.
- Red meat and fatty foods are not well-tolerated.
- Overly sweet foods may cause problems.
- Perfumes, aftershave, other toiletries, and smoke all can cause nausea.
- Give anti-nausea drugs as ordered. The timing is important. Some medications are taken on a regular schedule, some are taken before meals, and some are taken only if nausea occurs.
- If vomiting occurs within 30 minutes of taking pills, they may need to be retaken. Check with the Iowa City Hospice nurse before retaking pills.
- If pills don't stay down, some drugs can be given rectally.
- After eating or drinking, try sitting with the head of the bed up for at least one hour.
- Apply a cool cloth to the forehead.
- Provide good mouth care after vomiting.

Pain

Pain is the symptom most people worry about when facing a serious illness. One reason is that, historically, pain treatments were not well-researched and not used very well. There are now excellent ways to control pain, and nurses and physicians are much better educated about how to treat pain. From pills to patches to IVs to drops under the tongue to suppositories, pain now can be attacked from many angles.

- Pain is NOT a normal part of the dying process. With current therapies, pain can be treated and is not an inevitable part of death.
- Pain relief is a high priority and unrelieved pain is treated as an emergency for patients under the care of Iowa City Hospice.
- Almost all pain can be relieved to an acceptable level. It may take time to find the correct drug and to reach the effective dose.
- It is very rare that pain cannot be relieved. In such cases, hospitalization may be necessary to treat pain. In rare instances, sedation is an option.
- Not everyone has pain. Not all pain gets worse.
- Not all pain is related to disease. People with heart failure or cancer still get common colds, tension headaches and sore muscles.
- There is no benefit in tolerating pain. There may be harm.
- Pain has an effect on the body. It causes stress and the release of stress hormones. It increases fatigue and weakness. It causes muscle tension. It causes the patient to remain still, increasing problems caused by immobility.
- Pain has an effect on the spirit. It can increase fear and depression.
- Pain has an effect on the family and caregivers. Everyone suffers when one person suffers. They share the pain. They feel inadequate as caregivers.
- It helps if the pain can be described and good records are kept. A good description of pain helps the Iowa City Hospice. Interdisciplinary Team choose the right method of pain relief, the right dose of medication, the right schedule for the medications.
- In describing pain, many people are comfortable using numerical scales. If numbers are not useful, ask the nurse about scales made with colors (the patient chooses a color to represent levels of pain) or faces with expressions

from happy to very pained. The right pain scale is the one that works for each individual.

- As with most things related to pain, it's very personal. Following are examples of words that some people have used.

Sharp	Electric	Stabbing	Squeezing
Lightning-like	Pulsing	Tugging	Burning
Aching	Pressing	Piercing	

- Knowing where the pain is might help determine the cause. Oddly, pain can travel along a nerve or cause a reaction in a distant nerve, so the pain may not be right over the problem area.
- Questions about pain and time:
 - When did the pain start? What makes it start?
 - How long does it last?
 - When does it get worse? When does it get better?
 - How long after taking a medication did it start to work?
 - How long did the relief last?
 - What is the pain rating an hour after taking the medication?
- Pain relief is a team effort. It requires communication among the patient, the family, the caregiver and the Iowa City Hospice Interdisciplinary Team.
- Sometimes treating pain from several angles with a combination of drugs is very effective. Perhaps an opioid or narcotic drug might stop pain by affecting the nerve, while an anti-inflammatory drug, such as ibuprofen, decreases the inflammation.
- Drugs are not the only pain treatment. Sometimes chemotherapy, radiation, or surgery are used to relieve pain by reducing the size of a tumor or unblocking a clogged tube.
- Heat, cold, massage or relaxation techniques may help reduce pain.

Narcotics Facts

Addiction

- It is common for people to worry about addiction when pain drugs are suggested. Drugs used properly to treat pain do not cause addiction. Addiction does not come from use but from *abuse* of drugs.
- Persons with pain severe enough to require opioid treatment rarely become addicted to the drug.
- Withdrawal symptoms are due to physical dependence, not addiction.
- Physical dependence is a normal response to opioid therapy.
- Withdrawal symptoms are avoided by tapering of opioids in patients who no longer have pain.

Tolerance

- Persons on opioids develop tolerance to the medication over time.
- Higher doses are needed to provide relief. The common drugs used to treat severe pain can be gradually increased if the pain increases.
- There is no “ceiling” on the dose of opioids.
- Often times patients in palliative care require very large doses of opioids to treat pain.

Pain Medications

- Consistent pain should be treated with continuous pain medication.
- It is easier to prevent pain than to try to treat it when it is out of control. Postponing pain relief may actually let the pain get worse and require even more medication to bring it back under control.
- Iowa City Hospice uses the least invasive measures first, the ones that cause the least disruption in the patient's life.
- Pain drugs do not shorten life when administered properly.
- Pain drugs are safe when prescribed, monitored by the physician and taken as directed. Like almost any drug, taking too much or too often is dangerous. On the other hand, studies show uncontrolled pain can shorten the life span.

Side Effects

- Strong pain medications may have side effects such as sleepiness, nausea, or constipation. Some side effects can be alleviated by starting with a low dosage and escalating slowly as needed.
- Sleepiness and lethargy are common concerns; these side effects usually subside in 48 to 72 hours after a steady narcotic dose is maintained.
- Constipation is a continued side effect and must be treated appropriately.

Poor Appetite

Loss of appetite is normal as one nears the end of life, but it still can be very stressful. As appetite lessens, the following suggestions may help. The Iowa City Hospice nurse will help treat nausea and constipation to reduce the effects on appetite.

- Usual mealtimes may not work for someone with an unpredictable appetite. Snacks available in the refrigerator or at the bedside allow for eating whenever food looks good. Frequent nibbling may be easier on the stomach than bigger meals.
- The usual amount of food eaten will change. Pressure and forcing will only make the problem worse and may cause nausea or vomiting.
- Try avoiding liquids for an hour before meals as they can make one feel full.
- Favorite foods may lose their appeal. It's not unusual for someone who is ill to make a special request and then when it's ready, say it no longer sounds good.
- Avoid foods with strong odors or keep them covered.
- If serving pureed foods or other special diets, use garnishments to make them attractive.
- Supplements (liquids and puddings) are a way to get calories and protein without eating big meals.
- A sore mouth or sore teeth will hurt anyone's appetite. Report it to the Iowa City Hospice nurse.

Restlessness, Agitation, Anxiety

Restlessness (moving constantly, picking at covers, moving legs up and down) and agitation (a need to get up and move or “do something,” feeling distressed, feeling a sense of urgency, sometimes without knowing the cause) can be very upsetting for family members and caregivers.

Many diseases change the chemistry of the body and this can cause restlessness. Drugs and worries can contribute to the problem as well.

The Iowa City Hospice Interdisciplinary Team will try to identify the cause so the best treatment can be chosen. Sometimes it is not possible to isolate one cause, but the symptoms still can be addressed.

- Keep the environment calm and quiet. Lower the lights, turn the TV volume down, ask visitors to speak softly.
- Pain can increase anxiety. Make sure pain is treated.
- Check urinary function. A full bladder that cannot be emptied can create anxious behavior and considerable pain.
- Ask the Iowa City Hospice social worker or nurse about relaxation breathing.
- Being around a restless, anxious person can make others feel the same way. Speak as calmly as possible.
- Think about safety of someone who is moving a lot or wants to move about. Prevent falls, pad bed rails, and move objects that may be knocked off a table. If there is a catheter in place, make sure it cannot be pulled out.
- Call the Iowa City Hospice nurse. He or she and the physician will discuss treatments or changes that may help.
- The Iowa City Hospice social worker or spiritual counselor can also offer support.

Skin Care

Clean, healthy skin is important for comfort and for dignity. Both illness and immobility threaten skin, so the Iowa City Hospice team, the family and the caregiver need to:

- Report and treat any skin discomfort or problems.
- Prevent skin problems by encouraging or assisting the patient to change positions frequently.

The skin should be checked every day. A good time to do this is during the bath or when changing clothes. Look for:

- Redness or darkened areas.
- Cracked or dry, peeling skin or open areas.
- Warm areas.

Check these areas:

- Inside the mouth for unhealthy teeth or sore areas on the gums or tongue.
- Areas near any wounds, especially if there's drainage.
- Areas exposed to urine and stool.
- Bony areas that rub on the bed or against other bony areas, including elbows, sides of knees, inside knees where they rub together, hip bones, ears where they rub on the bed, back of the head, heels, bony sides of the feet, shoulders, spine, shoulder blades, tailbone and buttocks, hands if they rub against bed rails.

Preventing Problems

Common causes of skin problems are rubbing of skin on skin or skin against objects, dragging (shearing) of skin across surfaces, soiling, moisture, and pressure.

Rubbing. Be aware of areas rubbing back and forth against other bony areas or furniture. A person lying on her side may rub the insides of her knees and the bones inside her ankles together. A person lying against a bedrail or sitting with elbows against the recliner upholstery may experience rubbing against skin.

Prevention: Place soft towels/sheets/blankets/pillows between areas that may rub together. Examples: When a person lies on his side, place a small pillow between his knees. When a person has bed rails, pad them so that hands and feet don't rub against metal.

Dragging or shearing. When a patient is pulled across sheets or a chair, skin may stick and then drag against the surface. It may tear or wear through. Wrinkles and crumbs can tear at skin, too.

Prevention: The Iowa City Hospice nurse will educate on turning and moving the patient without dragging by using a draw sheet. Make sure clothing is easy to change so it won't be dragged against skin.

Soiling. Urine and stool, sweat, and wound drainage all are caustic to skin if not washed off frequently.

Prevention: The Iowa City Hospice nurse will work with family members and caregivers to manage urine and stool. There are padded pants and under pads, catheters, and other supplies that will help keep the patient clean and dry. To prevent dryness, lotions and gentle cleansing without drying soaps are helpful.

Moisture. Damp skin (from sweating, urine, humidity) is more vulnerable to infection and to breaking open. Dry skin is more fragile. Avoid extra baths.

Prevention: Keep the patient dry. Sometimes a towel or flannel sheet will help absorb perspiration.

Pressure. Pressure ulcers or bedsores occur when bone presses down onto beds or chairs. This can happen to the tailbone, buttocks, knees, feet, shoulders, spine, ankles, back of the head, ears, elbows and other areas. When we sit, our bones push down onto the chair seat. When we lie down, our bones push down on the bed. The skin is trapped between the bone and the bed or chair. When it is pushed on, blood is squeezed out of the area, so no oxygen or nutrition can get to the skin. Cells can begin to die within a few hours or less. Also, bone rubs against the skin. Such sores are very difficult to heal, so prevention is important.

Prevention: The most important way to prevent pressure sores is to change positions frequently. It does not have to be a major change, just a shift so that the skin gets a rest. If necessary, set a timer as a reminder to turn or shift, even at night. Gentle massage can increase circulation, but vigorous massage may harm tissue under the skin.

Swallowing

During the final days of life a patient may stop having the ability to swallow. This is normal. The Iowa City Hospice nurse can work to try thickened liquids or other dietary devices and teach how to prevent choking.

Urinary Function

As many diseases reach the last stages, urine may change in amount and appearance and may become strong smelling. The amount of urine becomes less and less. The color may darken, becoming dark orange or rust colored. This is normal near the end of life.

- As the patient weakens and perhaps becomes less responsive, it may be impossible to get to the bathroom or even a bedside commode.
- There are many kinds of padded underwear and bed pads available. For some people, a catheter is appropriate.
- Urine that *suddenly* stops flowing, that appears bloody or changes color, should be reported to Iowa City Hospice right away. Cloudy or strong smelling urine may indicate infection. Pain during urination also may indicate infection.
- The Iowa City Hospice nurse will teach the appropriate cares for the patient, and provide necessary supplies and equipment.

Weakness

Increasing weakness is to be expected at this time of life.

- Consider priorities. Save energy for what matters the most. This might mean accepting help getting bathed and dressed so that there is more energy to talk with a special visitor.
- Think safety. Weakness is difficult to accept, but a fall can have much worse ramifications.
- Support. Weakness can bring a sense of loss for what can no longer be done. Sharing those feelings may help.

SECTION 6: Final Days

Easing the Last Days

Following are some suggestions that may help as the end of life nears.

- Remember the importance of touch.
- Simplify tasks.
- Calm the environment. Dim bright lights, reduce sound. Do whatever brings peace.
- It is all right to limit visitors.
- Talk to, not over, the patient. He or she may be able to hear even though there seems to be no response.
- Visitors should announce their presence when entering the room or sitting at the bedside.
- Medications may be reduced or discontinued. Do not fear that this means Iowa City Hospice is no longer caring for the patient. The patient may no longer need many drugs and may be more comfortable without them. Those that are important for comfort will be continued.
- Likewise, certain therapies and tests may no longer be appropriate.
- Skin and mouth care continue to be important for comfort.
- It may help to convey to the patient how important he or she is to loved ones. Sometimes it is difficult for people near death to let go until they feel they have permission from the family and caregiver.
- This is a time for loved ones to think about what has been left unsaid. Family members and caregivers might express gratitude, make an apology, or tell the patient how he or she will be remembered.

Nearing the End of Life

As the end of life approaches, most people slow down gradually. At times, death has been expected for several days, goodbyes have been said, and death is peaceful. Some people die gradually and some die suddenly.

Signs of Decline: The Dying Process

Early or first signs:

- The patient may withdraw from people.
- Appetite and thirst decrease and then disappear.
- There may be restlessness. Some people pick at bedclothes.
- Sleep and weakness increase. Responsiveness may decrease.
- The patient may think, dream, or talk about people who have died.
- Days and nights may be confused.

Later signs:

- Urine and bowel output drops off. Urine may become dark as kidneys shut down.
- Breathing slows and become shallow. Congestion may cause a rattling sound. There may be long pauses between breaths.
- Skin may cool, especially on hands and feet, and become darker or slightly yellow.
- Sometimes sweating increases.
- Lips and mouth become dry.
- Bowel and bladder control is lost.

Signs Death Has Occurred

- Breathing stops. A few reflexive breaths may occur for several minutes.
- Skin may become pale or grayish.
- There is no pulse.
- Bowel and bladder may empty.
- The chin may drop and mouth remain open.

What to Do When Death Occurs

Call Iowa City Hospice 800-897-3052

During office hours, you will be connected to the Iowa City Hospice office Nurse.

After hours press "1" to be connected to the on call operator.

Ask them to: **"Call the Iowa City Hospice nurse on-call."**

The operator will ask for information and
the Iowa City Hospice Nurse will return your call immediately.

If you do not hear back within 15 minutes, call again and ask to be connected
directly to the Iowa City Hospice Nurse.

DO NOT call 911

Frequently Asked Questions

at the Time of Death

What should be done first at the time of death?

CALL IOWA CITY HOSPICE at 800-897-3052.

If a family member or caregiver is alone, we encourage calling a friend or family member. **Do NOT call 9-1-1 or call for paramedics.**

The Iowa City Hospice nurse will visit to make necessary phone calls and provide support.

What should be done next?

Note the time of day that the patient totally stopped breathing:

Who will contact the funeral home?

The Iowa City Hospice nurse.

What about the death certificate?

The funeral home will obtain the death certificate and provide the family with a limited number of copies.

What should be done with the medical equipment?

The Iowa City Hospice staff will call the medical equipment companies to have the equipment picked up. The companies will usually call the family within a day or two to arrange a pickup.

What should be done with all the leftover medications?

The Iowa City Hospice nurse will assist in disposal of medications.

Will there be someone there to help after the death?

Iowa City Hospice stays in touch with families and caregivers for at least 13 months after the patient's death. A bereavement counselor will contact the family members and caregivers approximately a month after the death of the patient, and regularly thereafter.

We strongly encourage family members and caregivers to call us for help—any time.

SECTION 7: Grief Support Services

As part of our care, we offer grief support without charge to anyone served by Iowa City Hospice. A bereavement counselor will contact you soon to talk about this service. We offer:

Supportive Phone Calls monthly or quarterly from staff or trained volunteers

Visits from bereavement counselors at our office or in our seven county service area

Literature on dealing with grief and a monthly help letter

Support Groups for Adults, Children and Families

Luncheons in outlying counties, open to all bereaved, providing an opportunity to connect and share common experiences with others

Memorial Services held in spring and fall that provide an opportunity for you to honor your loved one.

For more information or immediate assistance contact
an ICH Bereavement Counselor at
Bereavement@iowacityhospice.org

OR

(800) 897-3052

Dear Angie,

Thanks for all you did for me during this last year. You were only a phone call away. Everything you did was a help – articles mailed, time spent with me, phone calls all helped to get me where I am today.

Life took a different path after losing Larry. I realize it will never be the same as then but I'm trying very hard to make the best of each day. Being alone is hard. I miss his laughter and smiles but there are great memories, too. As ever, Judy Jones

The Iowa City Hospice Organization

Iowa City Hospice History

Iowa City Hospice served its first patient in 1983. The tireless work of our founders, however, began in 1979. Motivated by their experiences with loved ones at the end of life founders Martha Lubaroff and Mary Child began to discuss whether the relatively new field of hospice care could be supported in Johnson County.

Initial funding came from grants and community donations. In 1982, widespread community support allowed the first board of directors to appoint a medical director, Charles E. Driscoll, M.D. That fall, the first class of volunteers was trained, providing care to their first patient in March of 1983.

Martha is thrilled that Iowa City Hospice continues to provide exceptional hospice care and grief support services without regard for ability to pay. Martha is optimistic about the future of Iowa City Hospice, but cautions that with the arrival of for-profit hospice providers it is important to continue making it clear why Iowa City Hospice is the best choice.

“You love it, believe in it, and want it to keep going,” Martha says and adds, “I’d like it to be there for me.”

Supporting Iowa City Hospice

Iowa City Hospice simply could not provide our exceptional service - without regard for ability to pay – if it were not for the generous contributions of our community. When individuals volunteer, make a gift, or plan for a future gift to Iowa City Hospice, the donation stays in southeast Iowa and directly benefits the people we serve.

How to Help:

Every contribution has a positive impact and is deeply appreciated. Much more information on volunteer opportunities and ways to make a charitable gift are available on our web site, www.iowacityhospice.org or call us directly at 800-897-3052.

Volunteers, working side-by-side with health care professionals, bring a special compassion to Iowa City Hospice’s care. In addition to patient care, volunteers help Iowa City Hospice in many ways. Contact the Volunteer Coordinator to learn more about the many opportunities to use your talents to help.

Financial contributions enable Iowa City Hospice to continue its compassionate work and are often tax-deductible. Our development staff encourages your question and would be happy to discuss how you may make a meaningful gift. Types of donations might include:

Cash and on-line gifts of any amount are greatly appreciated. You may mail or bring your gift to Iowa City Hospice, 1025 Wade Street, Iowa City, IA 52240. You may also authorize a credit card donation by phone at 319-688-4213 or simply donate on line at our web site.

Memorial gifts are a meaningful way to honor a loved one while recognizing and thanking Iowa City Hospice for their care.

Honorary gifts are another meaningful way to honor someone special on a birthday, anniversary, holiday, or other special day. The person honored will be notified of your gift. You may also make your gift in honor of Iowa City Hospice caregivers who were especially helpful to your family.

Estate Gifts provide a means to improve the lives that follow through a **charitable bequest in a will or trust.**

Iowa City Hospice also raises funds through an Annual Fund letter sent in the fall, and two special events – the Walk for Dignity held in April and a golf outing held in August. Current information may be found on our website.

Additional Donor Information

- Iowa City Hospice is a 501(c)(3) not-for-profit charitable organization as determined by the Internal Revenue Service. Contributions not made in exchange for goods or services are tax-deductible as allowed by law.
- Our legal name is Iowa City Hospice, Inc. Our federal taxpayer ID number is 42-1154098.
- Iowa City Hospice is a nonprofit partner of *Leave A Legacy Iowa*[®]. Giving information is available at www.leavealegacyiowa.org.
- The Iowa City Hospice, Inc. Endowment Fund is held at the Community Foundation of Johnson County at www.communityfoundationofjohnsoncounty.org. The Community Foundation's telephone number is 319-337-0483.

Thank You for considering support for Iowa City Hospice.



This organization began as a vision shared by many community volunteers in 1979. We shared a common commitment: to enhance the quality of life for people at the end of life for people at the end of their lives. We never deviated from our belief that this should be a community-based non-profit organization that would never deny service to anyone.

Martha Lubaroff
Iowa City Hospice founder

Contact us at:

319-351-5665 800-897-3052

Fax: 319-351-5729

1025 Wade Street, Iowa City, IA 52240

info@iowacityhospice.org

www.iowacityhospice.org