

CareDimensions®

Compassionate expertise for advanced illness



Caring with Confidence
The Patient and Family Guide to Hospice Care



CareDimensions®

Compassionate expertise for advanced illness

Hospice 24-Hour Support

1-888-283-1722

In case of emergency, please DO NOT call 911.
Call us any time, day or night.

Your Hospice Team:

ENTER NAME

RN Case Manager:

Social Worker:

Chaplain:

Hospice Aide:

Volunteer:

Physician:

Clinical Manager:

Non-Discrimination Statement

Care Dimensions complies with applicable Federal civil rights laws and does not discriminate on the basis of diagnosis, race, color, national origin, age, gender, creed, disability, sexual orientation, gender identity, place of residence, veteran status, lifestyle, or the ability to pay for the services rendered. Care Dimensions does not exclude people or treat them differently because of diagnosis, race, color, national origin, age, gender, creed, disability, sexual orientation, gender identity, place of residence, veteran status, lifestyle, or the ability to pay for the services rendered.

Care Dimensions:

- Provides free aids and services to people with disabilities to communicate effectively with us, such as:
 - Qualified sign language interpreters
 - Written information in other formats (large print, audio, accessible electronic formats, other formats)
- Provides free language services to people whose primary language is not English, such as:
 - Qualified interpreters
 - Information written in other languages

If you need these services, please call 888-283-1722.

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You can also 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, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.

Free Language Assistance Services Are Available. Call 1-888-283-1722

Español (Spanish)

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-888-283-1722.

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ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 1-888-283-1722.

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注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1-888-283-1722

Kreyòl Ayisyen (French Creole)

ATANSYON: Si w pale Kreyòl Ayisyen, gen sèvis èd pou lang ki disponib gratis pou ou. Rele 1-888-283-1722.

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Русский (Russian)

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-888-283-1722.

(Arabic) العربية

ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل برقم 1- 888-283-1722

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ប្រយ័ត្ន: បើសិនជាអ្នកនិយាយភាសាខ្មែរ, សេវាជំនួយផ្នែកភាសា ដោយមិនគិតថ្លៃ គឺអាចមានសំរាប់អ្នក។
ចូរ ទូរស័ព្ទ 1-888-283-1722.

Français (French)

ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-888-283-1722.

Italiano (Italian)

ATTENZIONE: In caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Chiamare il numero 1-888-283-1722.

한국어 (Korean)

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-888-283-1722.

ελληνικά (Greek)

ΠΡΟΣΟΧΗ: Αν μιλάτε ελληνικά, στη διάθεσή σας βρίσκονται υπηρεσίες γλωσσικής υποστήριξης, οι οποίες παρέχονται δωρεάν. Καλέστε 1-888-283-1722.

Polski (Polish)

UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 1-888-283-1722.

हिंदी (Hindi)

ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। 1-888-283-1722.

ગુજરાતી (Gujarati)

સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિ:શુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 1-888-283-1722.

WELCOME

Thank you for choosing Care Dimensions to be a part of your care. On behalf of our entire staff, I would like to extend a warm welcome to you and your family.

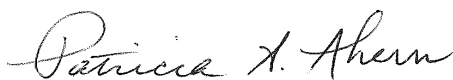
You have selected an organization that specializes in care for those with a life-limiting illness. You can be assured that you will receive the very best care, backed by the knowledge and experience we've gained through more than three decades of dedication to meeting the needs of patients and families. Our staff is committed to helping you live every day as fully and comfortably as possible.

Together with your loved ones, we will work to help you reach your goals, ensure your wishes are fulfilled, and provide compassionate physical, emotional and spiritual care of the highest quality.

This handbook provides information about our services and addresses some of the topics that patients and their families often ask about. As you look through these pages, please keep in mind that they are meant to supplement our help, not substitute for it. We are always here to answer your questions and address your concerns.

We believe it is our privilege to walk beside you on this journey of care. You can count on our support and expertise every step of the way.

Sincerely,



Patricia Ahern
President and CEO



OUR MISSION

Care Dimensions enriches quality of life for those affected by life-limiting illness, death and loss by providing exceptional care, support, education and consultation.

OUR VALUES

Compassion

Compassionate care is at the very heart of what we do. We provide steadfast caring that epitomizes empathy, kindness, respect and understanding.

Excellence

We are committed to providing the highest quality hospice and palliative care. We strive to exceed our customers' expectations and continuously improve our performance.

Collaboration

We work as a team, sharing respect, resources, knowledge and expertise to achieve common goals. We collaborate with our community partners to ensure seamless care for our patients and their loved ones.

Integrity

We uphold the highest ethical standards by being fair and honest with our customers and with each other. We act with integrity, respect privacy and confidentiality and use resources wisely.

Responsiveness

We identify and meet our customers' priorities and fulfill our promises through timely response, flexibility and accountability.

Innovation

We seek new opportunities and solutions and pioneer new programs and services to meet community needs.

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Note: Blue shading denotes information specific to caregivers.

Caring with Confidence: The Patient and Family Guide to Hospice Care

Hospice is a special kind of care for people with life-limiting illness and their families.

This resource guide is provided to reinforce the conversations you have with your hospice team and provide you with additional knowledge about the journey ahead.

It is our hope that this manual will help you feel as confident as possible about the care you will receive as a patient or that you will provide as a caregiver.

Hospice Is about Quality of Life

When you have a life-limiting illness, Care Dimensions offers you compassionate, expert care that helps you live each day to the fullest. This is a special time to focus on strengthening relationships and finding peace and meaning in each moment. Try to think of each day as an opportunity to experience something “one more time” rather than “one last time.”

Beyond managing pain and symptoms, hospice care honors who you are and what you believe. It provides assistance to family members as they care for loved ones, and it offers support to the bereaved throughout the grieving process.

This comprehensive care is what you and your family can expect to receive from Care Dimensions.

Honoring Your Wishes

One of the primary goals of hospice care is to honor your wishes whatever they may be. Advance care directives and planning described later on page 63 are a good way to help you and your family determine your wishes for care and treatment at the end of life.

For most people, chief among these wishes is to be without pain and discomfort, and to be cared for in your home so that you can be among family, friends and comfortable surroundings.

You and your caregivers are essential partners with us in this mission. To honor your wishes, we ask for your commitment to:

- Tell us about your pain, needs and any questions you may have, so we can address them quickly.
- Call us at 1-888-283-1722 if you have any concerns or changes in medical status. We have triage nurses available 24/7 to help you manage pain and symptoms or emergency situations.

Hospice at Home – Caring with Confidence

Your hospice team will care for you wherever you are. Most of the time, this means in your home. We also provide our services in hospitals, skilled nursing facilities, assisted living facilities and at Care Dimensions’ Kaplan Family Hospice House in Danvers and the Care Dimensions Hospice House in Lincoln on the Waltham line.

For the patient and the caregiver alike, home care can be both a rewarding, meaningful experience and one that is sometimes overwhelming, frustrating and stressful. Oftentimes, patients are not used to relying on others for care and caregivers sometimes find themselves required to perform procedures and tasks they have never done before. **Our hospice team will be with you every step of the way – teaching, supporting, listening and counseling.**

While the issues faced by patients and caregivers can be vast, this handbook is an effort to guide you through the process and increase your confidence when giving care. **Please talk with your hospice team if you have any questions.**

Care Dimensions has produced short videos for caregivers to help them feel more confident in providing care and to give them some tips on what they can do to make their loved ones more comfortable. Topics include: shortness of breath, restlessness/agitation, pain management, turning and positioning, and constipation. **You can view the videos at www.CareDimensions.org/CaregiverVideos**

What to Expect from a Visit

The members of your care team want to ensure that everyone gets the most out of every visit. The focus of each team member's visit will be slightly different due to their role, but each of their visits will have the same basic structure, so you'll know what to expect. For example, during every nursing visit, your RN case manager will ask you about your pain level, issues with voiding (incontinence, bowel movement, constipation, etc.), medication status and equipment supplies.

Some procedures and questions will be done by every team member. For example, you'll receive a call confirming when the team member will arrive. They'll also call to keep you updated if there is a change in arrival time, or for instance, a delay related to traffic. Every team member will also ask you general questions about how you're feeling, how you are handling feelings of sadness and anxiety, or if you have any concerns. They'll share this update with the rest of the team immediately through our electronic medical records, so everyone has access to your most recent and accurate health information.

Since caregivers at home are such a vital part of the care team, we pay special attention to how the caregiver is doing too. It is important to us that you understand all the information the team members share with you. We will use the well-known and effective "teach back" method in communicating and providing information, where we'll ask you to explain in your own words or show us what we have taught you. It is our way of checking how well we, as team members, have provided information to you. We want caregivers to feel comfortable in providing care, so that your family member or friend is as comfortable as possible.

Your Care Team

As a Care Dimensions patient, you will remain under the care of your attending physician (primary doctor). You will also have the assistance of your hospice team, who will work with you and your doctor to develop an individualized hospice plan of care that will support your goals and meet your needs.

YOUR HOSPICE TEAM INCLUDES:

Attending Physician: Your attending physician (or primary doctor) is in charge of your care and prescribes medications and any other appropriate treatments you may need. The hospice team will keep your doctor informed of any changes in your condition, and your doctor will approve any changes in your plan of care.

Hospice Physician: Your hospice physician, who is specially trained in palliative care and pain management, may:

- Consult with your doctor and the hospice team to ensure that your care is meeting your changing medical needs.
- Help manage your care by visiting you in your home when necessary, or in a nursing facility, hospital, or at the Kaplan Family Hospice House or the Care Dimensions Hospice House.

Nurse Practitioners: A nurse practitioner, who has advanced training in hospice and palliative care, may visit to assist the team or physician with symptom management.

Nurse: Your hospice nurse manages your care in consultation with your primary physician and other members of your hospice team. Your nurse will:

- Monitor your condition and coordinate all aspects of your care.
- Teach you and your caregivers about:
 - Medications
 - End-of-life care
 - Symptom management including sadness and anxiety
 - Decision making
 - Use of equipment
 - Safety
 - Individualized teaching as needed

Social Worker: A social worker can help you determine your goals of care at the end of life and may:

- Offer emotional support to you and your loved ones and offer ways to ease feelings of sadness and anxiety.
- Facilitate family meetings to address your care and comfort and to help resolve any conflicts or stressful situations.

- Provide information on healthcare decision making (Advance Directive or Health Care Proxy), referrals to other community resources, financial assistance, and funeral arrangements.

Chaplain (Spiritual Counselor): The chaplain offers non-denominational guidance and may:

- Provide support for issues such as faith, fear, loss, forgiveness, anger, or spiritual questioning.
- Contact or coordinate with the clergy of your faith community.

Hospice Aide: The hospice aide can assist with personal care and will:

- Help with bathing, eating, dressing, and personal grooming.
- Perform light homemaking such as changing patient's linen, assisting with the patient's laundry and meal preparation.
- Communicate their observations to the nurse case manager.

Child Life Specialists: Our certified child life specialists provide support to children and adolescents affected by the life-limiting illness or death of a loved one. They also provide guidance to parents or other adult caregivers about how children and adolescents think and talk about death, dying and grief. Using age-appropriate activities including books, games, and arts and crafts, the child life specialist helps children talk about their fears in a safe environment and gives them strategies for coping with their emotions. Child Life Specialists also provide support to our pediatric patients and families.

Volunteer: A hospice volunteer can visit on a regular basis or for a one-time need. Volunteers have extensive training and can offer services such as:

- Companionship, listening and providing a supportive presence.
- Helping with shopping, errands and light meal preparation.
- Reading, playing music, writing letters.

Complementary Therapists: Certified and licensed therapists are able to provide massage, music, and art therapy, while trained volunteers provide Reiki, compassionate touch, and pet therapy and visits to nurture the body, mind and spirit, ease sadness and anxiety, and enrich quality of life.

Other Therapies: Physical therapists, occupational therapists, speech therapists and nutritional counselors are available if determined to be medically required by your hospice diagnosis and the hospice team.

Primary Caregiver: Hospice patients at home receive most of their care from a loved one or friend who is an integral member of the hospice team. Primary caregivers provide basic physical care and emotional support to their patient, including bathing, giving medications and special comfort measures and report issues and observations to the hospice team.

Comprehensive Care Management

Your Care Dimensions team will coordinate all aspects of your care including physician visits and arranging for medical equipment, supplies and medications based on your hospice diagnosis and medical needs.

Care Dimensions' Specialized Programs

SPECIALTY MEDICAL PROGRAMS

- **Chronic Conditions Program** – Care Dimensions offers specialized care for patients with cardiac and respiratory diseases. This unique program is proven to reduce hospital and emergency department visits, while offering patients the opportunity to better manage their symptoms at home. Services include special medication packs to help with symptom management, detailed care guidelines to manage symptoms and additional support programs such as daily phone calls or telehealth monitoring devices.
- **Dementia Support Program** – Care Dimensions offers individualized services to support the unique needs of patients with moderate to advanced dementia. This team-based approach addresses the patient's physical, cognitive and emotional needs while providing vital, practical support for family and professional caregivers. Specially trained volunteers can provide companionship and activities suited to the patient's needs. If you would like to learn more about the program, please talk to your social worker.
- **Pediatric Program** – Care Dimensions offers hospice care for infants, children and adolescents. Led by a team of hospice and palliative care pediatricians from Boston Children's Hospital, a nurse practitioner, and nurses specialized in pain and symptom management for children, this program offers individualized care that may include continuing with disease-modifying treatments. Social workers, chaplains, child life specialists and bereavement counselors with advanced training in pediatric hospice provide extensive support not only to the patients themselves but to parents, siblings, grandparents, and other loved ones.

COMMUNITY PROGRAMS

- **Veterans Program** – Our Veterans Program offers additional services to veterans and their families, such as assisting with VA benefits, military funeral and memorial planning, supporting patients with Post-Traumatic Stress Disorder and providing a veteran-to-veteran volunteer. As a Level 5 Partner (the highest level) of the We Honor Veterans program, we are proud to present our veteran patients with a Freedom Rock to recognize their service to our country.

SUPPORT PROGRAMS

- **Complementary Therapies** – Care Dimensions offers an array of complementary therapies to nurture the body, mind and spirit and enrich the quality of life for our patients. Services include:
 - Massage (up to 4, based on therapist's recommendation)
 - Reiki
 - Compassionate touch
 - Music therapy
 - Art therapy
 - Pet therapy and visits

- **Bereavement Support** – Care Dimensions provides comprehensive bereavement services through our Bertolon Center for Grief and Healing in Danvers, at our Greater Boston office, and in community spaces in our service area. Early bereavement support (prior to the patient's death) is available, and grief support is available for 13 months after their death. Services include:
 - Support groups
 - Workshops and other educational programs
 - Remembrance services
 - Child life specialist
 - Individual counseling as appropriate
 - Suggested readings and other helpful resource materials
 - Newsletters
 - Information and referrals
 - Phone support

TECHNOLOGY SUPPORT

Care Dimensions uses several technology devices to supplement patient care and communication. This technology is never a substitute for nursing visits, but rather provides additional touch points and ways to communicate.

- **Telemonitoring Equipment** – Care Dimensions uses telemonitoring devices with some patients. The devices help patients and their caregivers track daily vital signs, weight and other symptoms. The data is reviewed by the hospice team, alerting them to patients who need further assessment before symptoms become critical.

Please talk to a member of your hospice team if you have any questions about the above programs.

Quality and Feedback

We strive to provide the highest quality services to our patients and their families. We rely on your feedback to let us know what we're doing right and what could be improved. We welcome your comments or questions at any time. You can speak to any member of your hospice team or contact the Clinical Manager listed on your introductory letter by calling 888-283-1722.

Patient and Family Advisory Council

The Care Dimensions Patient and Family Advisory Council (PFAC) is a diverse group of patients, family members, clinicians, staff and leadership that works in partnership to enhance the patient and family care experience. As the embodiment of the organization's commitment to innovation, improvement, and striving for the best patient and family experience, Care Dimensions launched the PFAC in 2018. Its goals include:

- Encourage greater understanding of the hospice experience through the eyes of the patient and family
- Channel patient and family specific needs, concerns and recommendations to staff and leadership for review
- Evaluate practices, programs and services and provide feedback
- Collaboratively work on projects that will enhance patient- and family-centered care

Everyone's hospice experience is an individual journey, and we are actively recruiting new members to share their diverse experience. To learn more about membership, or to suggest an issue or topic for PFAC to explore, contact PFAC@CareDimensions.org or call 781-373-6604.

Feeling Confident in Care Dimensions' 24-Hour Support System

1-888-283-1722

One call does it all.

Please remember to call hospice first in the case of an accident, fall or medical crisis. We want to honor your wishes and keep you in your home.

Please contact Care Dimensions first, even if you feel the need to call 911 or an ambulance. Hospice staff will help you manage the medical crisis, remain at home and feel more comfortable.

Emergency medical services (911) staff specialize in stabilizing people and transporting them to the nearest facility for life-saving measures.

24-Hour Support System

Care Dimensions provides nurses on call **24 hours a day** to meet our patients' and caregivers' needs. Even though your primary nurse case manager may not be working, there is **always** a nurse available to answer your questions or make a visit. Please call Care Dimensions at any time for questions, clarifications and to report changes in patient status including death.

Call the hospice nurse if:

- There is a significant change in the patient's condition – if you are concerned about a sudden or drastic change in any way. The hospice nurse can help manage symptoms over the phone or make a visit.
- The patient falls.
- There is hemorrhaging or heavy bleeding.
- The patient has severe pain that is new or not relieved after following the nurse's instructions.
- Death occurs – even if you are uncertain that death has occurred, call and let the nurse know.

Hospice 24-Hour Support:
1-888-283-1722

EMERGENCY NOTIFICATION SYSTEM

In the event of an emergency (extreme weather event, phone system outage, etc.), Care Dimensions has an emergency notification system for patients and families. You will be notified by an automatic phone call to the patient's phone numbers as provided at admission. This system will be used only in emergency situations, but is another way we can provide you with critical information or ways to contact us.

Feeling Confident about Safety

Please remember to call hospice first in the case of an accident or fall. We want to honor your wishes and keep you in your home.

**Hospice 24-Hour Support:
1-888-283-1722**

Hospice staff will help you manage the medical crisis, remain at home and feel more comfortable.

Emergency medical services (911) staff specializes in stabilizing people and transporting them to the nearest facility for life-saving measures.

Hospice Staff Safety

For the safety of our staff when they are visiting your home, we ask that:

- After dark, please turn on your outside lights near the door and house number.
- Pets should be secured when hospice staff is in the home.
- If staff feels unable to enter your home safely, she/he will call you to determine other ways to help.

Your Safety at Home

Our goal is to optimize your safety at home. The following tips and guidelines are designed to help you and your caregivers maintain a safe environment in your home at all times.

MEDICAL WASTE

- Household medical waste (such as bloody or soiled bandages and dressings, catheters, colostomy bags, disposable sheets and clothing, disposable gloves, etc.) should be placed in any plastic bag and securely closed before you place it in your regular trash.
- Liquid body fluids such as blood, vomit, or urine can be poured into your toilet and flushed or washed down the drain with hot water.
- To clean spills contaminated by blood or body fluids, wash the area with hot, soapy water (use disposable gloves).
- Wash soiled laundry apart from other laundry in hot, soapy water.

PREVENTING PATIENT FALLS

Here are some tips for preventing falls in the home:

BATHROOM

- Place a nightlight in the bathroom.
- Provide easy access in and out of the tub.
- Install grab-bars around the bath and/or shower.
- Use a shower bench or chair in the tub or shower.
- Remove loose scatter rugs from the bathroom floor and replace with a non-skid mat near the tub and toilet secured with suction cups or non-slip adhesive strips.
- Always make sure the floor is dry.
- Position the toilet at a convenient height. Use a raised toilet seat or commode, if necessary.

HALLWAYS

- Keep walls free from heavy paintings and objects that can be knocked down.
- Install railings or grab-bars on the walls.
- Install a nightlight.
- Remove scatter rugs from the floor.
- Eliminate clutter from hallways and other areas.

BEDROOM

- A lamp or light switch should be within reach of the bed.
- Install a nightlight in the bedroom.
- Keep a phone within reach of the bed or close to the floor in case of emergency.
- Consider installing padded rails around the bed, or ask your hospice team to get a hospital bed.
- Eliminate scatter rugs from the floor.
- If using a commode or urinal, make sure they are always within reach.
- Always ask for assistance when getting out of bed, as medications and dehydration can cause dizziness.
- Keep hospital bed in low position, except during times of direct care. Keep side rails up, except when a caregiver helps reposition the patient or provides personal care.

CAREGIVER'S TIPS:

- Consider using a baby monitor if you're concerned that the patient won't cooperate with always asking for assistance to get out of bed.
- Check the patient's legs for numbness or weakness before he/she stands or gets out of bed.

STAIRWAYS

- Have handrails on both sides of the stairwell.
- Keep the stairways well lighted, clear of objects and carpeting well secured.
- Apply a non-slip surface to stairs without carpeting.

CAREGIVER'S TIP:

- Assist the person up and down the stairs, if necessary.

OTHER GENERAL SAFETY PRECAUTIONS:

- Have emergency phone numbers handy.
- Be sure there is easily accessible, adequate lighting.
- Cords and wires should not cross the flow of traffic.
- Make sure there is space for walking, especially if a walker or cane is being used.
- Wear sturdy non-skid shoes or slippers with hard soles and good traction.
- Use sturdy chairs with armrests and elevate seat height with a firm cushion to help you rise to a standing position.
- Place everyday items at easy-to-reach levels.
- Some medications interact badly with alcohol, and may increase unsteadiness and other symptoms. Please check with your hospice team before drinking any alcoholic beverages.
- Consider obtaining a Personal Emergency Response System such as Life Line or other device to alert others if a fall occurs or help is needed. Your hospice social worker can help you arrange for this system.

FIRE SAFETY

- Smoke detectors and carbon monoxide detectors should be in place and operational.
- Plan two escape routes in case of fire.
- Know who to call for help in case of fire.
- Never enter a room where there is a fire.
- Close any door that will contain a fire.
- Never smoke in bed or in a recliner.
- **Never smoke near oxygen.**
- Install multi-purpose fire extinguishers and keep them ready to use.
- If you catch on fire, drop to the floor and roll until the fire is out.

ELECTRICAL SAFETY

- Keep cords and appliances away from water.
- Throw away or repair frayed or damaged electrical cords.
- Do not overload outlets with too many plugs, and do not put cords under rugs or near heaters.
- Avoid using portable space heaters. Portable space heaters need a three-foot clearance from anything that can burn such as furniture, draperies and walls. They should always be turned off when leaving the room or before going to sleep.

OXYGEN SAFETY

- Post “No Smoking” signs.
- Keep all sources of fire away from an oxygen canister and its tubing. Fire sources include open fires, cigarettes, stoves, candles, gas heaters, and combustible materials (such as oils, grease, aerosol sprays, lotions and solvents).
- Never use petroleum-based products (such as Vaseline or A&D ointment) in and around your nose. Mixing these with oxygen may cause burns. Instead, use water-based products (such as K-Y jelly).
- Store oxygen tanks in an open, well-ventilated area that is stable and secure.
- Turn off your oxygen when it is not in use.
- **Never smoke while using oxygen.**
- Use caution to prevent kinks in the oxygen tubing, and do not lay objects on the tubing.
- Do not leave the tubing in your bed or under the furniture cushions. If you leave the oxygen unit on while you are not using it, the oxygen will leak into these items. A spark or flame could cause a fire.
- Portable oxygen tanks should be transported in the back seat or trunk of the car.

Infection Control

HAND WASHING

Always wash your hands thoroughly, for at least 20 seconds:

- Before and after giving any care to the patient (even if wearing gloves).
- Before and after eating or preparing food.
- When handling soiled linens or cleaning objects soiled with urine, feces or blood.
- Before and after going to the bathroom, touching pets, coughing, sneezing or blowing your nose.
- Before you put gloves on and then again when you take them off.

WEAR DISPOSABLE GLOVES

Always use protective gloves when:

- You will come into contact with saliva, urine, feces or blood or give care to the mouth or genitals.
- You change disposable pads, diapers, or sanitary pads, and when you empty commodes or bedpans.
- You clean contaminated surfaces, such as bathrooms or soiled laundry.
- You have a rash, cut or open area on your skin.
- You give care to a person with open wounds or breaks in the skin.
- When removing gloves, peel down by turning them inside out and keeping the wet side on the inside.

GENERAL HOUSEHOLD PRECAUTIONS

- Use a disinfecting solution of one part household bleach mixed with ten parts water for cleaning contaminated surfaces and objects. Make a new batch every day and wear protective gloves when using.
- Wash soiled laundry separately from other laundry in hot, soapy water.
- Stay away from people with colds, the flu, cold sores, etc.
- Keep the home clean and well-ventilated.
- Medical supplies should be stored in an out-of-the-way place, yet easily accessible and close to the patient. Avoid putting supplies in an area that can become wet, such as on the bathroom sink. Wet packages are no longer clean or sterile and should be thrown away.
- Do not bend, recap or break needles, also called “sharps.” Place used needles in a puncture resistant container, such as a heavy plastic bottle with a tight-fitting lid. This sealed container can be disposed in your regular trash.

Weather Emergency Information

Be prepared for storms by keeping emergency supplies on hand:

- Flashlights with extra batteries
- Extra blankets
- Portable radio with extra batteries
- Charged cell phone
- Candles, sterno and matches (be mindful of fire safety precautions)
- First aid kit
- Manual can opener
- A few days' supply of water, required medications and food that does not need to be refrigerated or cooked.

Hospice staff will call you if a scheduled visit must be cancelled or changed.

Emergency Notification System

In the event of an emergency (extreme weather event, phone system outage, etc.), Care Dimensions has an emergency notification system for patients and families. You will be notified by an automatic phone call to the patient's phone numbers as provided at admission. This system will be used only in emergency situations, but is another way we can provide you with critical information or ways to contact us.

Feeling Confident in Providing Care & Comfort

Being a caregiver can be rewarding and meaningful, but it can also be stressful. It is our hope that this guide will assist you and help boost your confidence when giving care.

Your hospice team will review each of these topics with you. If you have questions, you can call for phone support or to request an extra visit.

Please remember that you are not alone. The entire hospice team has expertise in providing end-of-life care and will help you create a plan that works for you and your patient. Your nurse case manager will coordinate your hospice team to meet your needs. Care Dimensions staff is available 24 hours a day to support you and answer your questions.

Providing Care at Home

CAREGIVERS AT HOME

Hospice care at home relies on family or friends to provide the majority of day-to-day care to the patient. As your patient approaches the end of life and requires more care, you may sometimes feel that this is an overwhelming responsibility and that you are not equipped to provide medical care. Moreover, now that the goal for the patient's care has shifted from cure to comfort, you may also feel confused about how to best meet their needs.

Most of the patient's daily care will not need any special medical skills, and you will be more than qualified to perform these tasks. If there are more complicated procedures, your hospice nurse will be able to assist you or provide training or education.

It is helpful to keep a few general rules in mind when you care for your patient:

- **Communication** – Talk to your patient to let them know what you are doing when giving them physical care. Let them share their feelings about what is happening – sharing their thoughts on dying can be a comfort to them.
- **Independence** – It's hard for a person to relinquish all control and become completely dependent on others for help. When possible, let your patient make decisions and be involved in their care and daily routine.
- **Respect** – It's important to maintain your patient's dignity and privacy. Ask permission before starting personal care, keep them covered and knock on the door before you enter their room.
- **Stress Relief** – Look for ways to make things easier and to relieve the stress on your patient and yourself.

CAREGIVER SUPPORT

Care Dimensions has produced a series of videos for caregivers to help them feel more confident in providing care and to give them tips on what they can do to make their loved one more comfortable. Topics include: shortness of breath, restlessness/agitation, pain management, turning and positioning, and constipation. The videos can be viewed at www.CareDimensions.org/CaregiverVideos. Remember, you can always call Care Dimensions nursing support line at 888-283-1722 for advice or help 24 hours a day.

Providing care to a loved one can sometimes be stressful. Care Dimensions offers a monthly drop-in support group for caregivers where you can find mutual support from others and learn tools to help you along your journey of caring. Meetings are held at the Bertolon Center for Grief & Healing in Danvers. Check the online calendar at CareDimensions.org or call 855-774-5100 for dates and details.

YOUR HOSPICE TEAM

As outlined in the first section of this guide, your hospice team has many members who have various roles. They will make visits to your home depending on the patient's medical and psychosocial needs.

HOSPICE AIDES

Some patients may need more physical care than their caregiver can provide. In these instances, after your hospice nurse has assessed the patient's needs, she/he may assign a hospice aide to assist you. Your nurse will outline the assignments for the hospice aide, including length and frequency of visits. Your nurse will also supervise your hospice aide on a regular basis.

HOSPICE AIDES CAN HELP WITH THE FOLLOWING:

Personal patient care is the primary function of the hospice aide, which includes:

- Assisting with bathing, including bed baths or sponge baths in the bathroom or assisting in the shower.
- Performing hair, skin, and mouth care.
- Toileting assistance.
- Helping transfer the patient from bed to chair.
- Assisting with prescribed exercises.
- Assisting with walking.
- Reminding the patient to take medications that have been set out by caregiver or nurse.
- Repositioning the patient as ordered by the hospice nurse.
- Changing the bed.

In addition to personal care, the hospice aide may:

- Do the patient's laundry.
- Provide routine light housekeeping such as tidying the patient's room, doing dishes, and keeping the kitchen and bathroom neat and orderly.
- Prepare and serve meals to the patient including food to be served after the aide leaves.

HOSPICE AIDES CANNOT DO THE FOLLOWING:

- Cut toenails under any circumstances.
- Do heavy work such as washing floors, walls, windows, curtains or spring or fall house cleaning.
- Do heavy weekly laundry or any laundry other than the patient's.

- Transport patients in their car or the patient's/family's car.
- Perform care or services for other family members.
- Go to friends or neighbors of family to provide additional services not ordered by the nurse.
- Accept money and/or tips or personal gifts.
- Give their telephone number or address to patients or families.

HOSPICE AIDE SCHEDULING PROCEDURES

Hospice aides are critical members of the hospice interdisciplinary team. The following information is provided to help you better understand what to expect for hospice aide schedules and the factors that influence when your hospice aide is available:

- We will make every effort to send the aide to your home at the time of day you request; however, we cannot guarantee a particular time of day.
- We may change the hospice aide assigned to you. While we try to minimize these interruptions, we sometimes need to alter our aides' schedules to cover for sick calls and schedule changes that arise.
- When hospice aides are absent due to illness or other unusual circumstances, we will make every effort to send a replacement to your home, if you desire. Patients who require maximum levels of care will be covered first. If no replacement can be arranged, we will notify you as early as possible that day.
- When there are problems with the aide service that cannot be resolved or if the service is misused, we reserve the right to withdraw the hospice aide.
- Your hospice nurse and clinical manager will periodically re-evaluate ongoing needs for hospice aide services and adjust the schedule and frequency, if necessary.

Please review these procedures, and share any questions or concerns with your hospice nurse. We hope that you will keep these policies in mind and understand that they are necessary for us to be able to serve you in the best possible way.

Continuum of Care

SUPPLEMENTAL CARE IN THE HOME

Sometimes a patient's symptoms may become too difficult for caregivers to manage or a patient might not have suitable caregivers available, yet the patient still wants to remain home. Please speak with your hospice team to discuss your concerns and determine what resources might be available to help. The cost of supplemental nursing services may be covered depending on the patient's insurance coverage, or you can make arrangements to pay for them privately.

KAPLAN FAMILY HOSPICE HOUSE AND CARE DIMENSIONS HOSPICE HOUSE

Care can also be provided for brief periods at Care Dimensions' Kaplan Family Hospice House in Danvers and the Care Dimensions Hospice House in Lincoln for acute pain and symptoms that cannot be managed at home or for respite care; admission is based on eligibility requirements. Residential care is also available. The cost of these services may be covered depending on your patient's insurance coverage, or you can make arrangements to pay for them privately. Please see page 53 in the handbook for more information on our hospice houses.

RESIDENTIAL CARE

Care Dimensions provides care wherever a patient is located. We can seamlessly transition a patient to a residential care facility if care can no longer be provided at home. Please talk to a member of your hospice care team to discuss options or to receive a list of our preferred partners.

Home Care Supplies

We suggest the following list of supplies to be purchased or obtained by the caregiver that may be helpful in providing care in the home. This is a basic list for all patients, but your hospice team may suggest additional supplies based on patient-specific needs:

- Face cloths and towels
- Soap
- Hand sanitizer and liquid hand soap
- Moisturizing lotion (patient preference)
- Absorbent under pads, if needed
- Adult incontinence briefs, if needed
- Disposable plastic bags for disposal of body fluids and medical waste
- Disposable wipes
- Disposable latex-free gloves
- Sheets, especially extra fitted sheets (twin extra long fit best on hospital beds)
- Flat sheets to be used as a means to pull patient up in bed, if needed
- Several pillows

Care Dimensions will order and manage any medical equipment (bed, walker, commode, etc.) needed.

Tips to Safely Provide Direct Care

Providing direct patient care may involve many new tasks and procedures, but they oftentimes do not require any special skills, except patience and understanding. Make sure you involve the patient in their care and allow the patient to do as much as they can do. Ask the person how they would like to do something. Be flexible – the patient's needs may change depending on how they feel that day. Make sure you provide the patient with appropriate privacy, whenever possible. The following

sections provide tips to help you perform common tasks safely. If you have ANY questions on how to perform a task or procedure, please ask your hospice nurse to demonstrate it and guide you through the procedure.

MOVING THE PATIENT

Before you attempt to move the patient, remember the following tips to avoid injury from lifting:

- Wear practical shoes and comfortable clothes.
- To avoid hurting your back, keep your feet apart and bend at the knees, not at the waist.
- When you are moving a person, it is easier to pull than to push.

PERSONAL GROOMING

Being freshly bathed and shaved can make a major difference in how a patient feels. If the patient is strong enough, they may be able to handle most grooming unassisted. Unless the patient can shave himself, we strongly recommend using an electric razor to reduce the risk of cutting the patient or irritating the skin. Other members of the household should not share the patient's razor.

GIVING A BED BATH

Ask your hospice team if the patient requires some pre-medication prior to care to provide pain relief and added comfort. Here are some tips to providing a bath in bed:

Assemble all the items you need at the bedside:

- Large bowl of warm water
- Two towels
- Washcloth and soap
- Moisturizer
- Blanket to cover patient
- Container for soiled disposable diapers
- Except for the part of the body that you are washing, keep the patient covered with either a sheet or blanket to prevent them from being chilled.
- Wash one part of the body at a time, starting with the upper body and moving downward. Wash the genital area last.
- When you are washing the person's back and/or buttocks have them turn away from you in the bed. If the bed has side rails, make sure they are up on that side. If the bed has no side rails, use two chairs as a barrier to prevent a fall.
- Pat dry all areas to prevent chafing and apply moisturizer if necessary.

MAKING AN OCCUPIED BED

The best time to change the bed is when you have finished giving the patient a bed bath and the top sheet is already off.

- Assemble pillow cases, three sheets and disposable pad if the patient is incontinent.
- Roll the patient onto their side, away from you. Make sure that the side rails of the bed are up, or place several chairs on the opposite side as a barrier to prevent a fall.
- Pull out the sheets from under the mattress on your side and roll them lengthwise toward the patient.
- Bottom sheet: Fold one sheet lengthwise. Place it on the empty side of the bed, with the fold in the center of the bed, so that the fold runs from the head to the foot of the bed. This is the new bottom sheet.
- Beginning at the outside of the sheet, roll the top half of the folded (clean) sheet toward the patient until the roll rests against the patient.
- Draw sheet: The draw sheet goes across the middle of the bed, positioned under the patient more or less from the shoulders to below the hips. It is useful as a extra precaution in case of incontinence; you can also use it to help position the patient in the bed. Fold the draw sheet in half lengthwise, and then fold it in half again crosswise. Place it over the bottom sheet across the center of the bed, with the fold against the patient. Roll up the top half in the same way you did with the bottom sheet, ending up with a second roll up against the patient.
- Tuck in the unrolled halves of both sheets on your side of the bed.
- Before you ask the patient to move, be sure you remind them about the rolled-up sheets in the center of the bed. Have the patient roll over the rolled-up sheets to face you. They are now lying on the clean sheets. Put up the side rails on your side of the bed and move to the other side of the bed.
- Remove the used sheets.
- Pull the clean, rolled-up bottom sheet from under the patient. Unroll it and stretch it as tightly as possible to avoid wrinkles that can rub or irritate the skin. Tuck in the rest of the bottom sheet: top and bottom first, side last.
- Unroll, pull tight, and tuck in the draw sheet.
- Top sheet: Place the top sheet over the patient and tuck in.
- Change the pillowcases and reposition the pillows.
- The process gets easier the more practice you have!

CARING FOR THE SKIN

A person who spends most of the time in bed can develop breakdown of the skin, resulting in bedsores.

- Watch closely for skin irritation or places where there is contact, such as knees rubbing together when lying on one side.

- Change the person's position every couple of hours by moving them from side to side or onto the back. Place a pillow against the person's back to keep them in position. Watch our video demonstration at www.CareDimensions.org/CaregiverVideos.
- Massaging or padding pressure points (knees, elbows, feet, hips, shoulders, tailbone) can help prevent irritation. Heels can be elevated on pillows.

Certain areas of the skin seem to more prone to breakdown. Depending on the patient's position in bed, you should massage these vulnerable areas with any hypoallergenic lotion, such as Lubriderm, after warming it your hand:

- If the patient is frequently on their side, massage the ear, shoulder, ankle and hip.
- If the patient is on their back, massage the back of the head, shoulder blades, spine, elbows and heels.

CARING FOR THE MOUTH

A sore mouth or gums usually impairs a person's ability to eat. To care for a patient's mouth:

- Position the patient upright.
- Place a towel under the chin.
- Help the patient rinse their mouth with water.
- Gently brush the teeth with a soft-bristled toothbrush taking care not to irritate the gums. If this is too irritating, use a sponge-tipped applicator called a Toothette. Use toothpaste, toothpowder or baking soda and water to clean the teeth.
- Help the patient rinse out their mouth by placing a small basin under the chin.

CHANGING DISPOSABLE UNDERWEAR/ADULT DIAPER

The idea of wearing a diaper may be very difficult for the patient to accept and they may be embarrassed, requiring your utmost understanding.

Assemble the needed items:

- Disposable gloves
- Clean disposable underwear/diaper
- Bowl of warm water
- Soap, moisturizer and barrier cream (A&D ointment), if needed
- Washcloth and towels
- Container for the used underwear

Procedure for changing:

- Put on disposable gloves.
- While the patient is on their back, remove both side tabs of the diaper.
- Have the person turn on their side away from you and slip off the diaper. Make sure that the side rails of the bed are up, or place several chairs on the opposite side as a barrier to prevent a fall. Throw the diaper away.

- Wash the genital area carefully. Position the person so that you have easy access to the perianal area. Dry the area and apply moisturizer if needed. Also, you may wish to apply cornstarch to keep the area dry or A&D or Balmex if indicated by your nurse.
- Once the person is clean, have them roll on their side away from you. Place the opened diaper along the back. Tuck it under and then have the person return to their back.
- Bring the front of the diaper up between the person's legs and secure the adhesive tabs.

PAIN MANAGEMENT

Pain or some form of discomfort is not uncommon for a patient with a terminal illness. Managing the pain is a top priority of your hospice team and will be the focus of care you provide. Here are some general tips:

- Listen carefully to the patient and help them describe it – is it sharp, dull, achy, constant?
- Give ordered medication on time. Medication given late can result in the pain reaching a point that is difficult to bring under control.
- Keep a close record of the time and dosage of the medication given, the effect it has and how long the effect lasts. Each person's pain is different and it may take some modification to determine the best dose and schedule.
- Ask your nurse what side effects you should be watching out for.
- Help the patient find a comfortable position; use pillows or small cushions to relieve pressure or stiffness.
- Hot or cold packs may help joint or muscle pain. Ask your nurse how to apply these safely.
- Give a massage to help relieve discomfort and relax the patient.
- Ask your hospice nurse about Care Dimensions' complementary therapies – massage, Reiki, compassionate touch, music/art therapy, pet therapy – which may relieve stress and provide comfort.

If your patient cannot verbalize their pain because of weakness or confusion, watch for the following signs that could indicate pain and alert your hospice nurse immediately:

- Facial grimacing or wincing with movement
- Increased irritability, restlessness or inability to sleep
- Decreased appetite
- Avoidance of movement – staying in bed and not getting dressed.

FEEDING

Since food is often associated with caring and nurturing, our instinct is to encourage a patient to eat to “get stronger” or because we don’t want the person to starve. As difficult as it may be, it is important to respect the person’s wishes related to eating and drinking. Don’t try to force food or drink, or manipulate your loved one into eating or drinking. This could cause choking or increase their discomfort or guilt. It is a normal part of the dying process for a patient to eat and drink less as the body shuts down. End-of-life dehydration produces a mild euphoria, like morphine, so the only pain may be caused by a dry mouth. Small ice chips or lip moisturizers may keep the mouth and lips comfortable.

Common Signs and Symptoms

The following section is intended to help you understand some of the signs and symptoms you may see, comfort measures you may be able to offer, and when to call hospice for a nursing, social work, or chaplain visit. Watch our caregiver videos at www.CareDimensions.org/CaregiverVideos for more tips and advice.

SYMPTOM	WHAT IS IT	POSSIBLE CAUSES	WHAT TO DO	WHEN TO ALERT THE SKILLED NURSING FACILITY OR CALL HOSPICE
Anxiety/ Agitation (extreme restlessness)	State of uneasiness that can be seen in physical changes	<ul style="list-style-type: none"> • Pain • Shortness of breath • Repetitive behaviors • Status changes • Change in environment 	<ul style="list-style-type: none"> • Medication <ul style="list-style-type: none"> - Helps reduce the symptoms. • Offer light massage to hands or forehead. • Companionship <ul style="list-style-type: none"> - Stay with the person until the medication begins to work. • Speak softly and calmly <ul style="list-style-type: none"> - Keep your speech clear, simple, direct, and reassuring; - Don't say too much at once; - Read out loud. • Pay attention and respond with reassurance. • Eliminate extra noise <ul style="list-style-type: none"> - Turn off TVs and radios during conversations. • Music <ul style="list-style-type: none"> - Play music that you know the patient enjoys. • Open up the room. • With help from skilled nursing facility staff, go for a walk around the facility. 	<p>The skilled nursing facility staff and hospice nurse should be notified if:</p> <ul style="list-style-type: none"> • The anxiety, agitation or restlessness is new or suddenly increased. • Medication is not effective after one hour. • The patient is at risk for injury. • You can not keep the patient from wandering. <p>Remember that social workers and chaplains also play a vital role in managing distressing symptoms. Please let a hospice team member know if you want to see the social worker or chaplain more often.</p>

SYMPTOM	WHAT IS IT	POSSIBLE CAUSES	WHAT TO DO	WHEN TO ALERT THE SKILLED NURSING FACILITY OR CALL HOSPICE
Appetite	Any change in desire for, amount or frequency of food or fluids	<ul style="list-style-type: none"> Natural part of end of life 	<ul style="list-style-type: none"> Choice: <ul style="list-style-type: none"> Allow the patient to choose what, when, and how much to eat. Honor requests for special foods. Give small amounts. Offer ice chips or popsicles. Offer frequent mouth care – sponge mouth and gums with toothettes, use lip balm. Forcing or encouraging them to eat can cause discomfort. 	<p>The skilled nursing facility staff and hospice nurse should be notified if:</p> <ul style="list-style-type: none"> Sudden change in ability to swallow. Vomiting or diarrhea that continues for more than 24 hours. A significant change in the patient's level of alertness.
Breathing Pattern Changes	<p>Any change in frequency, depth, or sound of breaths</p> <p>Noisy wet breathing, gurgling with breathing</p>	<ul style="list-style-type: none"> Pain Respiratory illness Anxiety/fear Dying process Increasing weakness and inability to swallow secretions Dying process 	<ul style="list-style-type: none"> Medication <ul style="list-style-type: none"> Helps reduce the symptoms. Increase air circulation with a small fan blowing gently towards the face. Open the room – windows & doors. Changing position. Elevate the head of the bed or prop the person on two pillows. Gently wipe the mouth with a moist cloth. Sit with the patient. 	<p>The skilled nursing facility staff and hospice nurse should be notified if:</p> <ul style="list-style-type: none"> There is a significant change in breathing. Medication is ineffective after one hour.

SYMPTOM	WHAT IS IT	POSSIBLE CAUSES	WHAT TO DO	WHEN TO ALERT THE SKILLED NURSING FACILITY OR CALL HOSPICE
Confusion	Inability to think with usual speed or clarity; feeling disoriented; difficulty paying attention, remembering, and making decisions	<ul style="list-style-type: none"> • Pain • Lack of sleep • Chemical changes • Medication side effects 	<ul style="list-style-type: none"> • Medication • Speak softly and calmly <ul style="list-style-type: none"> - Announce yourself. - Do not touch them unexpectedly. - Keep your speech clear, simple, direct, and reassuring. - Don't say too much at once. - Offer light massage the hands or forehead. - Be alert and watch for their safety. - Companionship and reassurance. - Stay with the patient until the medication begins to work. - Eliminate extra noise. - Turn off TVs and radios during conversations. 	<p>The skilled nursing facility staff and hospice nurse should be notified if:</p> <ul style="list-style-type: none"> • Confusion is new or suddenly increased. • The patient is at risk for injury. • You can't keep the patient from wandering.
Changes in Elimination	Decrease in urine output	<ul style="list-style-type: none"> • Urine output decreases due to decreased fluid intake and slower circulation through the kidneys. • Some medications or other issues can cause urinary retention (body holds the urine making a person unable to urinate) 	<ul style="list-style-type: none"> • Run water while the patient attempts urination. • If catheterized, check tubing for kinks and un-kink. • Position drainage bag below level of body. 	<p>The skilled nursing facility staff and hospice nurse should be notified if:</p> <ul style="list-style-type: none"> • The patient is unable to urinate, or if catheterized, has no urine in the bag. • The patient is uncomfortable.

SYMPTOM	WHAT IS IT	POSSIBLE CAUSES	WHAT TO DO	WHEN TO ALERT THE SKILLED NURSING FACILITY OR CALL HOSPICE
Changes in Elimination	Constipation = Three or fewer bowel movements in one week; stool may be hard and dry	<p>Stool comes from sources within the body, not from food. People who eat very little will still produce stool. Even patients with liquid stool can have constipation. Constipation can be uncomfortable. Causes:</p> <ul style="list-style-type: none"> • Pain medications (narcotics) • Decreased appetite and fluid intake • Decreased activity 	<ul style="list-style-type: none"> • Fluid intake <ul style="list-style-type: none"> - Make sure the patient drinks as much as they can tolerate. • Activity <ul style="list-style-type: none"> - Walk as much as possible, when able • Medications – laxatives • The patient is unable to urinate, or if catheterized, has no urine in the bag. • The patient is uncomfortable. 	<p>The skilled nursing facility staff and hospice nurse should be notified if:</p> <ul style="list-style-type: none"> • Severe abdominal pain. • Fever. • Persistent cramps or vomiting. • No bowel movements for three days.
Emotional, Spiritual, or Mental Changes. Unusual Communication	<p>Behavior that is out of character</p> <p>Decreased socialization/ Withdrawal</p> <p>Vision-like experiences</p>	<ul style="list-style-type: none"> • Transitioning through end of life. • Possible pre-cursor to confusion. • Transitioning through end of life. • Can progress to seemingly coma-like state. • Transitioning through end of life. • They may see or hear things you cannot. 	<ul style="list-style-type: none"> • Offer acceptance. • Sit with them. • Talk. • Listen. • Allow them to limit visitors and assist by acting as gate-keeper. • Offer support. • Continue to speak soothingly even if you think they can't hear. • Offer acceptance. • Affirm experiences. • Soothe them if they seem frightened by it. 	<p>The skilled nursing facility staff and hospice nurse should be notified if:</p> <ul style="list-style-type: none"> • You are distressed by what you are seeing. • The patient appears to be uncomfortable. <p>Remember that social workers and chaplains also play a vital role in managing distressing symptoms. Please let a hospice worker know if you need to see the social worker or chaplain more often.</p>

SYMPTOM	WHAT IS IT	POSSIBLE CAUSES	WHAT TO DO	WHEN TO ALERT THE SKILLED NURSING FACILITY OR CALL HOSPICE
Fatigue/ Drowsiness/ Increased sleeping	<p>Feelings of tiredness or exhaustion not relieved by resting</p> <p>Drowsiness – falling asleep easily or waking up hard</p> <p>Increasing hours of sleep</p>	<ul style="list-style-type: none"> • Pain • Lack of sleep • Metabolic changes • Medication side effects • Transitioning through end of life 	<ul style="list-style-type: none"> • Sit with them. • Hold their hand. • Offer light massage to hands or forehead. • Speak softly and calmly <ul style="list-style-type: none"> - Keep your speech clear, simple, direct, and reassuring - Don't say too much at once; read out loud. • Plan, schedule and prioritize activities at optimal times of the day. • Eliminate or postpone activities that are not a priority. 	<p>The skilled nursing facility staff and hospice nurse should be notified if:</p> <ul style="list-style-type: none"> • The patient has sleeplessness at night.
Nausea/ Vomiting	The feeling of needing to throw up	<ul style="list-style-type: none"> • Metabolic changes • Medication side effects 	<ul style="list-style-type: none"> • Medications – anti-nausea • Have them take slow deep breaths • Offer clear, cold, flat fluids • Sour foods – can reduce nausea 	<p>The skilled nursing facility staff and hospice nurse should be notified if:</p> <ul style="list-style-type: none"> • Vomiting of blood – more than just a few streaks. • Sudden onset, severe pain, nausea, or vomiting. • Blood in stool. • Black tarry stool. • Foul smelling vomit.

SYMPTOM	WHAT IS IT	POSSIBLE CAUSES	WHAT TO DO	WHEN TO ALERT THE SKILLED NURSING FACILITY OR CALL HOSPICE
Restlessness	<p>Repetitive motions</p> <p>Moving about the bed; antsy</p>	<ul style="list-style-type: none"> • Metabolic changes • Medication side effects • Decreased oxygen circulation 	<ul style="list-style-type: none"> • Sit with them. • Hold their hand. • Offer light massage to hands or forehead. • Speak softly and calmly: <ul style="list-style-type: none"> - Keep your speech clear, simple, direct, and reassuring. - Don't say too much at once. - Read out loud. 	<p>The skilled nursing facility staff and hospice nurse should be notified if:</p> <ul style="list-style-type: none"> • You are distressed by what you are seeing. • The patient appears to be uncomfortable. <p>Remember that social workers and chaplains also play a vital role in managing distressing symptoms. Please let the hospice team know if you need to see the social worker or chaplain more often.</p>
Skin Temperature/ Color changes	<p>Lower body temperature</p> <p>Higher body temperature</p> <p>Darker or splotchy looking patches</p>	<ul style="list-style-type: none"> • Decreased circulation • Decreased metabolism • Tumor activity • Infection • Decreased circulation • Decreased metabolism 	<ul style="list-style-type: none"> • Provide blankets for warmth – not electric. • Request room be kept at a standard/comfortable temperature. 	<p>The skilled nursing facility staff and hospice nurse should be notified if:</p> <ul style="list-style-type: none"> • You are distressed by what you are seeing. • The patient appears to be uncomfortable.

THE FOLLOWING SHEET IS TO HELP YOU EXPLAIN SYMPTOMS TO THE HOSPICE TEAM. IF YOU WOULD LIKE TO USE THIS TOOL, PLEASE LET YOUR NURSE, SOCIAL WORKER, OR CHAPLAIN KNOW AND WE WILL MAKE COPIES FOR YOU.

Edmonton Symptom Assessment System:
(revised version) (ESAS-R)

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
<hr/>												
No Tiredness <i>(Tiredness = lack of energy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
<hr/>												
No Drowsiness <i>(Drowsiness = feeling sleepy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
<hr/>												
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
<hr/>												
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
<hr/>												
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
<hr/>												
No Depression <i>(Depression = feeling sad)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
<hr/>												
No Anxiety <i>(Anxiety = feeling nervous)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
<hr/>												
Best Wellbeing <i>(Wellbeing = how you feel overall)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
<hr/>												
No _____ Other Problem <i>(for example constipation)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____

Patient's Name _____

Date _____ Time _____

Completed by (check one):

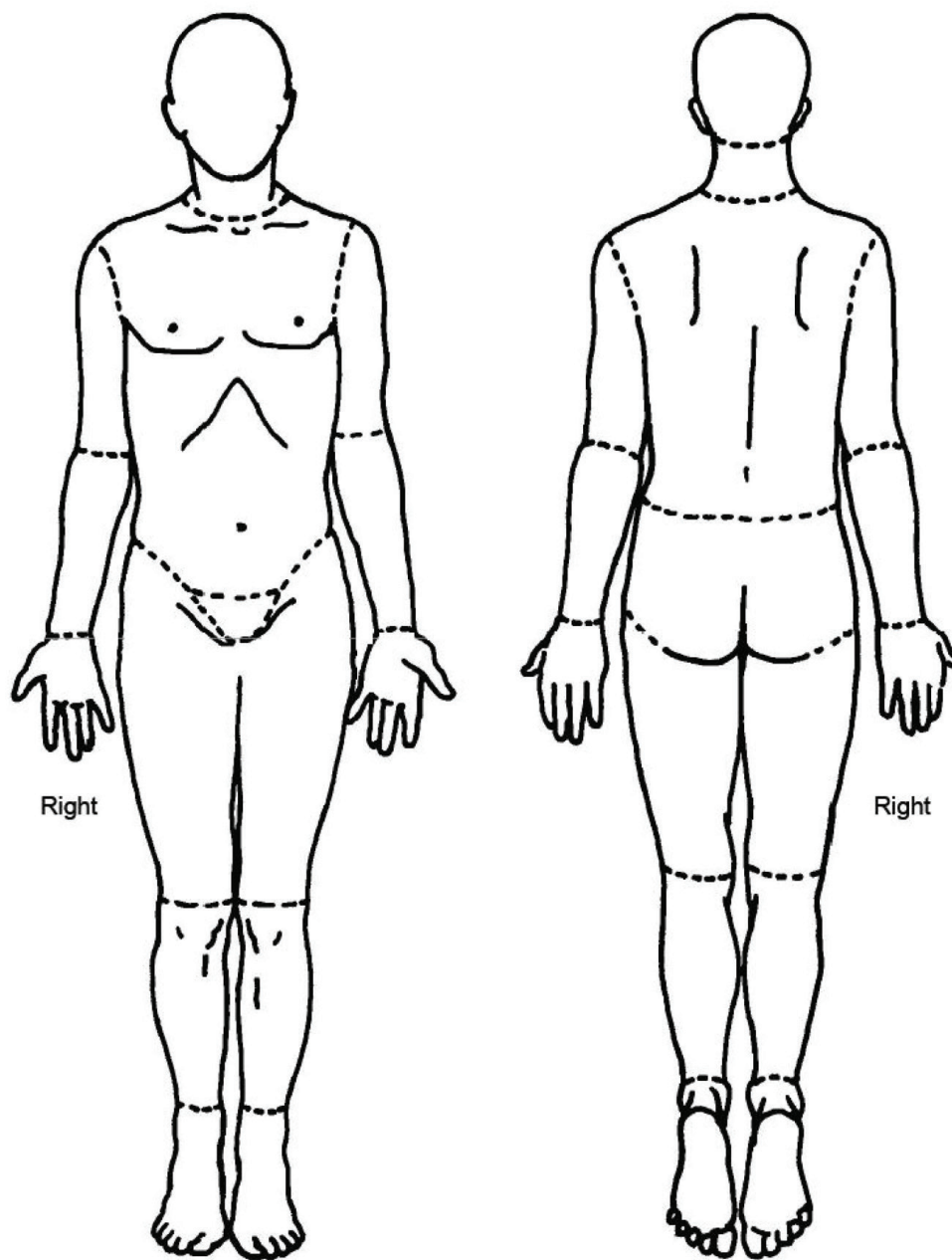
- ☐ Patient
☐ Family caregiver
☐ Health care professional caregiver
☐ Caregiver-assisted

BODY DIAGRAM ON REVERSE SIDE

ESAS-r

Revised: November 2010

Please mark on these pictures where it is that you hurt:



Feeling Confident About Medications

The following section is provided to help you understand the uses and side effects of medications frequently used for pain and symptom management.

As with any medication, the more information you have, the better able you are to prevent errors and to take care of yourself or your loved one.

Medications Related to the Hospice Diagnosis

Your hospice nurse will consult with your attending physician to obtain appropriate medications that will be needed to keep you comfortable such as for pain, breathing issues or agitation. The nurse will then teach you about the medications, why they're being given and what possible side effects they might have. The nurse will give you a form that will make it easier for you to keep track of which medications are to be taken for what symptoms, as well as when and how they are to be taken.

Care Dimensions partners with Long Term Pharmacy Solutions, a pharmacy that also serves as the pharmacy benefit manager, to meet your medication needs, 24 hours a day. At the time of admission to hospice, the admission nurse assesses your medication needs, confers with your attending physician to obtain any needed medication orders, and calls Long Term Pharmacy Solutions to order necessary medications.

According to The Centers for Medicare and Medicaid guidelines, if you have Medicare Part D drug coverage, your pharmacy must invoice Care Dimensions for all your medications. We will work with your physician and pharmacy to determine which medications are related to your hospice diagnosis and medically necessary, and therefore covered under the Medicare hospice benefit. Medically necessary medications that are unrelated to your hospice diagnosis will be covered by your Medicare Part D plan. Any prescription medications you continue to take that are determined not to be medically necessary will become your financial responsibility.

Please do not hesitate to speak to your Care Dimensions social worker or nurse if you are having any difficulties with insurance coverage for your medications. We will work closely with you to ensure that these issues are resolved.

At each visit, the hospice nurse monitors the supply of medications related to your hospice diagnosis to ensure a timely refill. Your refills or new orders are transmitted to Long Term Pharmacy Solutions and will be delivered to your home by their courier service.

Please keep medications out of the reach of children and use only as directed by your hospice nurse and/or provider.

What to Know about Taking Narcotics (opioids)

Narcotics (opioids) are medications used to treat symptoms of pain and shortness of breath in hospice patients. These medications are highly regulated by law and require a prescription by a specially licensed practitioner. Prescribers and patients are tracked in a state-wide pharmacy database.

There are short-acting and long-acting forms. Some examples include:

Fentanyl patch (Duragesic®) – long-acting	Methadone - long-acting
Hydrocodone with acetaminophen (Vicodin®) – short-acting	Morphine IR – short-acting Morphine ER (MS Contin®) – long-acting
Hydromorphone (Dilaudid®) – short-acting	Oxycodone immediate release – short-acting

- These medications help you feel more comfortable and are very safe when taken as directed and closely monitored.
- Call Care Dimensions at 888-283-1722 immediately if you experience side effects or unusual reactions to a medication or have any questions about your medications.

Common myths about narcotics (opioids):

- **Addiction:** Addiction to narcotics is very rare for hospice patients. Addiction is misuse or abuse of medication over a long period of time and will not occur when monitored and used correctly.
- **Overdose:** Overdosing is the act of taking a potentially lethal dose of medication either by accident or on purpose. This will NOT occur if the medications are used correctly and as directed by your hospice team. If you suspect the hospice patient has experienced an overdose call Care Dimensions (888-283-1722).
- **Sedation:** Using narcotics to control pain does not mean that you will be too sedated to function. You may feel drowsy for a few days, but for most people this side effect goes away as you use the medication.
- **End of life:** Narcotics do not speed up the dying process and are important for comfort and symptom management at the end of life.
- **Breathing problems:** Narcotics, when taken carefully and as prescribed, do not typically cause breathing to slow or stop. Many patients with lung diseases take narcotics to help them breathe more easily.
- **“Save until the end or they won’t work”:** Narcotics are an effective medication at any stage of illness when the patient is suffering from pain or shortness of breath. There is no maximum dose of a narcotic and the dose may need to be increased as the disease progresses or symptoms worsen.

Do's and Don't with Narcotic (opioid) Safety

Do	Don't
<ul style="list-style-type: none"> • Take the exact dosage prescribed and at the correct times. It's important to stay on schedule. • Tell your hospice nurse if you have a history of substance abuse or addiction. You could benefit from special monitoring or support when starting these medications. • Call your hospice nurse if you miss a dose or take medication incorrectly • Keep track of how much you are taking • Protect your narcotic medications <ul style="list-style-type: none"> • Keep them in a secure place, like a lock box • Keep them safely away from children – out of sight and out of reach • Keep them safely away from confused patients • Report any side effects immediately including: cold/clammy skin, unsteady walking, confusion, seeing things that are not there (hallucinations) • Take medication to prevent constipation (difficult, hard, or dry bowel movements) • Dispose of unused medication properly • Review all medications with your hospice nurse to check for drug interactions • Call Care Dimensions (888-283-1722) if you experience unpleasant or unusual reactions to a medication. 	<ul style="list-style-type: none"> • DON'T suddenly stop taking narcotics (opioids) if you have been taking them regularly for over 2 weeks. These medications need to be tapered off to avoid unwanted symptoms and side effects. • DON'T use alcohol or other substances while taking narcotics (opioids) • DON'T share, sell, or give your narcotics (opioids) to friends or family. This act is illegal and dangerous. • DON'T take any narcotics (opioids) from friends or family. This act is illegal and dangerous. • DON'T cut a pain patch or crush extended release tablets or capsules. • DON'T drive or perform activities that may put you in danger while on narcotics (opioids). Laws in Massachusetts and New Hampshire forbid driving while taking these medications.

How to Prevent Harmful Drug Interactions

Some medications can react harmfully if taken together. One medication may make another more powerful, or may keep it from working at all. Or, they may combine to create serious side effects. Always tell your hospice nurses about ALL the medications you are taking, including over-the-counter drugs, vitamin supplements and homeopathic drugs (home remedies).

Taking Too Many Medications

Many patients have more than one disease or disorder requiring treatment with different medications. While these medications may benefit you, they may also pose serious risk unless you use them with care. Always know what you are taking and why. Follow all the instructions for using drugs safely. Make sure that any over-the-counter medications you use are safe to use with your prescription medications.

Caregiver's Tips:

GIVING MEDICATIONS RECTALLY

Some medicine for pain and other symptom control may need to be given rectally if the patient cannot swallow pills. Your hospice nurse will provide education on how to administer medication rectally if needed.

GIVING MEDICATIONS SUBLINGUALLY (UNDER THE TONGUE)

Often at end of life, liquid medications are given under the tongue or between the cheek and gums. If the patient has stopped swallowing, these ways of giving the medication are still used. The medications are absorbed through the blood vessels in the mouth. Your hospice nurse will provide education on how to administer medication under the tongue.

Side Effects

The seriousness of any side effect depends on the medication and the person taking it. Some side effects are minor and others serious enough to result in the substitution of another medication. Your hospice nurse will discuss possible side effects that could occur from medications. To minimize side effects, understand what to expect from medications before taking them. Carefully read the labels and any inserts that may come with the medications. Ask the hospice nurse or your physician about potential side effects. Immediately call hospice to report any adverse reactions and/or allergies.

Storage of Medications

- Medications should be stored separately from other poisonous drugs and chemicals.

- Medications should be kept out of the reach of children, pets, and confused or disoriented patients.
- Drugs requiring refrigeration are to be stored inside the refrigerator.

Disposal of Medications

- Family or caregivers are encouraged to dispose of prescription medications in their homes when:
 - The patient no longer needs them; and/or
 - The prescription medication has expired
 - After the patient's death.
- Families and caregivers will be advised that medications may be disposed of in one of the following methods to ensure that medication disposal is secure, convenient, and consistent to prevent drug diversion:
 - Medication Disposal System
 - Many police stations and pharmacies have receptacles where you can drop off unused or expired medications for proper disposal.
 - Medication Take-back Program – conducted twice per year by the Drug Enforcement Agency (DEA) to drop-off unwanted medications. Check this website for further information: https://www.deadiversion.usdoj.gov/drug_disposal/takeback/index.html
 - Household Trash
 - Flushing

If no drug-take back sites, locations, or programs are available in your area, and there are no specific instructions in the medication guide or package insert, then follow these steps to dispose of medications in trash at home:

Care Dimensions staff and volunteers are prohibited from removing or transporting medications from the home.

Please refer to the following consumer guidelines for safe medication disposal from the U.S. Food and Drug Administration.



Food and Drug Administration, "Where and How to Dispose of Unused Medicines." 1 May 2019. <https://www.fda.gov/drugs/disposal-unused-medicines-what-you-should-know/drug-disposal-dispose-non-flush-list-medicine-trash>

How to Dispose of Unused Medicines

Is your medicine cabinet full of expired drugs or medications you no longer use? How should you dispose of them?

Many community-based drug “take-back” programs offer the best option. Otherwise, almost all medicines can be thrown in the household trash, but consumers should take the precautions described below.

A small number of medicines may be especially harmful if taken by someone other than the person for whom the medicine was prescribed. Many of these medicines have specific disposal instructions on their labeling or patient information leaflet to immediately flush them down the sink or toilet when they are no longer needed. For a list of medicines recommended for disposal by flushing, go to www.fda.gov/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/EnsuringSafeUseofMedicine/SafeDisposalofMedicines/ucm186187.htm.

Drug Disposal Guidelines and Locations

The following guidelines were developed to encourage the proper disposal of medicines and help reduce harm from accidental exposure or intentional misuse after they are no longer needed:

- Follow any specific disposal instructions on the prescription drug labeling or patient information that accompanies the



medicine. Do not flush medicines down the sink or toilet unless this information specifically instructs you to do so.

- Take advantage of programs that allow the public to take unused drugs to a central location for

proper disposal. Call your local law enforcement agencies to see if they sponsor medicine take-back programs in your community. Contact your city's or county government's household trash and recycling service to learn about



medication disposal options and guidelines for your area.

- Transfer unused medicines to collectors registered with the Drug Enforcement Administration (DEA). Authorized sites may be retail, hospital or clinic pharmacies, and law enforcement locations. Some offer mail-back programs or collection receptacles ("drop-boxes"). Visit the DEA's website (www.deadiversion.usdoj.gov/drug_disposal/index.html) or call 1-800-882-9539 for more information and to find an authorized collector in your community (www.deadiversion.usdoj.gov/pubdispsearch/spring/main?execution=e1s1).

If no disposal instructions are given on the prescription drug labeling and no take-back program is available in your area, throw the drugs in the household trash following these steps:

1. Remove them from their original containers and mix them with an undesirable substance, such as used coffee grounds, dirt or kitty litter (this makes the drug less appealing to children and pets, and unrecognizable to people who may intentionally go through the trash seeking drugs).
2. Place the mixture in a sealable bag, empty can or other container to prevent the drug from leaking or breaking out of a garbage bag.

FDA's Ilisa Bernstein, Pharm.D., J.D., offers a few more tips:

- Scratch out all identifying information on the prescription label to make it unreadable. This will help protect your identity and the privacy of your personal health information.
- Do not give your medicine to friends. Doctors prescribe medicines based on your specific symptoms and medical history. Something that works for you could be dangerous for someone else.

- When in doubt about proper disposal, ask your pharmacist.

Bernstein says the same disposal methods for prescription drugs could apply to over-the-counter drugs as well.

Why the Precautions?

Some prescription drugs such as powerful narcotic pain relievers and other controlled substances carry instructions for flushing to reduce the danger of unintentional use or overdose and illegal abuse.

For example, the fentanyl patch, an adhesive patch that delivers a potent pain medicine through the skin, comes with instructions to flush used or leftover patches. Too much fentanyl can cause severe breathing problems and lead to death in babies, children, pets and even adults, especially those who have not been prescribed the medicine.

"Even after a patch is used, a lot of the medicine remains in the patch," says Jim Hunter, R.Ph., M.P.H., an FDA pharmacist. "So you wouldn't want to throw something in the trash that contains a powerful and potentially dangerous narcotic that could harm others."

Environmental Concerns

Some people are questioning the practice of flushing certain medicines because of concerns about trace levels of drug residues found in surface water, such as rivers and lakes, and in some community drinking water supplies.

"The main way drug residues enter water systems is by people taking medicines and then naturally passing them through their bodies," says Raanan Bloom, Ph.D., an environmental assessment expert at FDA. "Many drugs are not completely absorbed or metabolized by the body and can enter the environment after passing through wastewater treatment plants."

"While FDA and the Environmental


Protection Agency take the concerns of flushing certain medicines in the environment seriously, there has been no indication of environmental effects due to flushing," Bloom says.

"Nonetheless, FDA does not want to add drug residues into water systems unnecessarily," adds Hunter.


FDA reviewed drug labels to identify products with disposal directions recommending flushing down the sink or toilet. This continuously updated listing can be found at FDA's Web page on Disposal of Unused Medicines (www.fda.gov/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/EnsuringSafeUseofMedicine/SafeDisposalofMedicines/ucm186187.htm).

Disposal of Inhaler Products

Another environmental concern involves inhalers used by people who have asthma or other breathing problems, such as chronic obstructive pulmonary disease. Traditionally, many inhalers have contained chlorofluorocarbons (CFCs), a propellant that damages the protective ozone layer. CFCs have been phased out of inhalers and are being replaced with more environmentally friendly inhaler propellants.

Read handling instructions on the labeling of inhalers and aerosol products, because they could be dangerous if punctured or thrown into a fire or incinerator. To ensure safe disposal that complies with local regulations and laws, contact your local trash and recycling facility. 

Find this and other Consumer Updates at www.fda.gov/ForConsumers/ConsumerUpdates

 Sign up for free e-mail subscriptions at www.fda.gov/consumer/consumerenews.html

Medicines Recommended for Disposal by Flushing

Listed by Medicine and Active Ingredient

This list from the U.S. Food and Drug Administration (FDA) tells you which medicines you should flush when they are no longer needed. Links in the list below direct you to medicine information for consumers that includes specific disposal instructions.

Medicine	Active Ingredient
Abstral, Actiq, Duragesic, Fentora, Onsolis	Fentanyl
Anexsia, Hysingla ER, Lortab, Norco, Reprexain, Vicodin, Vicoprofen, Zohydro ER	Hydrocodone
Apadaz	Benzhydrocodone/ Acetaminophen
Arymo ER, Embeda, Kadian, Morphabond ER, MS Contin, Avinza	Morphine
Belbuca, Bunavail, Butrans, Suboxone, Subutex, Zubsolv	Buprenorphine
Combunox, Oxaydo (formerly Oxecta), OxyContin, Percocet, Percodan, Roxicet, Roxicodone, Targiniq ER, Xartemis XR, Xtampza ER, Roxybond	Oxycodone
Daytrana transdermal patch system	Methylphenidate
Demerol	Meperidine
Diastat/ Diastat AcuDial rectal gel	Diazepam
Dilaudid, Exalgo	Hydromorphone
Dolophine, Methadose	Methadone
Nucynta, Nucynta ER	Tapentadol
Opana, Opana ER	Oxymorphone
Xyrem oral solution	Sodium Oxybate

FDA believes that the known risk of harm, including death, to humans from accidental exposure to the medicines listed above, especially potent opioid medicines, far outweighs any potential risk to humans or the environment from flushing these medicines. FDA will continue to conduct risk assessments as a part of our larger activities related to the safe use of medicines.

For disposal information, specific to another medication you are taking please visit Drugs@FDA. Once there type in the medication name and click on search. Then click on the label section for that specific medication. Select the most recent label and search for the term “disposal.”

Our Hospice Houses

While hospice care is usually provided in the patient's home, occasionally pain and symptoms or crisis situations are more easily managed by a brief stay at the Kaplan Family Hospice House in Danvers or at the Care Dimensions Hospice House in Lincoln. Patients must meet inpatient clinical eligibility guidelines determined by their insurance coverage. Our hospice houses provide a warm, home-like setting where patients receive skilled care, comfort, emotional and spiritual support from hospice nurses, physicians, social workers and spiritual counselors.

The Kaplan House offers 20 private rooms and the Care Dimensions Hospice House has 18 private rooms, complete with:

- Fold-out beds so that family and friends may spend the night.
- Private bathroom and shower.
- Private patios overlooking landscaped gardens and wetlands. Patient beds can be wheeled outside. (Some rooms in Lincoln have window seats instead of a patio.)
- TV, DVD and CD player for patient and family use.
- Medical equipment that can be hidden from sight when not in use.
- A specially equipped pediatric suite is available.

Comfortable common areas include living rooms, children's play area with toys, computer facilities, as well as a chapel/contemplation room, library, and kitchen/dining areas.

To see a video tour or photo album of our houses, please visit www.CareDimensions.org/Kaplan or www.CareDimensions.org/CDHH or ask your nurse or social worker.

VISITING POLICY

Our hospice houses welcome all visitors 24 hours a day. Care Dimensions affirms equal visitation rights for all patients and visitors without regard to their race, color, religion, gender identity, sexual orientation, national origin, age, disability, veteran status, marital status, or any other legally protected status.

ELIGIBILITY FOR CARE

Our hospice houses offer several levels of care to meet each patient's particular needs:

- Inpatient care (alternative to hospitalization) for complex pain and symptoms that require skilled care to manage; admission is based on eligibility requirements.
- Respite care lasting up to five days is a way to relieve caregivers when they are exhausted or have to be away. This is based on availability.

- Residential care enables our hospice houses to become the home of patients who have no suitable residence or caregiver to deliver hospice care. This is based on availability and requires a room and board charge.

FINANCIAL CONSIDERATIONS

Medicare, Medicaid and most insurance plans cover all or part of our hospice house care for inpatient and respite care determined by clinical needs and inpatient eligibility guidelines. Residential care is available for patients who can pay privately, similar to private nursing home payments.

Feeling Confident as a Caregiver: Taking Care of Yourself

Receiving the support you need,
can help you be a successful
caregiver.

Caring for Yourself

Providing care to a loved one can sometimes be stressful. Caring for yourself is the best way to ensure that you, as a caregiver, will be able to manage the emotional and physical strain that is commonly experienced by those who care for hospice patients. Here are a few helpful reminders:

- **Eat well.** No matter how you feel emotionally, your body continues to require a well-balanced diet.
- **Get rest and a good night's sleep.** Take a nap while the patient rests and ask your family and friends not to interrupt these rest periods. If your sleep at night is disturbed because of caring for the patient, you need this extra rest during the day.
- **Exercise** within the limits set by your physician.
- **Take time for yourself.**
- **Let others help you.** Friends and family need and want to help – let them. Hospice volunteers also are available to help with errands or to stay with your patient while you go out.
- **Ask for help.** Your hospice social worker can help you explore options for the resources you need.
- **Try a support group.** Care Dimensions offers a monthly support group for caregivers where you can find mutual support from others and learn tools to help you along your journey. Meetings are held at the Bertolon Center for Grief & Healing in Danvers. Check the online calendar at www.CareDimensions.org/calendars, or call 855-774-5100 for dates and details.

Family Medical Leave Act & Veterans' Benefits

If you have any questions regarding the Family Medical Leave Act, Veteran's benefits or any other benefit questions, please ask your hospice social worker.

Support for Children

There's a lot to do when someone you love gets sick. So it's not surprising that children's needs and feelings – whether they are grandchildren, siblings or children of patients – can sometimes get lost in the process. Kids cope best when:

- Parents provide age-appropriate medical information and allow children to talk and ask questions.
- Schools are aware when there is a serious illness in the family and teachers are sensitive and supportive.
- Relatives or friends are able to provide support for routine activities.

We're here to support your entire family. We have specially trained child life specialists and resources to help you talk to children about the end of life. Please talk to your social worker if you need assistance in talking with your children.

Grief Support Services

Care Dimensions has an extensive bereavement program with services provided at the Bertolon Center for Grief & Healing in Danvers, in our Greater Boston office in Waltham and at community locations. We provide support throughout your grieving process, which may start as soon as the patient is admitted to hospice care. Our staff offers individual counseling and group support, as well as opportunities to remember and celebrate your loved one. Our library includes books and videos for children and adults that can be used in our office or borrowed for use in your own home.

Following the death of your loved one, a member of our staff will contact you by phone, letter, or visit to provide support throughout the first 13 months of your loss. Please contact your social worker for more information about our programs, call our Grief Support staff at 855-774-5100, or visit our website at www.CareDimensions.org/grief for more resources.

What is Grief?

Grief is a natural reaction to a change in or the end of a relationship. The death of a loved one or friend may be one of the most significant events of our lives; its impact affects everything we do.

While there are common themes and experiences of grief, the way one person grieves can be quite different from the way another does, and there is no "right" or "wrong" way to grieve. You can find differences in grieving even among people who have all lost the same person.

ANTICIPATORY GRIEF

Grief often begins with a diagnosis of terminal illness. The feelings of loss you and your family may be experiencing before the death occurs is called anticipatory grief. This is a normal process and may affect different people in different ways.

Some physical signs of anticipatory grief might include:

- Heightened fear, anxiety, depression.
- Loss of energy and vitality.
- Stomach and intestinal upsets, loss of appetite.
- Tightness in the chest, dizziness, shortness of breath.
- Change in sleep patterns.

Some social and behavioral signs might include:

- Increased or decreased desire for support from family and friends.
- Communications breakdown and misunderstanding due to increased tension.
- Imagining the actual event of the death.
- A sense of unreality or disbelief.
- Worry about finances.
- Heightened sensitivity, frequent crying, mood swings.
- Uncertainty about the dying process and feelings of lack of control.

Anticipatory grief can help you prepare for a loss by giving you time to:

- Absorb the reality of the loss over time.
- Say goodbye and complete unfinished business.
- Reassign family roles.
- Adjust to the changes that may occur after the death.

Suggestions for dealing with the effects of anticipatory grief:

- Take care of yourself physically.
- Allow yourself to fully experience the emotions that arise, and talk out your feelings with those you trust.
- Allow friends, family, clergy and your hospice team to support you through this difficult time.
- Give yourself permission to say “No” to any responsibilities that can be postponed.
- Be patient with yourself.

Grief is a personal journey that can take unexpected paths. Giving yourself permission to grieve as you go along will help you manage your grief process once your loved one has died.

THE GRIEVING PROCESS

Grieving can be very painful and overwhelming. People respond to grief in a variety of ways. Many wonder whether there is a right way to grieve and whether the feelings are normal. Here are some very common feelings that you may encounter:

- Feeling emotionally numb.
- Knowing that the death has occurred, but having difficulty believing that the death has really happened.
- Feeling tightness in the throat or heaviness in the chest or in the pit of one's stomach.
- Having a loss of appetite or a desire to eat more than usual.
- Having a desire to smoke, drink, or use drugs (especially tranquilizers) in a greater amount than before.
- Feeling restless and looking for activity and finding it difficult to concentrate and complete tasks.

- Having difficulty sleeping, waking in the middle of the night, and often dreaming of your loved one.
- Being overly concerned with your health and even developing symptoms similar to those of your loved one.
- Feeling exhausted and lacking in energy.
- Feeling low at times of birthdays, holidays, and special occasions.
- Spending money on things usually not purchased.
- Talking things over with the deceased person.
- Feeling mood changes over the slightest things.
- Feeling guilty for what was said or not said or for not having done enough for your loved one.
- Being angry or irritated at the wrong person or the wrong circumstance or at the world.
- Feeling intensely angry with your loved one for leaving you.
- Having difficulty making decisions on your own.
- Sensing your loved one's presence, believing you hear his or her voice or expecting him or her to come back.
- Experiencing an intense preoccupation with the life of the deceased.
- Assuming mannerisms or traits of your loved one.
- Feeling that life has lost its purpose and you don't have a future.
- Not wanting to be with people or having difficulty initiating contact with others.
- Not feeling needed any longer.
- Crying at unexpected times.
- Difficulty remembering how your loved one looked when she/he was well.

Feeling Confident Your Goals and Wishes Will Be Honored

Making sure your wishes are known by your family and the members of your hospice team assures that you will receive the care and treatment you want, where you want it.

Advance Care Planning

Advance care planning helps you and your loved ones gain a better sense of your values, preferences, and wishes related to care and treatment during serious illness and at end of life. It provides information to others about your health care wishes in case illness or injury prevents you from telling them yourself, and it relieves your loved ones of the burden of having to decide what you might want in the circumstances.

Advance care planning is a process. It is one way the Care Dimensions team supports you as your partner in health care. We will ask to see advance care planning documents if you already have them in place. If you have not completed them and would like to do so, your hospice social worker or nurse can help. It is important to note that you can always change your mind about advance directives. Care Dimensions does not require patients to have these documents.

Advance Directives

“Advance Directives” is a common term for legal documents (statements) that are made by anyone describing treatments that should or should not be given, or identifying a person who can make medical decisions in the event the individual is unable to speak for him or herself. Advance Directives put your wishes in writing. They do not say “don’t treat me.” They say, “treat me the way I want to be treated.”

Health Care Proxy – Under Massachusetts law, if you are at least 18 years old and competent, you may complete a Health Care Proxy form, which lets you choose another person (called your Health Care Agent) to make health care decisions for you if you cannot. The purpose of the Health Care Proxy is to make sure that your wishes are respected if you become unable to speak for yourself. In your health care proxy document you can specify what types of care and treatment you want and do not want.

If You Don’t Have a Health Care Proxy – All adults have the same legal rights to accept or refuse medical care. If you become unable to make or communicate your health care decisions, you still have those same rights, but someone else must then make health care decisions for you. If you have not completed a Health Care Proxy, your family may be asked to make decisions based upon what they believe you would want. If you have no family, or if there is a disagreement about what treatment you would want, a court may be asked to appoint a legal guardian to make those decisions on your behalf.

Do Not Resuscitate (DNR) Order and Comfort Care Protocol – A DNR Order is a physician’s order that tells health care providers not to attempt CPR (cardiopulmonary resuscitation) if your heart or breathing stop. If you have a DNR order from your physician, the hospice team will provide a Comfort Care Form. It is important to have the Comfort Care Form to show ambulance personnel in the event you need to be transported to a health care facility. A DNR order is not required to choose hospice care.

Medical Orders for Life-Sustaining Treatment (MOLST) – Medical Orders for Life-Sustaining Treatment are written instructions about certain life-sustaining medical treatments, from a physician, nurse practitioner or physician assistant to other health professionals (e.g. nurses, emergency responders), based on the patient’s own preferences. The MOLST form includes instructions about resuscitation and other life-sustaining treatments. And, unlike a DNR order, the MOLST form can be used to refuse or request treatments. Talk to your hospice nurse if you would like to discuss obtaining MOLST documentation.

Having Conversations and Making Decisions

It can be difficult to talk about end-of-life issues, but it is much easier for both the patient and the family if wishes and goals are discussed before a crisis occurs. Making your wishes known to your family will provide your loved ones with the direction they need to carry out your wishes. Your hospice social worker can help guide you through this process.

Planning Documents — Personal Directive or Living Will

A personal directive or living will describes what type of future medical treatment you want or don’t want when you are seriously ill. Living wills are not legally binding in Massachusetts. However, they may be used together with a Massachusetts Health Care Proxy form to guide your Health Care Agent, family members and doctors about which treatments you would like to receive and how aggressively to use treatments to sustain life. There are several tools you can use to guide you through your decision making. Here are three that Care Dimensions recommends:

Five Wishes – This booklet includes a health care proxy form and basic planning tool is formatted into five sections that help guide you based on your beliefs and values. Ask your social worker for a free form or download it at www.agingwithdignity.org for \$5.

Honoring Choices – This organization provides free Massachusetts Health Care Proxy forms (in 9 languages), planning tools, and discussion guides to start to make your health care plan. Ask your social worker for a free “Getting Started” toolkit or download any of the documents for free at www.honoringchoicesmass.org

The Conversation Project – This offers Conversation Starter Kits (in 10 languages) to help people have conversations with their family members or other loved ones about their wishes regarding end-of-life care. Additionally, they have kits about how to choose a Health Care Proxy, discussion guides for families of people with dementia, how to have a discussion with your physician, and how to have a discussion with your seriously ill child. All starter kits are available to download for free at www.theconversationproject.org

Please visit www.CareDimensions.org/PlanningAhead for links to downloadable forms and tips for advance care planning.

If You're Facing a Difficult Decision

Challenging questions can arise during hospice care. Often, they can be resolved simply by meeting with your hospice team. Sometimes, however, addressing an ethical dilemma requires the help of Care Dimensions' Ethics Advisory Committee, a resource to help you, your family and caregivers with difficult decisions involving:

- Respect for patient and family wishes (treatment choices)
- Comfort and pain control (quality of life)
- Religious or cultural understanding (Advance Directives)

Any patient, family member, physician, Care Dimensions team member or volunteer involved in a patient's care can initiate a care team meeting or ethics consultation. For a care team meeting, ask your nurse, chaplain or social worker to schedule an appointment. To schedule an ethics consultation, call 888-283-1722 and ask for the coordinator of social work or spiritual care.

- There is no charge for an ethics consultation.
- The recommendations of the Ethics Advisory Committee will become part of your medical record.
- The consultation, like all medical treatment, is confidential.
- A further consultation may always be held at your request.

Feeling Confident at the Time of Death

Just as with a birth, we do not know exactly when a person will die. However, for those with a terminal illness, there are signs we look for that signal death is approaching. The hospice team will prepare you for the signs you will see as death approaches, as described in the following section.

When you think death has occurred or you are unsure, please call Care Dimensions at 1-888-283-1722.

Please do NOT call 911 or the police. A hospice nurse will come to you and make the necessary arrangements.

Understanding Physical Changes and Symptoms

As life draws to a close, you may feel vulnerable, frightened and concerned about what will happen next. Your hospice team can help you understand what might happen as death approaches. Understanding the common signs of approaching death can help you prepare to say goodbye and reduce your concerns about the dying process. Though some of these signs can be distressing, knowing that they are to be expected may lessen your fears.

Though each person is unique, most hospice patients experience similar physical changes as life nears its natural end. These transformations can develop over many months, or occur in just weeks or days:

- **Changes in appetite and thirst.** As death nears, patients are likely to eat less and expend less energy. The body's natural instinct is to dehydrate. This makes it easier to breathe and prepares the patient for a more comfortable death. Please do not encourage or force the patient to eat or drink if they aren't hungry or thirsty.
- **Increased sleep and difficulty getting out of bed.** Metabolic changes now may make the patient feel drowsier, take more naps and sleep for longer periods at night.
- **Restlessness or disorientation.** Metabolic changes and decreases in oxygen circulation may also cause the patient to feel restless or confused. They may think or talk about seeing family members or friends who have died. Talk to your hospice nurse about medication that can help reduce restlessness.
- **Decreased body temperature.** As circulation slows down, the patient may feel cooler. Blankets will help keep them warm. Don't use an electric blanket.
- **Increased body temperature.** The patient may develop a fever because of decreased metabolism. Cancerous tumors also produce heat.
- **Skin changes.** End-stage illness, along with decreased nutrition and fluid intake, can cause skin to weaken and become dry and sensitive. You and your hospice team should help the patient to change positions frequently to avoid bedsores.
- **Breathing changes.** The patient may experience a change in breathing patterns, breathing more rapidly or more slowly, or pausing between breaths. If they are also experiencing shortness of breath, talk to your hospice nurse about steps to help the person breathe easier.

Understanding Emotional Changes

Just as the body prepares physically for death, a dying person needs to prepare emotionally and mentally for this transition. As death approaches, the patient may be experiencing the following:

- **Less interest in the outside world.** They may no longer have strength or the interest in regular activities of daily life or having visitors.
- **Less talkative.** Talking takes energy and the patient may now prefer non-verbal ways of communicating.
- **Less socially interested in others.** As the patient's thoughts turn inward, they may want only a few people near.
- **Memory changes.** The patient's memories of long ago may seem more recent and they may forget what happened yesterday.
- **Focusing on loved ones who have died.** The patient may be thinking more about deceased friends and family, and may even feel like they are seeing or hearing them too.

Communication

As death approaches, the patient may become more withdrawn and less responsive. Though you may find it challenging to communicate now, remember that hearing is the last sense to be lost, so even if the patient doesn't answer they likely know what you are saying. This time with your loved one is very meaningful, and it's important to:

Pay attention to everything your loved one says in these final days.

You will treasure these last days together. Your family members will also want to hear about your conversations, even if they seem insignificant to you at the time.

Ask open-ended questions.

You might say, "What are you thinking or feeling now?"

Do not push for answers.

If the patient doesn't reply, let it go. They may be unable to express experiences in words and may feel frustrated.

Do not argue or challenge the patient's reality. Instead, accept and validate what they say.

For example, you might say, "You said you saw your grandfather here in the room talking about what comes 'after.' Do you want to talk about it?"

If you don't know what to say, it's OK to simply sit quietly with your loved one.

Touching the person's hand or forehead lets them know you are present. You can reassure them by saying, "I'm right here beside you."

When Death Occurs

As a caregiver, it may not be obvious to you when death comes. The two main signs of death are no breathing and no heartbeat. There may also be a loss of bowel or bladder contents.

If you sense that the patient has died, call Care Dimensions at 888-283-1722. You do not need to call for an ambulance or the police.

PLEASE DO NOT CALL 911.

A hospice nurse will come to assist you and provide support to you and your family. The nurse will notify your physician and the funeral director. The funeral director will come to your home after the physician has been notified. Remember, you can spend as much time as you would like with your loved one's body. The funeral home doesn't need to remove your loved one until you are ready. Once your loved one's body has been removed, you can call the funeral home to make arrangements.

PREPARING YOUR LOVED ONE

Family members may have different feelings about being with their loved one's body. Some may want to sit at the bedside or bathe the person. Others may not be comfortable with the transition. A hospice team member can assist you in preparing the body for the funeral home. You may want to dress them in a particular outfit, or put a special blanket over their body as they leave the home. You can walk the body out to the hearse. If you prefer this to be a private time, the team member can leave after making the necessary calls.

What Children Need When Death Occurs

How children react to death depends on their previous experiences, relationship with the patient, individual personality and stage of development. Share your feelings with them. Admit that everyone is sad and that you may cry, but assure them that you will be all right and so will they. Above all, remain attentive to their safety amidst all the distraction and activity, and offer lots of hugs and physical contact during this difficult time.

Children deserve time to experience the dying process and say goodbye. When your loved one's death is imminent, it may help to take any involved children to the funeral home so they can be prepared for the visitation and/or funeral. Then, when death occurs, consider involving the children in decisions for the funeral or memorial service. Some questions you may want to help them consider might be:

- Whether or not to attend or participate in the service.
- Which type of casket to select.
- Whether or not to view the body.
- What special objects to place in the casket.

- What clothes the person should wear for burial.
- What type of grave marker to select and what will be written on it.
- What type of urn to choose for cremated remains.
- Where to spread the ashes or bury the body.
- What flowers, music and/or readings will be selected for the service.
- Whether or not to be involved in the ritual of closing the casket for the last time.

After the funeral, remember to continue including your children in choices, such as:

- Where they would like to sleep that night.
- Which of your loved one's possessions they would like to keep.
- If they would like to see the cremated remains.
- If they would like to see the obituary or death certificate.
- If they would like to be part of a support group with other children or teens.
- How they might like to memorialize your loved one on their birthday or the anniversary of their death.
- When they'll feel ready to return to school.

Care Dimensions has child life specialists who can assist you in talking to children or answer any questions you may have about children and grief. We have two publications: *Telling the Kids – What Grown-ups Can Do When Someone Is Seriously Ill* and *Children, Teens and Grief – A Guide for Families* (ask your social worker for a copy or download from www.CareDimensions.org), as well as a lending library with numerous books and resources to help you and your children. Please ask a member of your hospice team if you would like additional resources for your children.

Practical Matters

In the days and weeks following your loved one's death, you may feel overwhelmed by the many details that seem to need immediate attention. It may be challenging for you to concentrate, make decisions or handle more than one task at a time. To support you during this time, we have gathered some information that we know has helped other families sort through tasks following a death. While some things may require immediate attention others can wait. Call Care Dimensions and speak to one of our experienced grief counselors if you want suggestions or ideas about caring for yourself or dealing with your grief.

WRITING AN OBITUARY

Your funeral home has a guide to help you tell the story of your loved one's life.

You can include a statement about where memorial contributions can be sent. For instance, if you feel that Care Dimensions was helpful to you and your loved one, you might want to specify that contributions be made to Care Dimensions so that other families can receive the same compassionate care at end of life. If you choose

to name Care Dimensions or the one of our hospice houses, please list the following address for donations: Care Dimensions, 75 Sylvan Street, Suite B-102, Danvers, MA 01923, or online donations at www.CareDimensions.org.

We can also supply you with pre-printed Tribute Donation Envelopes by calling 978-750-9318.

THINGS TO CONSIDER WITHIN THE FIRST TWO DAYS

- Make a list of family members, friends, clergy who should be contacted. You may want to delegate some or all of these calls to others.
- Ensure that proper funeral arrangements are in process.
- Let the funeral home know if there are any special requests for the funeral, including military honors.
- Contact employers (yours and your loved one's, if applicable) and children's/grandchildren's school teachers.
- Locate your loved one's will or letter of instruction, if one exists.
- Contact Social Security to notify them of death.
- Determine whether any of your loved one's property needs to be safeguarded, for example a vacant home or vehicle.

THINGS TO CONSIDER WITHIN THE FIRST TWO WEEKS

- Locate important records such as titles, deeds, and life insurance policies.
- Consider consulting an attorney to discuss and seek guidance around the estate.
- Order at least 15 death certificates from the funeral home.
- Contact the executor of the estate, if it is not you.
- Notify life insurance companies of the death and request claims forms.
- If applicable, notify mortgage company or landlord of the death.
- Determine if any bills must be paid immediately.
- Notify creditors of the death.
- Notify credit card companies and cancel any credit cards on which the person was the only signer.
- Visit your post office and fill out a form notifying them of your loved one's death.

THINGS TO CONSIDER WITHIN THE FIRST MONTH

- If you have not already done so, make a final review of the financial documents in your loved one's name.
- Locate safety deposit box, if applicable.
- If vehicles are held in joint tenancy, change motor vehicle titles to reflect ownership only by the surviving joint tenant.
- If stocks or bonds are held in joint tenancy, contact stockbroker to change records to reflect ownership only by the surviving joint tenant.

Grief Support Services

Care Dimensions not only provides compassionate care for those who are dying, but also for those who are grieving. Our bereavement program provides support at the Bertolon Center for Grief & Healing in Danvers, in our Waltham office and at community locations throughout our service area. Our staff offers individual counseling and group support, as well as opportunities to remember and celebrate your loved one. Following the death of your loved one, a member of our staff will contact you by phone, letter or visit to provide support through the first 13 months of your loss.

See page 58-60 of this guide for more information about grief or visit our website www.CareDimensions.org/grief for more resources. Please contact your social worker for more information about our programs or call our Grief Support staff at 855-774-5100.

SUGGESTED READINGS:

*Understanding Your Grief: Ten Essential Touchstones
for Finding Hope and Healing Your Heart* – Alan D. Wolfelt

Paradoxes of Mourning – Alan D. Wolfelt

*Healing After Loss: Daily Meditations for
Working Through Grief* – Martha Whitmore Hickman

How You Can Support Care Dimensions

Many times, our patients, their families, and friends ask how they can help Care Dimensions in our work to care for the dying, comfort the grieving and educate the community. We are touched and most grateful for these offers of support. As a not-for-profit organization, we rely on charitable contributions to help fulfill our mission.

Contributions from our community are vital to Care Dimensions. Our operations are partly funded through sources such as Medicare, Medicaid, commercial insurance, and private payments. However, because we provide the same high quality care to all terminally ill patients regardless of their ability to pay, we must also rely on the generosity of individuals, businesses, and foundations to help us cover expenses for those without insurance or financial means and to support innovative programs and services that are not covered by insurance, such as grief support, volunteer training, complementary therapies and palliative care.

If we've helped you, you can help your friends and neighbors by telling them about Care Dimensions if there comes a time when they need us. Let them know about the expert, compassionate care your loved one received. Tell them about the kinds of services we provide, and our specialized programs that can be tailored to each patient's needs. Share with them how reassuring it is to have a real person answering your calls, 24/7. Of course, there are other hospices, but they're not all the same. There's a reason Care Dimensions is preferred by families in our community. By sharing your experience, you'll be helping us to keep helping others.

There are also many other lasting ways you can contribute to Care Dimensions including:

MEMORIAL GIFTS

A memorial gift is a meaningful way to honor the memory of someone who has touched your life. Many families request memorial gifts be made to Care Dimensions in lieu of flowers when announcing their loved one's death. All gifts are acknowledged and family members are notified when tributes are received. If you choose to name Care Dimensions or our hospice houses, **please list the following address for donations:** Care Dimensions Hospice, 75 Sylvan Street, Suite B-102, Danvers, MA 01923, or online donations at www.CareDimensions.org. If you would like to receive pre-printed Tribute Donation Envelopes, please call 978-750-9318.

HONORING A CARE DIMENSIONS TEAM MEMBER

If you would like to honor a staff member or volunteer, please share this information when making your gift. We will be sure to notify the team member of your generosity.

MEMORIAL OPPORTUNITIES

Loved ones can be honored in the Gardens of Remembrance and in our two hospice houses. They provide a lasting way to memorialize a love one while supporting the mission of Care Dimensions. We are grateful to the many people who have supported Care Dimensions in this way. Donors are recognized throughout the year.

CASH, APPRECIATED SECURITIES, GIFTS THROUGH DONOR ADVISED FUNDS

There are many ways to make gifts to Care Dimensions. In addition to cash, some donors prefer to make contributions of appreciated securities, through their annual IRA distributions, or by recommending support from a Donor Advised Fund. Each offers different tax considerations, so we recommend that you contact your tax advisor or financial planner.

LEGACY GIVING

Some donors prefer to support Care Dimensions through their estates. Gifts may be made through wills, bequests, life insurance, or other vehicles. Each offers different tax considerations, so we recommend that you contact your tax advisor or financial planner. Donors who indicate that they are including Care Dimensions in their estate plans are recognized as members of the David Sherman Legacy Society.

ANNUAL EVENTS

We hold several fundraising events throughout the year: The Walk for Hospice and the Tree of Lights celebrations.

MATERIAL DONATIONS

In most cases, we are unable to accept donations of household goods, vehicles, books, artwork, or collectibles.

For more information about how you can support Care Dimensions, please call our Development office at 888-283-1722 or visit www.CareDimensions.org/giving

Understanding Medicare Hospice Benefits

Medicare Hospice Benefits pay only for care related to the terminal illness. Your regular Medicare benefits or health insurance continues to pay for care unrelated to the terminal illness.

As a Care Dimensions patient, you and your family receive a wide variety of services designed to provide you with expert end-of-life care. These services are covered by Medicare, Medicaid and most private insurance plans. Through Medicare, you may be eligible to receive Medicare Hospice Benefits, which cover virtually all healthcare costs related to the terminal illness.

MEDICARE HOSPICE BENEFITS PAY FOR:

- Physician guidance
- Hospice nurse visits
- Hospice aide services
- Spiritual counselor services
- Social worker services
- Bereavement counseling and support
- Volunteer assistance
- Medications for terminal illness symptom management and pain relief
- Medical equipment and supplies for your terminal illness
- Physical, speech and occupational therapy, if deemed necessary by your hospice team
- Dietary counseling
- Laboratory work

ELIGIBILITY REQUIREMENTS:

You can receive Medicare Hospice Benefits if you meet all of the following conditions:

- You are a Medicare Part A beneficiary and meet Medicare guidelines for hospice care.
- A physician certifies that you have a terminal illness and that you may not live beyond six months.
- You choose to use your Medicare Hospice Benefits by signing a hospice Medicare benefit election form. This voluntary election indicates you understand the nature of your illness and the characteristics of hospice care.
- You receive care from a Medicare-certified hospice, such as Care Dimensions.

MEDICARE PAYMENTS

Medicare pays Care Dimensions directly, freeing families from most of the paperwork.

Medical Forms

The following pages include copies of these forms:

- Medicare Hospice Benefits
- Insurance and Reimbursement
- Charges for Hospice Services
- Notice of Care Dimensions Privacy Practices
- Patient Rights and Responsibilities
- Election of Medicare Hospice Benefit Form
- Informed Consent for Hospice Services Form
- Statement of Revocation of Hospice Benefit Form
- MassHealth Hospice Election Form
- Massage/Reiki Therapy Patient Release Form



This [official government](#) booklet includes information about Medicare hospice benefits:

- ★ Who's eligible for hospice care
- ★ What services are included in hospice care
- ★ How to find a hospice provider
- ★ Where you can find more information



Welcome

Choosing to start hospice care is a difficult decision. The information in this booklet and support from a doctor and trained hospice care team can help you choose the most appropriate health care options for someone who's terminally ill.



The information in this booklet describes the Medicare Program at the time this booklet was printed. Changes may occur after printing. Visit [Medicare.gov](https://www.medicare.gov), or call 1-800-MEDICARE (1-800-633-4227) to get the most current information. TTY users can call 1-877-486-2048.

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Hospice care

Hospice is a program of care and support for people who are terminally ill (with a life expectancy of 6 months or less, if the illness runs its normal course) and their families. Here are some important facts about hospice:

- Hospice helps people who are terminally ill live comfortably.
- Hospice isn't only for people with cancer.
- The focus is on comfort (palliative care), not curing an illness.
- A specially trained team of professionals and caregivers provide care for the "whole person," including physical, emotional, social, and spiritual needs.
- Services typically include physical care, counseling, drugs, equipment, and supplies for the terminal illness and related conditions.
- Care is generally given in the home.
- Family caregivers can get support.

Palliative care

Palliative care is the part of hospice care that focuses on helping people who are terminally ill and their families maintain their quality of life. If you're terminally ill, palliative care can address your physical, intellectual, emotional, social, and spiritual needs. Palliative care supports your independence, access to information, and ability to make choices about your health care.

Care for a condition other than your terminal illness

Your hospice benefit covers care for your terminal illness and related conditions. Once you start getting hospice care, your hospice benefit should cover everything you need related to your terminal illness, even if you remain in a [Medicare Advantage Plan](#) or other [Medicare health plan](#).

After your hospice benefit starts, you can still get covered services for conditions not related to your terminal illness. [Original Medicare](#) will pay for covered services for any health problems that aren't part of your terminal illness and related conditions. However, you must pay the [deductible](#) and [coinsurance](#) amounts for all Medicare-covered services you get to treat health problems that aren't part of your terminal illness and related conditions.

Important: If you were in a Medicare Advantage Plan before starting hospice care, and decide to stay in that plan, you can get covered services for any health problems that aren't part of your terminal illness and related conditions. You can choose to get these from either your plan or Original Medicare. For more information on hospice care if you're in a Medicare Advantage Plan or other Medicare health plan, see page 10.

Note: If you start hospice care on or after October 1, 2020, you can ask your hospice provider for a list of items, services, and drugs that they've determined aren't related to your terminal illness and related conditions. This list must include why they made that determination. Your hospice provider is also required to give this list to your non-hospice providers or Medicare if requested.

How your hospice benefit works

If you qualify for hospice care, you and your family will work with your hospice provider to set up a plan of care that meets your needs. For more specific information on a hospice plan of care, call your state hospice organization. Visit [Medicare.gov/contacts](https://www.medicare.gov/contacts), or call 1-800-MEDICARE (1-800-633-4227) to find the number for your state hospice organization. TTY users can call 1-877-486-2048.

You and your family members are part of a team that may also include:

- Doctors
- Nurses or nurse practitioners
- Counselors
- Social workers
- Pharmacists
- Physical and occupational therapists
- Speech-language pathologists
- Hospice aides
- Homemakers
- Volunteers

In addition, a hospice nurse and doctor are on-call 24 hours a day, 7 days a week, to give you and your family support and care when you need it.

A hospice doctor is part of your medical team. You can choose to include your regular doctor, a nurse practitioner, or a physician's assistant on your medical team as the attending medical professional.

The hospice benefit allows you and your family to stay together in the comfort of your home, unless you need care in an inpatient facility. If your hospice provider decides you need inpatient hospice care, your hospice provider will make the arrangements for your stay.

Who's eligible for the hospice benefit

If you have [Medicare Part A](#) (Hospital Insurance) **AND** meet all of these conditions, you can get hospice care:

- Your hospice doctor and your regular doctor (if you have one) certify that you're terminally ill (you're expected to live 6 months or less).
- You accept comfort care (palliative care) instead of care to cure your illness.
- You sign a statement choosing hospice care instead of other Medicare-covered treatments for your terminal illness and related conditions.

Note: Only your hospice doctor and your regular doctor (if you have one) can certify that you're terminally ill and have 6 months or less to live.

Finding a hospice provider

To find a hospice provider, talk to your doctor, or call your state hospice organization. Visit [Medicare.gov/contacts](https://www.Medicare.gov/contacts), or call 1-800-MEDICARE (1-800-633-4227) to find the number for your state hospice organization.

You can also visit [Medicare.gov/care-compare](https://www.Medicare.gov/care-compare) to find hospice providers in your area.

Medicare only covers your hospice care if the hospice provider is Medicare approved. Visit [Medicare.gov/care-compare](https://www.Medicare.gov/care-compare) to find Medicare-approved hospice providers in your area.

If you belong to a [Medicare Advantage Plan](#) and want to start hospice care, ask your plan to help you find a hospice provider in your area. Your plan must help you locate a Medicare-approved hospice provider in your area.

What Medicare covers

You can get a one-time only hospice consultation with a hospice medical director or hospice doctor to discuss your care options and management of your pain and symptoms. You can get this one-time consultation even if you decide not to get hospice care.

Once your hospice benefit starts, **Original Medicare** will cover everything you need related to your terminal illness, but the care you get must be from a Medicare-approved hospice provider.

Hospice care is usually given in your home, but it also may be covered in a hospice inpatient facility. Depending on your terminal illness and related conditions, the plan of care your hospice team creates can include any or all of these services:

- Doctor services
- Nursing care
- Medical equipment (like wheelchairs or walkers)
- Medical supplies (like bandages and catheters)
- Prescription drugs
- Hospice aide and homemaker services
- Physical and occupational therapy
- Speech-language pathology services
- Social worker services
- Dietary counseling
- Grief and loss counseling for you and your family
- Short-term inpatient care (for pain and symptom management)
- Short-term respite care
- Any other Medicare-covered services needed to manage your terminal illness and related conditions, as recommended by your hospice team

Note: If you pay out-of-pocket for an item or service your doctor ordered, but your hospice provider refuses to give it to you, you can file an appeal with Medicare. Contact your State Health Insurance Assistance Program (SHIP) if you need help filing or understanding an appeal. For more information on filing a claim or an appeal, visit [Medicare.gov/claims-appeals](https://www.medicare.gov/claims-appeals) or call 1-800-MEDICARE.

Respite care

If your usual caregiver (like a family member) needs rest, you can get inpatient respite care in a Medicare-approved facility (like a hospice inpatient facility, hospital, or nursing home). Your hospice provider will arrange this for you. You can stay up to 5 days each time you get respite care. You can get respite care more than once, but only on an occasional basis.

What your hospice benefit won't cover

When you start hospice care, you've decided that you no longer want care to cure your terminal illness and related conditions, and/or your doctor has determined that efforts to cure your illness aren't working. Medicare won't cover any of these once your hospice benefit starts:

- **Treatment intended to cure your terminal illness and/or related conditions.** Talk with your doctor if you're thinking about getting treatment to cure your illness. You always have the right to stop hospice care at any time.
- Prescription drugs that **aren't** for your terminal illness or related conditions.
- **Care from any provider that wasn't set up by the hospice medical team.** You must get hospice care from the hospice provider you chose. The hospice team must give or arrange all care that you get for your terminal illness and related conditions. You can't get the same type of hospice care from a different hospice, unless you change your hospice provider. However, you can still see your regular doctor, nurse practitioner, or physician's assistant, if you've chosen him or her to be the attending medical professional.
- **Room and board.** Medicare doesn't cover room and board. However, if the hospice team determines that you need short-term inpatient or respite care services that they arrange, Medicare will cover your stay in the facility. You may have to pay a small [copayment](#) for the respite stay.
- **Care you get as a hospital outpatient (like in an emergency room), care you get as a hospital inpatient, or ambulance transportation,** unless your hospice team arranges it or it's unrelated to your terminal illness and related conditions.

Note: Contact your hospice team **before** you get any of these services, or you might have to pay the entire cost.

Hospice care if you're in a Medicare Advantage Plan or other Medicare health plan

Once you start getting hospice care, [Original Medicare](#) will cover everything you need related to your terminal illness, even if you choose to remain in a [Medicare Advantage Plan](#) or other [Medicare health plan](#).

If you were in a Medicare Advantage Plan before starting hospice care, **you can stay in that plan as long as you pay your plan's premiums**. You can choose to get covered services for any health problems not related to your terminal illness from either your plan or Original Medicare.

What you pay will depend on the plan and whether you follow the plan's rules, like seeing in-network providers. If your plan covers extra services that Original Medicare doesn't cover (like dental and vision benefits), your plan will continue to cover these extra services as long as you continue to pay your plan's premiums and other costs.

For more information about Original Medicare, Medicare Advantage Plans, and other Medicare health plans, visit [Medicare.gov](https://www.Medicare.gov) or call 1-800-MEDICARE (1-800-633-4227). TTY users can call 1-877-486-2048.

Information about Medicare Supplement Insurance (Medigap) policies

If you have a [Medigap policy](#), it will cover your hospice costs for drugs and respite care. Your Medigap policy will also help cover health care costs for problems that aren't part of your terminal illness and related conditions. Call your Medigap policy or your State Health Insurance Assistance Program (SHIP) for more information.

To get more information about Medigap policies, visit [Medicare.gov](https://www.Medicare.gov) or call 1-800-MEDICARE.

What you pay for hospice care

Medicare pays the hospice provider for your hospice care. There's no [deductible](#). You'll pay:

- **Your monthly [Medicare Part A](#) (Hospital Insurance) and [Medicare Part B](#) (Medical Insurance) premiums.**
- **A [copayment](#) of up to \$5 per prescription for outpatient prescription drugs for pain and symptom management.** In the rare case the hospice benefit doesn't cover your drug, your hospice provider should contact your Medicare drug plan (if you have one) to see if your plan covers it.
- **5% of the Medicare-approved amount for inpatient respite care.**

For example, if Medicare approves \$100 per day for inpatient respite care, you'll pay \$5 per day and Medicare will pay \$95 per day. The amount you pay for respite care can change each year.

Important: Once your hospice benefit starts, [Original Medicare](#) will cover everything you need related to your terminal illness. Original Medicare will also pay for covered services for any health problems that aren't part of your terminal illness and related conditions. See page 5 for more information.

Note: If you need to get inpatient care at a hospital for your terminal illness and/or related conditions, your hospice provider **must** make the arrangements. The cost of your inpatient hospital care is covered by your hospice benefit and paid to your hospice provider. Since the hospice provider and the hospital have a contract, they work out the payment between them. However, if you go to the hospital and your hospice provider did **not** make the arrangements, you might be responsible for the entire cost of your hospital care.

How long you can get hospice care

Hospice care is for people with a life expectancy of 6 months or less (if the illness runs its normal course). If you live longer than 6 months, you can still get hospice care as long as the hospice medical director or other hospice doctor recertifies that you're terminally ill.

Hospice care is given in benefit periods. You can get hospice care for two 90-day benefit periods followed by an unlimited number of 60-day benefit periods. A benefit period starts the day you begin to get hospice care, and it ends when your 90-day or 60-day benefit period ends. At the start of the first 90-day benefit period, your hospice doctor and your regular doctor (if you have one) must certify that you're terminally ill (with a life expectancy of 6 months or less).

Important: At the start of each benefit period after the first 90-day benefit period, the hospice medical director or other hospice doctor must recertify that you're terminally ill, so you can continue to get hospice care. Once your hospice benefit starts, you don't need to "re-choose" hospice care for each new benefit period.

Note: You have the right to change your hospice provider once during each benefit period.

Stopping hospice care

If your health improves or your illness goes into remission, you may no longer need hospice care. You always have the right to stop hospice care at any time. If you choose to stop hospice care, the hospice provider will ask you to sign a form that includes the date your care will end.

No one should ask you to sign any forms about stopping your hospice care at the time you start hospice. Stopping hospice care is a choice only you can make, and you shouldn't sign or date any forms until the actual date that you want your hospice care to stop.

Stopping hospice care (continued)

If you were in a [Medicare Advantage Plan](#) when you started hospice, you can stay in that plan while getting hospice care, by continuing to pay your plan's [premiums](#). If you stop your hospice care, you're still a member of your plan and can continue to get Medicare coverage from your plan after you stop hospice care. See page 10 for more information.

If you weren't in a Medicare Advantage Plan when you started hospice care, and you decide to stop hospice care, you can continue in [Original Medicare](#). If you're eligible, you can go back to hospice care at any time.

Your Medicare rights

As a person with Medicare, you have certain guaranteed rights, including:

- The right to get care that meets professionally recognized standards. If you believe that the care you're getting is below this standard, and you're dissatisfied with the way your hospice provider has responded to your concern, you have the right to contact a [Beneficiary and Family Centered Care Quality Improvement Organization \(BFCC-QIO\)](#). Visit [Medicare.gov/contacts](https://www.medicare.gov/contacts), or call 1-800-MEDICARE (1-800-633-4227) to get the phone number for your BFCC-QIO. TTY users can call 1-877-486-2048.
- The right to ask for a review of your case. If your hospice provider or doctor believes that you're no longer eligible for hospice care because your condition has improved, and you don't agree, you have the right to ask for a review of your case. Your hospice provider should give you a notice that explains your right to an expedited (fast) review by a BFCC-QIO. If you don't get this notice, ask for it. This notice lists your BFCC-QIO's contact information and explains your rights.

To see a full list of your rights, visit [Medicare.gov/claims-appeals/your-medicare-rights](https://www.medicare.gov/claims-appeals/your-medicare-rights), or call 1-800-MEDICARE.

How to submit a quality of care complaint

If you or your caregiver has a complaint about the quality of care you get from your hospice provider, you can file a complaint with your hospice provider directly. If you are uncomfortable filing a complaint with your hospice provider, or if you're dissatisfied with how your hospice provider has responded to your complaint, you can file a complaint with your BFCC-QIO by visiting [Medicare.gov/claims-appeals/file-a-complaint-grievance/filing-a-complaint-about-your-quality-of-care](https://www.medicare.gov/claims-appeals/file-a-complaint-grievance/filing-a-complaint-about-your-quality-of-care) or calling 1-800-MEDICARE (1-800-633-4227). TTY users can call 1-877-486-2048.

For more information

To learn more about Medicare eligibility, coverage, and costs and get official Medicare publications and resources, visit [Medicare.gov](https://www.Medicare.gov) or call 1-800-MEDICARE.

To get help finding a hospice provider:

- Visit [Medicare.gov/care-compare](https://www.Medicare.gov/care-compare).
- Talk to your doctor.
- Call your state hospice organization.

Visit [Medicare.gov/contacts](https://www.Medicare.gov/contacts), or call 1-800-MEDICARE to find the number for your state hospice organization.

For free health insurance counseling and personalized help with insurance questions, call your State Health Insurance Assistance Program (SHIP). To find the contact information for your SHIP, visit [shiptacenter.org](https://www.shiptacenter.org) or call 1-800-MEDICARE.

For more information about hospice, contact these organizations:

- **National Hospice & Palliative Care Organization (NHPCO)**
Visit [nhpco.org](https://www.nhpco.org), or call 703-837-1500.
- **National Association of Home Care & Hospice**
Visit [nahc.org](https://www.nahc.org), or call 202-547-7424.
- **Visiting Nurse Associations of America (VNAA)**
Visit [vnaa.org](https://www.vnaa.org), or call 202-508-9498.
- **Hospice Foundation of America (HFA)**
Visit [hospicefoundation.org](https://www.hospicefoundation.org), or call 1-800-854-3402.

CMS Accessible Communications

To help ensure people with disabilities have an equal opportunity to participate in our services, activities, programs, and other benefits, we provide communications in accessible formats. The Centers for Medicare & Medicaid Services (CMS) provides free auxiliary aids and services, including information in accessible formats like Braille, large print, data/audio files, relay services and TTY communications. If you request information in an accessible format from CMS, you won't be disadvantaged by any additional time necessary to provide it. This means you'll get extra time to take any action if there's a delay in fulfilling your request.

To request Medicare or Marketplace information in an accessible format you can:

1. Call us:

For Medicare: 1-800-MEDICARE (1-800-633-4227)

TTY: 1-877-486-2048

2. Email us: altformatrequest@cms.hhs.gov

3. Send us a fax: 1-844-530-3676

4. Send us a letter:

Centers for Medicare & Medicaid Services Offices of Hearings
and Inquiries (OHI)

7500 Security Boulevard, Mail Stop S1-13-25

Baltimore, MD 21244-1850

Attn: Customer Accessibility Resource Staff

Your request should include your name, phone number, type of information you need (if known), and the mailing address where we should send the materials. We may contact you for additional information.

Note: If you're enrolled in a Medicare Advantage Plan or Medicare Prescription Drug Plan, contact your plan to request its information in an accessible format. For Medicaid, contact your State or local Medicaid office.

Nondiscrimination Notice

The Centers for Medicare & Medicaid Services (CMS) doesn't exclude, deny benefits to, or otherwise discriminate against any person on the basis of race, color, national origin, disability, sex, or age in admission to, participation in, or receipt of the services and benefits under any of its programs and activities, whether carried out by CMS directly or through a contractor or any other entity with which CMS arranges to carry out its programs and activities.

You can contact CMS in any of the ways included in this notice if you have any concerns about getting information in a format that you can use.

You may also file a complaint if you think you've been subjected to discrimination in a CMS program or activity, including experiencing issues with getting information in an accessible format from any Medicare Advantage Plan, Medicare Prescription Drug Plan, State or local Medicaid office, or Marketplace Qualified Health Plans. There are three ways to file a complaint with the U.S. Department of Health and Human Services, Office for Civil Rights:

1. Online:

hhs.gov/civil-rights/filing-a-complaint/complaint-process/index.html.

2. By phone:

Call 1-800-368-1019. TDD user can call 1-800-537-7697.

3. In writing: Send information about your complaint to:

Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Room 509F, HHH Building
Washington, D.C. 20201



Insurance and Reimbursement

Care Dimensions provides its services without regard to insurance coverage or a patient's ability to pay for care. The following information describes hospice coverage under Medicare, Medicaid and many commercial insurance plans.

Medicare and Medicaid Hospice Benefits

Medicare (Part A) and most Medicaid plans cover all Care Dimensions services related to the management of the patient's terminal illness, as long as they are medically necessary and provided in accordance with the patient's Hospice Plan of Care. In addition to professional services of Care Dimensions staff, Medicare/Medicaid reimbursement covers the cost of medications, medical supplies, durable medical equipment and medically necessary procedures, related to the patient's hospice diagnosis.

Levels of Care: Medicare/Medicaid reimburse hospice services on a per diem (per day basis) for four different levels of hospice care, depending upon medical necessity and in accordance with the patient's Hospice Plan of Care. The reimbursement is computed to cover the average daily cost of care, although on a given day the service needs and related costs may be higher (or lower).

1. **Routine Home Care** – The most common level of care. Provides physical, spiritual and emotional support to the hospice patient and his/her family and caregivers in a home, assisted living or long-term care facility (even a hospital). This care is provided through intermittent visits by nurses, social workers, chaplains, volunteers, hospice aides and other professionals as needed.
2. **Respite Care** – Care for up to five days in Care Dimensions' Kaplan Family Hospice House, or in a contracted facility to provide relief for the patient's caregiver(s).
3. **Inpatient Care** – Provides short-term care at the Kaplan Family Hospice House (or in a contracted inpatient facility) when necessary, for pain and other symptoms that cannot be safely or effectively managed at home.
4. **Continuous Care** – Provides up to 24-hour care per day for patients during brief periods of medical crisis as necessary to prevent hospitalization and to maintain the patient at home. For a patient to qualify for Continuous Care, ongoing skilled nursing assessments and interventions must be required for such symptoms as unmanaged pain, uncontrolled seizures or hemorrhaging, severe agitation that poses a safety threat, etc.

Need for Prior Authorization: Because the Medicare/Medicaid Hospice Benefit covers only services that are authorized as medically necessary for the management of the patient's terminal illness and included in the patient's Hospice Plan of Care, any services provided outside the home require the prior authorization of the patient's Hospice Nurse (or the Care Dimensions Patient Care Manager, in the event the Nurse is unavailable). Examples include, but are not limited to: diagnostic tests (i.e., blood tests, x-rays, CT scans, MRI, etc.), chemotherapy, radiation treatments, outpatient procedures, emergency room visits, hospitalization and ambulance transportation.

In the event that you are unsure about whether prior authorization is required, please call the Care Dimensions Patient Care Manager at 888-283-1722.

Discontinuing Hospice Care: If your condition improves (for example if your illness goes into remission) or stabilizes, you may no longer qualify for hospice services under the Medicare/Medicaid hospice benefit. In this case, your hospice team will work with you, your family and your Attending Physician to develop a safe and effective discharge plan for you. You can resume Care Dimensions services at any time if your condition worsens and you meet the Medicare/Medicaid hospice eligibility requirements.

You also can decide to stop receiving hospice care at any time for any reason. If you make this decision, you will be asked to sign a *Statement of Revocation of the Hospice Benefit* form, and your hospice team will work with you, your family and your Attending Physician to develop a plan for continuity of care with other service providers as needed.

Commercial Insurance Plans

Coverage for hospice services under many other commercial insurance plans is similar to Medicare and Medicaid, but coverage varies. If you have insurance other than Medicare or Medicaid, Care Dimensions will help you determine your coverage by contacting your insurance carrier for you. You will receive written confirmation from our billing office as to the expected insurance reimbursement and any co-payments or deductibles.

For patients whose insurance plan does not provide full coverage for hospice care, or for those patients who have no insurance coverage, we offer a sliding fee scale based on need. Memorial donations and community support enable us to maintain a flexible billing policy for those who need it.

Please contact us at 888-283-1722 if you have any questions or concerns. We wish to make a difficult time easier and will work with you in any way we can to be of support and assistance.

Charges for Hospice Services

For eligible Medicare, CHAMPUS, and Division of Medical Assistance (Medicaid) recipients, hospice care is covered at 100%. Other insurance coverage for hospice care is dependent upon the patient's plan and usually requires prior approval by the insurance carrier. Any co-payments and deductibles will be billed to the patient after receiving partial payment from the insurance carrier. Hospice services are available to all, regardless of insurance coverage or ability to pay. For patients without adequate insurance coverage or financial resources, the Hospice social worker will provide you with information and an application for free or reduced fee care. Patients approved for free or reduced fee care through Hospice will receive written confirmation regarding their payment responsibility.

The rates that Care Dimensions charges for its services, unless other contractual agreements have been made with a particular insurance carrier or unless a patient qualifies for free or reduced fee care, are as follows:

Per Diem Rates

Routine Home Care - all inclusive of nursing, social work, chaplain, volunteer, hospice aide, therapies, nutritional counseling, medical director, bereavement counseling, pharmacy, home medical equipment.	\$250.00/day (excluding physician fees) \$200.00/day (excluding physician fees and drugs and DME)
Continuous Care- RN Continuous Care - HA	\$70.00/hour \$50.00/hour
General Inpatient Hospice Care	\$1000.00/day depending on facility (excluding physician fees)
Respite Care	As negotiated; dependent upon facility or home setting

Per Visit Rates

Skilled Nursing	\$110.00/visit
Hospice Aide	\$50.00/hour
Medical Social Worker	\$120.00/visit
Physical/Occupational/Speech Therapy	\$110.00/visit
Nutritional Counseling	no charge
Bereavement Counseling	no charge
Continuous Care - RN	\$70.00/hour
Continuous Care - HA	\$50.00/hour



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 read this carefully.

Our Responsibilities

Care Dimensions is required by law to protect the privacy of your health information. We are required to provide you with this Notice of Privacy Practices to describe our legal duties and your rights with respect to your protected health information. We are also required to abide by the terms of this Notice which is currently in effect, and to notify you in the event of a breach of your unsecured health information.

How We May Use & Disclose Your Health Information

The following describes the ways we may use and disclose your health information for treatment, payment and health care operations.

Treatment: Care Dimensions may use and disclose your health information to coordinate care within the hospice and with others involved in your care, such as your attending physician, members of the hospice's interdisciplinary team and other health care professionals who have agreed to assist us in coordinating your care. For example, we may disclose your health information to a physician involved in your care who needs information about your symptoms to prescribe appropriate medications.

Payment: Care Dimensions may use and disclose your health information so that we or others may bill and receive payment for the care you receive from us. For example, we may be required by your health insurer to provide information regarding your health care status, your need for care and the care that Care Dimensions intends to provide to you so that the insurer will reimburse you or the hospice for services provided and received.

Health Care Operations: Care Dimensions may use and disclose health information for its own operations to facilitate the functioning of the hospice and as necessary to provide quality care to all of our patients. Health care operations may include such activities as:

- Quality assessment and improvement activities.
- Activities designed to improve health or reduce health care costs.
- Protocol development, case management and care coordination.
- Contacting health care providers and patients with information about treatment alternatives and other related functions that do not include treatment.

- Professional review and performance evaluation.
- Training programs, including those in which students, trainees or practitioners in health care learn under supervision.
- Training of non-health care professionals.
- Accreditation, certification, licensing or credentialing activities.
- Review and auditing, including compliance reviews, medical reviews, legal services and compliance programs.
- Business planning and development, including cost management and planning related analyses and formulary development.
- Business management and general administrative activities of the Hospice.

For example Care Dimensions may use your health information to evaluate its performance, combine your health information with other patients in evaluating how to more effectively serve all hospice patients, or disclose your health information to members of the hospice's workforce for training purposes.

ADDITIONAL PERMITTED USES AND DISCLOSURES OF HEALTH INFORMATION

As Required by Law: We will disclose your health information when we are required to do so by any Federal, State or local law.

Public Health Risks: We may disclose your health information for public activities and purposes in order to:

- Prevent or control disease, injury or disability, report disease, injury, vital events such as birth or death and the conduct of public health surveillance, investigations and interventions.
- Report adverse events, product defects, to track products or enable product recalls, repairs and replacements and to conduct post-marketing surveillance and compliance with requirements of the Food and Drug Administration.
- Notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease.
- Notify an employer about an individual who is a member of the employer's workforce in certain limited situations, as authorized by law.

Abuse, Neglect Or Domestic Violence: We are allowed to notify government authorities if we believe a patient is the victim of abuse, neglect or domestic violence. We will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

Health Oversight Activities: We may disclose your health information to a health oversight agency for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. However, we may not disclose your health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits.

Judicial And Administrative Proceedings: We may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal as expressly authorized by such order or in response to a subpoena, discovery request or other lawful process, but only when we make reasonable efforts to either notify you about the request or to obtain an order protecting your health information.

Law Enforcement: As permitted or required by State law, we may disclose your health information to a law enforcement official for certain law enforcement purposes as follows:

- As required by law for reporting of certain types of wounds or other physical injuries pursuant to the court order, warrant, subpoena or summons or similar process.
- For the purpose of identifying or locating a suspect, fugitive, material witness or missing person.
- Under certain limited circumstances, when you are the victim of a crime.
- To a law enforcement official if we have a suspicion that your death was the result of criminal conduct, including criminal conduct at the hospice.
- In an emergency in order to report a crime.

Coroners And Medical Examiners: We may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

Funeral Directors: We may disclose your health information to funeral directors consistent with applicable law and, if necessary, to carry out their duties with respect to your funeral arrangements. If necessary to carry out their duties, we may disclose your health information prior to and in reasonable anticipation of your death.

Organ, Eye Or Tissue Donation: We may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for the purpose of facilitating the donation and transplantation.

Research Purposes: We may, under certain circumstances, use and disclose your health information for research purposes. Before we disclose any of your health information for research purposes, the project will be subject to an extensive approval process. This process includes evaluating a proposed research project and its use of health information and trying to balance the research needs with your need for privacy. Before we use or disclose health information for research, the project will have been approved through this research approval process. Additionally, when it is necessary for research purposes and so long as the health information does not leave our organization, it may disclose your health information to researchers preparing to conduct a research project, for example, to help the researchers look for individuals with specific health needs. Lastly, if certain criteria are met, we may disclose your health information to researchers after your death when it is necessary for research purposes.

Limited Data Set: We may use or disclose a limited data set of your health information, that is, a subset of your health information for which all identifying information has been removed, for purposes of research, public health, or health care operations. Prior to our release, any recipient of that limited data set must agree to appropriately safeguard your health information.

Serious Threat To Health Or Safety: We may, consistent with applicable law and ethical standards of conduct, disclose your health information if, in good faith, we believe that such 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.

Specified Government Functions: In certain circumstances, the Federal regulations authorize us to use or disclose your health information to facilitate specified government functions relating to military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations and inmates and law enforcement custody.

Worker's Compensation: We may release your health information for worker's compensation or similar programs.

OTHER USES AND DISCLOSURES OF YOUR HEALTH INFORMATION TO WHICH YOU MAY AGREE OR OBJECT

Facility Directory: We may disclose certain information about you, including your name, your general health status, your religious affiliation and where you are in the hospice's facility, in a hospice directory while you are in the hospice inpatient facility. We may disclose this information to people who ask for you by name. Please inform us if you want to restrict or prohibit some or all of the information provided in the directory.

Persons Involved in Your Care: When appropriate, we may share your health information with a family member, other relative or any other person you identify if that person is involved in your care and the information is relevant to your care or the payment of your care. We also may notify your family about your location or general condition or disclose such information to an entity assisting in a disaster relief effort.

You may ask us at any time not to disclose your health information to any person(s) involved in your care. We will agree to your request unless circumstances constitute an emergency or if the patient is a minor.

Fundraising Activities: Care Dimensions, our hospice foundation, or our business associate may use information about you, including your name, address, telephone number and the dates you received care, in order to contact you for fundraising purposes. You have the right to opt-out of receiving these communications from us. If you do not want us to contact you for fundraising purposes, notify the Development Associate at 888-283-1722 and indicate that you do not wish to receive fundraising communications.

AUTHORIZATIONS TO USE OR DISCLOSE HEALTH INFORMATION

Other than the permitted uses and disclosures described above, Care Dimensions will not use or disclose your health information without an authorization signed by you or your personal representative. If you or your representative signs a written authorization allowing us to use or disclose your health information, you may cancel the authorization (in writing) at any time. If you cancel your authorization, we will follow your instructions except to the extent that we have already relied upon your authorization and taken action.

The following uses and disclosures for your health information will only be made with your signed authorization:

1. Uses and disclosures for marketing purposes;
2. Uses and disclosures that constitute a sale of health information;
3. Most uses and disclosures of psychotherapy notes, if we maintain psychotherapy notes; and
4. Any other uses and disclosures not described in this Notice.

YOUR RIGHTS REGARDING YOUR HEALTH INFORMATION

You have the following rights regarding your health information:

- **Right to request restrictions:** You have the right to request restrictions on uses and disclosures of your health information for treatment, payment and health care operations. You have the right to request a limit on the disclosure of your health information to someone who is involved in your care or the payment of your care. We are not required to agree to your request, unless your request is for a restriction on a disclosure to a health plan for purposes of payment or health care operations (and is not for purposes of treatment) and the medical information you are requesting to be restricted from disclosure pertains solely to a health care item or service for which you have paid out-of-pocket in full. If you wish to make a request for restrictions, please contact Care Dimensions' Medical Records Department at 888-283-1722.
- **Right to receive confidential communications:** You have the right to request that we communicate with you in a certain way. For example, you may ask that the hospice only conduct communications pertaining to your health information with you privately with no other family members present. If you wish to receive confidential communications, please contact the Care Dimensions' Clinical Manager and/or the Practice Manager overseeing your care at 888-283-1722. We will not request that you provide any reasons for your request and will attempt to honor any reasonable requests for confidential communications.
- **Right of access to inspect and copy your health information:** You have the right to inspect and copy your health information, including billing records. A request to inspect and copy records containing your health information may be made to Care Dimensions' Medical Records Department at 888-283-1722. If you request a copy of your health information, we may charge a reasonable fee for copying and assembling costs associated with your request.

You have the right to request that we provide you, an entity or a designated individual with an electronic copy of your electronic health record containing your health information, if we use or maintain electronic health records containing patient health information. We may require you to pay the labor costs incurred in responding to your request.

- **Right to amend health care information:** You or your representative has the right to request that we amend your records, if you believe that your health information is incorrect or incomplete. That request may be made as long as the information is maintained by us. A request for an amendment of records must be made in writing to Care Dimensions' Director of Compliance and Medical Records at 888-283-1722. The Hospice may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your health information records were not created by us, if the records you are requesting are not part of our records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy or if, in our opinion, the records containing your health information are accurate and complete.
- **Right to an accounting:** You or your representative has the right to receive an accounting of disclosures of your health information made by Care Dimensions for the previous six (6) years. The accounting will not include disclosures made for treatment, payment or health care operations unless we maintain your health information in an Electronic Health Record (EHR). The request for an accounting must be made in writing to Care Dimensions' Medical Records Department at 888-283-1722. The request should specify the time period for the accounting starting on or after April 14, 2003. We would 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.

- **Right to opt-out of fundraising:** You or your representative have the right to opt-out of receiving fundraising communications. Instructions for how to opt-out are included in each fundraising solicitation you receive.
- **Right to receive notification of a breach:** You or your representative has the right to receive notification of a breach of your unsecured health information. If you have questions regarding what constitutes a breach or your rights with respect to breach notification, please contact Care Dimensions' Director of Compliance and Medical Records at 888-283-1722.
- **Right to a paper copy of this notice** You or your representative have a right to a separate paper copy of this Notice at any time, even if you or your representative have received this Notice previously. To obtain a separate paper copy, please contact Care Dimensions' Medical Records Department at 888-283-1722.

CHANGES TO THIS NOTICE

Care Dimensions reserves the right to change this Notice. We reserve the right to make the revised Notice effective for health information we already have about you, as well as any health information we receive in the future. We will post a copy of the current Notice in a clear and prominent location to which you have access. The Notice also is available to you upon request. The Notice contains, at the end of this document, the effective date. In addition, if we revise the Notice, we will offer you a copy of the current Notice in effect.

IF YOU HAVE ANY QUESTIONS REGARDING THIS NOTICE

Care Dimensions has designated the Director of Compliance and Medical Records as its contact person for all issues regarding patient privacy and your rights under the Federal privacy standards. You may contact this person at 75 Sylvan Street, Suite B-102, Danvers, MA 01923, phone number 888-283-1722.

COMPLAINTS

You or your personal representative has the right to express complaints to the hospice and to the Secretary of the U.S. Department of Health and Human Services if you or your representative believes that your privacy rights have been violated. Any complaints to Care Dimensions should be made in writing to the Vice President of Quality and Compliance at Care Dimensions, 75 Sylvan Street, Suite B-102, Danvers, MA 01923, phone number 888-283-1722. We encourage you to express any concerns you may have regarding the privacy of your information. You will not be penalized in any way for filing a complaint.

EFFECTIVE DATE

This Notice is effective **September 23, 2013**.

75 Sylvan Street, Suite B-102, Danvers, MA 01923

888-283-1722

CD 019 1/15/03 (Revised 1-14-2020)



Patient Rights & Responsibilities

Care Dimensions' mission is to enrich the quality of life for anyone affected by a life-limiting illness. Our primary goal is to provide assistance that enables patients to stay at home or wherever they choose to live, to enhance the patient's comfort, and to teach their caregivers the necessary skills for hands-on care. Care Dimensions staff, the patient, family and significant others work together as a caregiving team. Care Dimensions does not provide care or procedures that are curative in nature or that prolong life.

As a patient of Care Dimensions, you have the right to:

1. Be cared for by an interdisciplinary team who will provide high quality comprehensive hospice services, and to have care and conflicts in care handled in an ethical manner.
2. Have a clear understanding of the availability of and access to hospice services and the hospice team 24-hours a day, seven days a week, and be informed of the hospice services/products and equipment available directly or by contract.
3. Receive services that recognize the dignity of each person, regardless of diagnosis, race, age, gender, creed, disability, sexual orientation, gender identity, place of residence, veteran status, lifestyle, or the ability to pay for the services rendered.
4. Be treated with courtesy and respect for privacy, security and property; and be free from any mental or physical abuse, neglect or exploitation by hospice staff.
5. Be fully informed about your health status to enable you to participate in your plan of care. The Care Dimensions team will assist you and your caregiver in identifying which services and treatments will help you attain your goals including the names and professional disciplines of persons who will provide care, the frequency of visits by each team member, and be advised in advance of any changes to your plan of care.
6. Be fully informed regarding the potential benefits and risks of all medical treatments or services suggested, and to accept or refuse those treatments and to be informed of the possible consequences of such refusal.
7. Be provided with information about the Patient Self-Determination Act as a means of formulating an advance directive, to receive service whether or not an advance directive had been executed, and to have Care Dimensions comply with any advance directive in accordance with state law.
8. Make informed decisions about care and treatment plans, and receive information about your care and treatment in a way that is understandable to you.
9. Not receive any experimental treatment without your specific consent and full understanding of potential benefits and risks.
10. Confidentiality with regard to personal health information as well as social and/or financial circumstances, according to the Care Dimensions Notice of Privacy Practices.
11. Voice grievances regarding patient care, treatments, advance directive implementation, and/or respect for person or privacy without being subjected to discrimination or reprisal, and have any such grievances investigated by Care Dimensions, and receive a response from Care Dimensions regarding the investigation and resolution of the grievance. To voice a grievance, call the Care

Dimensions Vice President of Quality and Compliance at 888-283-1722. If you do not receive satisfactory resolution of your grievance you may call the Division of Health Care Quality at 617-753-8150 or Community Health Accreditation Program (CHAP) at 800-656-9656 (24 hours/day).

12. Report any instances of abuse, neglect or mistreatment of a patient, or misappropriation of a patient's property as noted in the Massachusetts Patient Abuse Law at MGL Chapter 111, sections 72F-72L, and 105 CMR 155.000 relating to nursing homes and rest homes, and hospice and home health agencies. If you are aware of any instances, you are encouraged to report these conditions to Care Dimensions VP of Quality and Compliance at 888-283-1722 and to write or fax:
Complaint Unit
Massachusetts Department of Public Health
Division of Health Care Facility Licensure and Certification
99 Chauncy Street
Boston, MA 02111
Fax number: 617-753-8165, DPH Hotline: 1-800-462-5540
13. Be informed of the extent to which payment may be expected from your insurance, third party payers or public benefit programs; to be informed of any charges not covered by your insurance or for which you may be liable; and to receive this information, orally and in writing, within 14 days of the date Care Dimensions becomes aware of any changes in insurance coverage or charges.
14. Be informed of Care Dimensions' ownership status and its affiliation with any entities to which the patient is referred.
15. Revoke the election of hospice services at any time; request transfer or discharge from hospice and/or Care Dimensions services; be notified in advance of care options, transfers and when and why care will be discontinued; participate in the selection of alternative options for care or referral to other agencies; and receive education, instructions and requirements for continuing care following transfer/discharge.
16. Receive information about Care Dimensions' liability insurance upon request.

As a Care Dimensions patient, you have the responsibility to:

1. Participate in the development of and to follow your plan of care, including instructions given for performing a procedure or using a piece of equipment.
2. Provide Care Dimensions with accurate and complete health information, including changes in physical symptoms, psychosocial or spiritual concerns.
3. Express any concerns about your understanding of your health status and services or your ability to comply with instructions.
4. Remain under a doctor's care while receiving hospice services.
5. Assist Care Dimensions staff in developing and maintaining a safe environment in which your care can be provided and establishing a back-up plan for emergencies.
6. Notify Care Dimensions in advance of any visit you must cancel.
7. Seek authorization in advance for any services not expressly ordered by Care Dimensions staff and included in your hospice plan of care. Failure to seek such authorization may result in personal financial responsibility.

NOTES

[illegible]



Compassionate Expertise for Advanced Illness

Care Dimensions, one of the nation's first hospice programs and the region's largest, provides services in over 100 communities in Massachusetts.

As a non-profit, community-based leader in advanced illness care, we honor diversity and welcome patients of all race, color, national origin, age, disability, religion, sexual orientation or gender expressions. Our services include:

- Hospice
- Palliative care
- Specialized care programs: *Dementia, Cardiac and Lung Diseases, Pediatrics, Developmentally disabled adults*
- Meeting the unique needs of: *Veterans and the LGBTQ community*
- Kaplan Family Hospice House and Care Dimensions Hospice House
- Grief support
- HomeMD - primary care at home
- Care Dimensions Learning Institute

Main: 888-283-1722

Referrals: 888-287-1255

Referral Fax: 978-774-4389

CareDimensions.org



WE HONOR VETERANS



ATTENTION: If you do not speak English, language assistance services, free of charge, are available to you. Call 1-888-283-1722 (TTY: 7-1-1).

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-888-283-1722 (TTY: 7-1-1).

ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 1-888-283-1722 (TTY: 7-1-1).