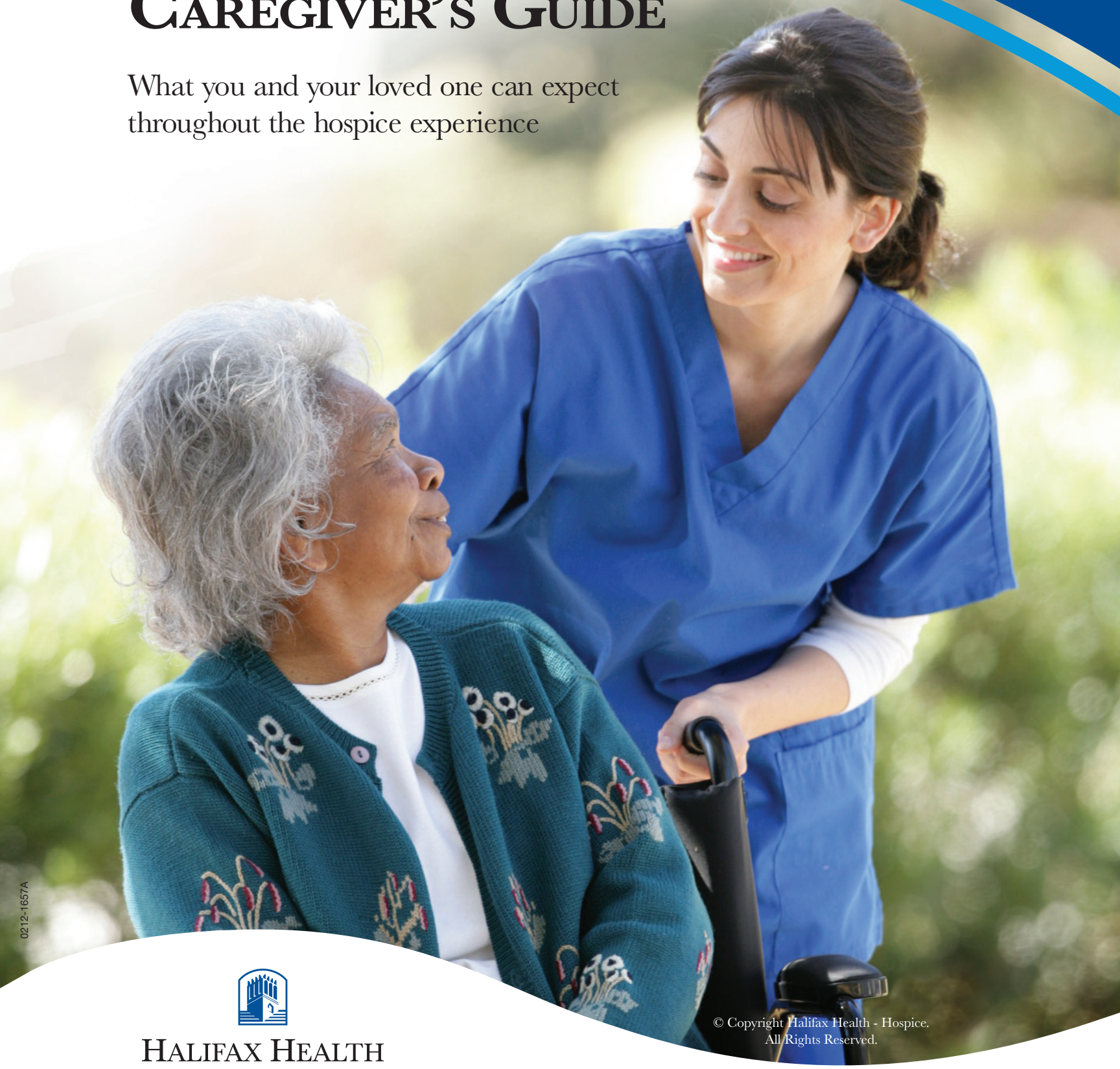
Caregiver's Guide

What you and your loved one can expect throughout the hospice experience



0212-1657A

Halifax Health
Hospice
Licensed since 1979

halifaxhealth.org/hospice | 800.272.2717

General Information

Caregiver's Guide

0212-1657B

Symptom Guide

Equipment

Preparing for Death

General Information

IMPORTANT PHONE NUMBERS

HALIFAX HEALTH - HOSPICE: EMERGENCY (24 hours/day, every day).....800.272.2717
Serving Volusia, Flagler Orange and Osceola Counties
halifaxhealth.org/hospice
Patient Referral….....386.425.4757
Admissions Fax.....386.322.5146

CARE CENTERS
Ormond Beach, 235 Booth Road, Ormond Beach.....386.425.3150
Port Orange, 3800 Woodbriar Trail, Port Orange 386.425.4752
Southeast Volusia, 4140 S. Ridgewood Avenue, Edgewater.....386.425.8950
West Volusia/Orange City Care Center.....386.425.7600

OFFICES
Port Orange (Main).....386.425.4701
DeLand …….....386.425.9888
Orange/Osceola…….....407.825.9848
Ormond …….....386.425.7900

GRIEF COUNSELING & SUPPORT
Bereavement…….....386.425.4738
Traumatic Loss Program……...386.425.3337
Tender Paws Pet Loss……....386.425.3337

LAWRENCE E. WHELAN BEGINAGAIN CHILDREN'S GRIEF CENTERS
East Volusia…….....….386.425.3100
West Volusia…….....….....386.425.9889
FlaglerCounty……...…...386.425.3100
New Smyrna Beach…….....……386.425.3100
Orange/ Osceola……..…….....407.825.9848

RESALE SHOPS
New Smyrna Beach, 720 S. Dixie Frwy ……..... .....386.426.7308
Orange City, 876 Saxon Blvd …….....386.456.0240
Ormond Beach, 160 S. Nova Rd., Unit132……..……..386.672.2915
Palm Coast, 122-126 Flagler Plaza Dr.....386.439.0333
Port Orange, 3830-A S. Nova Rd 386.761.6045

General Information

IMPORTANT PHONE NUMBERS

Your Halifax Health - Hospice Team (please print)

Telephone #: _____
Team: _____
Attending Physician: _____
Nurse: _____
Social Worker: _____
Halifax Health - Hospice Chaplain: _____
Certified Nursing Assistant: _____
Volunteer: _____

Your Community Support

Your Pastor: _____
Contracted Pharmacy: _____
Other Pharmacy: _____
Contracted Equipment & Oxygen: _____
Funeral Home: _____
Ambulance: Before calling 911 for an ambulance, please call your Halifax Health - Hospice nurse.
Keep DNR (Do Not Resuscitate order) taped to the refrigerator or headboard of the bed.

YOUR HALIFAX HEALTH - HOSPICE TEAM

Physician Services

Every patient enrolled with Halifax Health-Hospice has an "attending physician" who is ultimately responsible for that patient's individualized plan of care. This "attending" can be your own doctor from the community, or one of the skilled physicians or nurse practitioners on our own medical team. If you have your own doctor, our medical team will work closely with that community physician to provide additional medical support and resources. At Halifax Health - Hospice, our experienced, board certified physicians, meet weekly with your nurses, chaplains, nursing assistants, and social worker to make changes as needed to the plan of care and ensure the highest quality clinical services.

Registered Nurses

Nurses monitor the patient's physical health and communicate changes, medication needs, and any signs of disease progression to the patient's primary physician. Nurses also teach caregivers and family members how to manage the day-to-day care of the patient. Many people who think they could never provide physical care to sick loved ones find an enormous amount of inner strength during this period. Caregivers perform extraordinary tasks in loving and sensitive ways, and many are thankful that they were able to give this last gift to their loved one.

Certified Nursing Assistants

CNAs are available to provide or help with personal care such as bathing, bed making, light housekeeping, etc. They are available to visit as often as you and your nurse feel is needed to assist with personal care and other daily activities.

Medical Social Services and Counseling

Many families benefit from the services provided by Halifax Health - Hospice social workers who are available to visit as often as needed. They provide emotional support, assist with financial concerns and are available to help patients and loved ones sort through the sometimes overwhelming issues and feelings surrounding a life-limiting illness. If you need assistance with community resources, your social worker will be able to help you.

Spiritual Staff

Spiritual questions and concerns can arise at the end of life whether one is "religious" or not. Spiritual care in Hospice validates the view of spirituality held by the patient and family to be the framework from which spiritual care is provided. Spiritual concerns surrounding meaning and worth, anger and fear, guilt and forgiveness, hope and grief, sacraments and rituals can be addressed as patients and families desire. If you already belong to a faith community in the area, our chaplains can help notify members of that community and let them know what support you would like from them.

Bereavement Counseling

Bereavement services are available to the family and significant others for one year following the death of the patient to assist in working through feelings of loss and grief. Bereavement is also extended to the staff and residents of nursing facilities.

Dietary Counseling

Nutritional needs, appetite, and thirst can change in the last months to weeks of life and can be a concern for patients and families. Our medical team will help advise you on these issues. For particularly challenging nutritional problems, we add a dietician to your team.

Physical, Occupational and Speech Therapy

As the need arises in collaboration with patient/family and Halifax Health - Hospice Care Team, therapy will be evaluated and provided through a contractual agreement.

Other Therapies

Clinical aromatherapy includes the use of oils, which may or may not have a detectable scent, to assist in symptom management, relaxation, comfort, and grieving. Aromatherapy is available in all Halifax Health - Hospice Care Centers.

Music can be beneficial during times of restlessness, anxiety, pain and shortness of breath. Halifax Health - Hospice Care Centers feature the C.A.R.E. Channel, which displays beautiful nature scenes accompanied by gentle, relaxing music, 24 hours a day. The channel is accessible in all the patient rooms.

Pets hold a special place in their owner's hearts and may offer comforting therapy for many patients. For this reason, pet visitation is permitted in our Care Centers.

Volunteers

Volunteers fill a vital role as care team members by supporting the patient, loved ones and the Halifax Health - Hospice staff. If volunteer support is desired, a trained volunteer will contact the patient or caregiver to determine how he or she can be of help. Some of the many services volunteers provide are listed below:

- Preparing simple meals
- Doing simple household tasks
- Helping write letters
- Running errands
- Reading to the patient
- Assisting patients and staff in the Care Center

INTRODUCTION

A Concept of Care

Halifax Health - Hospice provides physical, emotional, and spiritual care to patients with life-limiting illnesses and their loved ones with the goal of enhancing comfort and improving quality of life.

Hospice Background

The term "hospice," from the same linguistic root as "hospital" and "hospitality," dates back to medieval times, when it was used to describe a place of shelter and rest for weary travelers on long journeys. The term was first applied to specialized end-of-life care in 1967, when Dr. Cicely Saunders established St. Christopher's Hospice in a residential suburb of London. Today, the term "hospice" refers to the concept of humane and compassionate care which can be implemented
in a patient's home, nursing home, hospital, or wherever the patient resides.

Halifax Health - Hospice began in 1979 as an all-volunteer organization, serving 60 patients in Volusia County. Now, teams of professionals and volunteers across the Volusia/Flagler region continue to serve from the heart, caring for thousands of patients every year.

At Halifax Health - Hospice, hospice is a "Journey of Care" that centers on treating the person, not the disease. Nurses, social workers, counselors, nursing assistants, chaplains and volunteers are all a part of this experience, helping patients live as comfortably and completely as possible. The path varies with each person, but patients never have to travel the path alone.

WHEN YOU NEED HELP AFTER HOURS

Your regular Halifax Health - Hospice team works from 8:00 am to 4:30 pm on weekdays, but our on-call staff is available to help you 24 hours a day, 7 days a week.

The Halifax Health - Hospice phone number: 800.272.2717

During periods of high volume, you may be speaking to an operator. Please give the operator the following information:

- The patient's name
- The caller's name
- The phone number
- The problem

After leaving your message with an operator, a staff member will call you back within 20 minutes to answer your questions and arrange a visit if needed. We ask that you please keep your phone line clear for the return call. If your call has not been returned after 20 minutes, please call again.

When you should call

Emergencies may include:

- Pain not helped with medicine
- Vomiting not helped with medicine
- Unexpected changes, such as fever, confusion, shortness of breath
- Family crisis
- Emotional or spiritual crisis
- Unexplained changes in the patient's condition
- Death of the patient
- Any concern that you may have

When Halifax Health - Hospice staff visits after dark

- Please turn on outside lights so that the door and house number are well-lit.
- If your house number is not easily seen, please ask someone to watch for the Halifax Health - Hospice staff person.
- Please be aware that if the nurse or staff member feels they cannot enter your home safely, they will call you and use other means to help you with the emergency.

A Concept of Care

Physicians, healthcare professionals, family members, and patients themselves are all welcome to call or visit our office to discuss hospice services. Due to privacy issues, however, Halifax Health - Hospice asks that any concerned individuals discuss hospice with the patient or a family member first before calling us. To be admitted to the Halifax Health - Hospice program, the following criteria are considered:

The Patients must:

- Live in Volusia, Flagler, Orange or Osceola County.
- Have a life expectancy of approximately six months if the disease follows its normal course.
- Have a 24-hour caregiver available when they can no longer meet their own needs, or they must be willing to make an alternative plan of care.
- Desire management of symptoms to provide comfort versus aggressive care.

The Admission Process

The admission process begins with a call from Halifax Health - Hospice. To begin creating a patient chart, we will ask for some general information such as name, address and insurance information. At this point, we will establish a time to admit the patient to our program.

What to expect during the basic admission process:

- A Halifax Health - Hospice Representative will talk with the patient and identify their wishes and goals.
- Halifax Health - Hospice services will be explained in detail and the patient or designee will sign informed consent.
- Financial information is reviewed so that the patient and caregiver have an understanding of financial responsibility. Medicare, Medicaid or insurance documents will be completed and signed. No patient will be denied services because of inability to pay.
- A physical assessment of the patient will be done.
- The nurse will collaborate with the attending physician regarding pain and symptom control.
- Helpful suggestions will be given regarding daily care and comfort measures. Individual patient education will begin if indicated.
- The ongoing plan of care for the patient and family will begin, addressing any problems or concerns that arise during the admission visit.

Specific services available to benefit Halifax Health - Hospice patients are listed below:

- Home visits by registered nurses, social workers, counselors, other healthcare professionals and chaplains as needed.
- Nurses, social workers, and chaplains are on-call 24 hours a day, 7 days a week.
- Provision of medical equipment (such as oxygen and hospital beds) and all necessary medications to the patient's terminality..
- Short term supportive care as appropriate and available.
- Short-term inpatient care as appropriate and available..
- Personal and practical care by a certified nursing assistant (CNA).
- Training for the caregiver (friend or family member) to learn how to better assist the patient when Halifax Health - Hospice staff are not present.
- Education about the illness, what to expect as the disease progresses, and how to cope with limitations.
- Individual and family counseling, spiritual support.
- Assistance with funeral arrangements.
- Bereavement support for caregivers and family members.

Your Medical Records

Halifax Health-Hospice maintains a medical record for each patient. The information in your medical record is protected by state and federal law. Halifax Health-Hospice takes steps to protect patient privacy and may use and disclose your medical information only as permitted or required by law. Patients have certain information-related rights, such as the right to restrict uses and disclosures of your personal medical information. This and other information-related rights are described in the Notice of Privacy Practices given during the admission process.

NOT-FOR-PROFIT ORGANIZATION

Halifax Health - Hospice is a 501(C)3 organization whose mission is to provide quality healthcare to terminally ill patients, regardless of ability to pay. Charitable contributions are used to provide care to patients with inadequate financial resources and to offer expanded services in the community.

Contributions to Halifax Health - Hospice take many forms. Some are modest memorial gifts; others are major estate bequests and some are corporate or foundation grants for specific purposes. If you or someone you know is seeking financial or tax advice relating to a gift, we can recommend specific, professional resources.

To learn more about how you can help our not-for-profit hospice, call the Fund Development office at 386.425.4701.

PLEASE LET US KNOW HOW WE'RE DOING

At Halifax Health - Hospice, we are firmly committed to providing you with the highest quality hospice services. If you have questions at any stage of the hospice journey, please feel free to discuss them with any of the healthcare professionals on your team. And if you encounter a problem with any aspect of our care, please let us know so we can resolve it for you as soon as possible.

Should you feel uncomfortable discussing a problem or issue with your Team Members, please call the Halifax Health - Hospice, Director of Quality or our Executive Director at 386.425.4701. Your input is extremely valuable to us as we continue to improve our services in any way we can. We are interested and we care.

PATIENT RESPONSIBILITIES

- To notify Halifax Health - Hospice of changes in your condition (e.g. hospitalization, changes in the plan of care, symptoms to be reported).
- To follow the Plan of Care.
- To notify Halifax Health - Hospice if the visit schedule needs to be changed.
- To inform Halifax Health - Hospice of the existence of, and any changes made to, Advance Directives.
- To provide a safe environment for care to be received.
- To carry out mutually agreed responsibilities.
- To provide to the best of your knowledge accurate and complete information about present complaints, past illnesses, hospitalizations, medications, and other matters related to your health.

CONSUMER ASSISTANCE NOTICE

To report abuse, neglect, or exploitation: Call 1.800.96.ABUSE (1.800.962.2873)

Agency for Health Care Administration complaint hotline: 1.888.419.3456

In compliance with Florida Statute 641.511(11), commercial health maintenance organization (HMO) members have the right to contact the following organizations for assistance with issues concerning their rights as HMO members:

Agency for Health Care Administration
2727 Mahan Drive
Mail Stop #3
Tallahassee, FL 32308-5403
P: 850.412.3688
F: 850.921.0158

The Statewide Provider and Subscriber Assistance program
2727 Mahan Drive, Building 1
Mail Stop #45
Tallahassee, FL 32308
P: 850.412.4502 or 888.419.3456
F: 850.413.0900

The Florida Department of Insurance
200 East Gaines Street – Larson Building
Tallahassee, FL 32399
P: 850.413.2150

Should you need to reach the grievance department for any HMO with which this agency participates, we can provide an address and toll-free telephone number upon request. If you do not have the address of your plan's Member Services Department, Halifax Health - Hospice will help you obtain it. Please call the local number listed below to obtain any necessary information.

Port Orange 386.425.4701
Ormond Beach 386.425.7900
DeLand 386.425.9888
Flagler 386.425.3201
Orange/Osceola 407.825.9848
Toll Free 800.272.2717

DISASTER INFORMATION

Halifax Health-Hospice requires that each patient has a disaster preparedness plan. Your social worker will help you develop such a plan so you and your loved ones will know where you will be and who will be caring for you during a disaster.

What should I do if the area is under a tropical storm or hurricane watch or warning?

During a watch. Begin making preparations (secure food, water, batteries, radio, shelter, personal belongings, etc.). Consider purchasing a weather radio.

During a warning. Seek shelter if recommended by officials. If you live in a storm surge zone, low-lying/flood prone area, mobile/manufactured home or recreational vehicle, or require a respirator or other electric-dependent medical equipment, you should go to a shelter, or if possible, leave the area for a safer place. Halifax Health - Hospice is not able to transport or find lodging for patients and families but we are able to answer questions and provide advice. If you leave the area, please advise your Halifax Health - Hospice team of your destination and a contact number.

What about my medications?

Because we cannot predict the length of time a storm may linger, it is important to make sure that you have at least two weeks worth of medication on hand. Make sure your prescription records and any other important medical information is easy to take with you should you need to leave your home quickly.

What should I do if I have an appointment with my Halifax Health - Hospice team during a time of emergency?

Your Halifax Health - Hospice team will call you as soon as possible once the official emergency conditions are over to reschedule your appointment. Remember, Halifax Health - Hospice will continue to be available by phone as long as there is phone service. Emergency visits may not be possible while it is unsafe for our staff to be on the road.

If I need shelter and my area is under a mandatory evacuation, should I go to a hospital for shelter?

NO. Only medical emergencies will be treated at local hospitals. If you need to evacuate, you should first seek shelter with relatives, friends or in a hotel/motel. Use emergency shelters as a last resort.

How do I know which shelters are open?

When there is an impending threat of severe weather, county emergency managers will announce shelter openings on the radio, television and in the newspapers.

Should I register in advance with the county emergency management office?

YES, if you need transportation to a local shelter or if you are a patient with special needs. Contact county emergency management to determine if your medical requirements can be accommodated at the special-needs shelter. Your Halifax Health - Hospice team can assist you if needed.

NO, if you have your own source of transportation and shelter.

Special needs include:

- Patients requiring oxygen.
- Patients needing assistance with medications.
- Patients who have diabetes.
- Patients who have lung/respiratory problems.

If I am a special-needs patient, who will assist me with transportation?

For transportation to a local shelter in Volusia county, please contact Votran at 386.322.5100 in Daytona Beach, 386.424.6800 in Southeast Volusia, or 386.943.7033 in West Volusia.
To register in Flagler county, contact Emergency Management at 386.586.5111 or online at flagleremergency.com.
To register in Osceola County, contact Osceola County Health Department at 407-343- 2133. To register in Orange County, contact Orange County Office of Emergency Management at 407-836- 9140 or their website at FLGetAPlan.com.

What should I do with my pet?

To discuss sheltering assistance, call Volusia County Animal Services at 386.248.1790 in Daytona Beach, 386.423.3369 in Southeast Volusia, or 386.740.5241 in West Volusia. In Flagler county, contact Emergency Management at 386.586.5111 or online at flagleremergency.com
To discuss sheltering assistance for Orange County, please call the Orange County Animal Services at 407.836.3111 or online at animalservices@ocfl.net. To discuss sheltering assistance for Osceola County, please call Osceola County Animal Services at 407.742.8000 or online at osceolacountypets.com.

Disaster Information

Volusia County Emergency Management
3825 Tiger Bay Road, Suite 102
Daytona 386.258.4088
West Volusia 386.736.5980
New Smyrna Beach 386.423.3395

Citizen's Hotline
Call only during emergency/disaster
volusia.org 866.345.0345

Flagler County Emergency Management
1769 Moody Blvd., #3, Bunnell, FL 32110 ..... 800.374.9689

Flagler County Emergency Information Line
Call only during emergency/disaster
flagleremergency.com 386.437.8202

Orange County Emergency Management
6590 Amory Ct., Winter Park, FL 407.836.9140

Osceola County Emergency Management
2586 Partin Settlement Road, Kissimmee, FL ..... 800.374.9689 or 407.742.9000

DON'T LEAVE HOME WITHOUT THEM

When evacuating to a shelter, bring the following items:

- **All required medications and medical support equipment:** wheelchair/walker, oxygen, feeding equipment, ostomy supplies, etc. Any specific medication or care instructions. Name and phone number of physician/hospice/hospital where you receive your care.
- **Special Dietary Needs:** only regular meals will be provided.
- **Sleeping Gear:** pillows, blankets, portable cot or air mattress, folding chairs.
- **Important Papers:** i.e., insurance papers, doctor's orders, advance directives.
- **Identification:** with photo and current address.
- **Cash:** check cashing/credit card services may not be available for several days after the storm. BUT don't bring too much! There will be no place to secure money or valuables at the shelter.
- **Comfort Items:** personal hygiene items, snacks, small games, cards, etc.
- **Extra Clothing:** an extra set of comfortable clothing and a few extra sets of underwear and socks.
- **Your Caregiver:** He or she should accompany you to the shelter.

Remember:

A shelter is a lifeboat, not a cruise ship, and like a lifeboat, should only be used as a last resort.
If you have completed a special needs registration form, you are registered with the County Emergency Management office. In the event of an evacuation, you may receive an automated phone call instructing you on what to do. If you do not receive a call, contact the office in your area.

More detailed information is available in the Disaster Preparedness Guide for Volusia county residents online at volusia.org/emergency or Flagler county residents at flagleremergency.com. Osceola county residents at osceola.org and Orange county residents at orangecountyfl.net

HEALTHCARE ADVANCE DIRECTIVES – THE PATIENT'S RIGHT TO DECIDE

Introduction

Every competent adult has the right to make decisions concerning his or her own health, including the right to choose or refuse medical treatment.

When a person becomes unable to make decisions due to a physical or mental change, such as being in a coma or developing dementia (like Alzheimer's disease), they are considered incapacitated. To make sure that an incapacitated person's decisions about healthcare will still be respected, the Florida legislature passed laws about healthcare advance directives (Chapter 765, Florida Statutes). The law recognizes the right of a competent adult to make an advance directive instructing his or her physician to provide, withhold, or withdraw life-prolonging procedures; to designate another individual to make treatment decisions; and/or to indicate the desire to make an anatomical organ donation after death.

What is an advance directive?

It is a written or oral statement about how a person wants medical decisions made should they be unable to make them.

1. Some people put their wishes in writing while they are healthy, often as part of their estate planning.
2. Other people make advance directives when they are diagnosed with a life-threatening illness.

Three types of advance directives are:

1. Living Will
2. Healthcare Surrogate Designation
3. Anatomical Donation

A person might choose to complete one, two, or all three of these forms. The following information is provided to help in deciding what forms are needed.

What is a living will?

It is a written or oral statement regarding the kind of medical care a person wants or does not want if unable to make their own decisions. You may wish to speak to your healthcare provider or attorney to be certain the living will is completed in a way that clearly communicates the person's wishes.

What is a healthcare surrogate designation?

It is a document naming another person as a representative to make medical decisions for someone who is unable to make them. Similar to a living will, a healthcare surrogate designation allows a person to include instructions about any treatment they want or do not want. An alternate surrogate may also be designated.

What is an anatomical (organ) donation?

An illness like cancer or a treatment like radiation or chemotherapy does not automatically prevent people from being organ donors. If the patient wishes to make the gift of organ donation, please let the nurse and social worker know. This is a personal decision that only the patient can make, but it is important for him or her to talk about it with the family and your Halifax Health - Hospice team as early as possible. Halifax Health - Hospice works locally with Trans Life and we are here to help with decisions and complete all the paperwork that organ donation requires.

What are some other healthcare designations?

Before making a decision about an advance directive, there are other options to consider as well as additional sources of information, including the following:

DPOA – as an alternative to a healthcare surrogate, or in addition to, the designation of a Durable Power of Attorney may also be done. Through a written document, another person can act on a person's behalf. It is similar to a healthcare surrogate, but the person can be designated to perform a variety of activities (financial, legal, medical, etc.). When someone is chosen for durable power of attorney, it is important to ask the person if he or she will agree to take this responsibility, discuss how matters should be handled, and give the person a copy of the document. An attorney can be consulted for further information or Chapter 709, Florida Statutes can be read.

DNR - Many hospice patients arrange to have a **Do Not Resuscitate** (**DNR**) order written, stating their preference to forego cardiopulmonary resuscitation (CPR) in case their heart and/or lungs should fail. CPR is one of the most aggressive forms of medical care, and contrary to what we often see on TV and in movies, the truth is that CPR attempts RARELY succeed with terminally ill patients. The process can be painful or scary and "successful" CPR with very ill patients often means that life is prolonged just a few more hours or days, but in a sicker and more uncomfortable state. This makes it harder to achieve the major goals of hospice care – to maximize physical comfort, provide emotional and spiritual support, and to strive for a peaceful death.

For the majority of hospice patients whose preference is not to have CPR, the state of Florida requires that a DNR form be signed by the patient (or the patient's medical decision maker if he or she is not able to sign) and the patient's doctor. Our Halifax Health - Hospice staff can help with this, but while we do recommend a DNR, it's important to understand that **a DNR order is not required for anyone to have hospice care**. At Halifax Health - Hospice, we believe that the patient and the family have the right to make choices, including choices about CPR. Our job is to provide the information needed to help the patient and family talk about and make these difficult choices.

What is the assurance that wishes are honored?

- Patients, families, loved ones and doctors should talk about healthcare wishes.
- Wishes should be recorded in a "living will" or similar form.
- Someone trusted should be named as the "healthcare surrogate," or "Durable Power of Attorney" for healthcare. A form can be filled out to name this person in writing. He or she can then make healthcare decisions for the patient if he/she is unable to make them.
- Ask the Halifax Health - Hospice team about living wills and other forms that can be used to put a person's wishes in writing.

What is the assurance that specific wishes about CPR are honored?

- If someone does **not** want CPR, they should complete a DNR form and post it in the home. Give copies to the patient's doctor and caregivers (including the Halifax Health - Hospice team).
- If the patient **does** want CPR, the caregivers should be told to call 911 first if the patient is found without a pulse and/or not breathing. Paramedics will come, attempt CPR, and take the patient to the nearest emergency room.
- If the patient does want CPR and Halifax Health - Hospice staff is with him or her at the time the heart or lungs fail, the staff member will:
  - Help call the paramedics.
  - Begin CPR (if he or she is trained in CPR – please note that not all of our employees are CPR certified).
  - Keep the patient comfortable until paramedics arrive.

How can Halifax Health - Hospice help with these choices?

At Halifax Health - Hospice, we understand that these decisions can be very challenging. Team members will be happy to talk with the patient about any of these issues, and/or provide written information about CPR, DNR orders, options to CPR, living wills, etc. The patient's healthcare wishes can change over time, and our Halifax Health - Hospice team will periodically review his or her wishes with the caregiver(s).

Is the patient required to have an advance directive under Florida law?

No, there is no legal requirement to complete an advance directive. However, if the patient has not made an advance directive, decisions about his/her healthcare or an anatomical donation may be made by a court-appointed guardian, a spouse, an adult child, a parent, an adult sibling, an adult relative, or a close friend.

The person making decisions for the patient may or may not be aware of his/her wishes. When an advance directive is made, it should be discussed with the significant people in the patient's life, which will better assure that his/her wishes will be carried out in the desired way.

Is an attorney required to prepare the advance directive?

No, the procedures are simple and do not require an attorney, though one may be consulted. However, an advance directive, whether it is a written document or an oral statement, needs to be witnessed by two individuals and at least one of the witnesses must be someone other than a spouse or a blood relative.

Can advance directives be changed?

Yes, anyone may change or cancel his/her own advance directive at any time. Any changes should be written, signed and dated. However, an advance directive also may be changed by oral statement, physical destruction of the advance directive or by writing a new advance directive.

If the patient's driver's license or state identification card indicates he or she is an organ donor, but the patient no longer wants this designation, contact the nearest driver's license office to cancel the donor designation and a new license or card will be issued.

What if an advance directive was completed in another state and someone needs treatment in Florida?

An advance directive completed in another state, as described in that state's law, can be honored in Florida.

What should be done with advance directives once they are completed?

- Give one copy of the advance directive to your healthcare surrogate (and alternate surrogate). Discuss your specific wishes with them and make sure they are willing to take this responsibility.
- The healthcare provider, attorney, and the significant persons in the patient's life should know that there is an advance directive and where it is located. They should also have a copy.
- A copy of the advance directive (and other important paperwork) should be kept in a file. Some people

keep original papers in a bank safety deposit box. If this is done, a copy should be kept at the house, along with information concerning the location of the safety deposit box.

- A card or note should be kept in the patient's purse or wallet that states that there is an advance directive and where it is located.
- If an advance directive is changed, make sure your healthcare provider, attorney and the significant persons in the patient's life have the latest copy.

Other Resources and Websites include:

- doh.state.fl.us
- MyFlorida.com. Type DNRO in the site's search engine or call 850.245.4440.
- To read about organ and tissue donation to persons in need, go to the Agency for Health Care Administration's Web site; organdonor.gov.
- Aging with Dignity, online at agingwithdignity.org or call 888.594.7437.
- American Association of Retired Persons (AARP), online at aarp.org. Type "advance directives" into the site's search engine.
- Caring Connections, online at caringinfo.org or call 800.658.8898.
- The Halifax Health - Hospice staff – we are always here to help.

Halifax Health - Hospice supports the right of each individual to exercise his or her rights to the extent that such action does not conflict with federal or state laws or statutes.

PATIENT FINANCIAL INFORMATION

Halifax Health - Hospice accepts all patients regardless of their ability to pay for services. Prior to or at the time of admission, we will request insurance information so that we may determine whether your insurance has a hospice benefit. Halifax Health - Hospice will work with your insurance company to identify what, if any, your financial responsibility may be and keep you and your insurance company informed of the services Halifax Health - Hospice has provided.

Generally, most insurance plans and Medicaid follow the Medicare guidelines for coverage. For each day a patient is on our program, there is a charge based on the patient's level of care. Each of these levels of care must meet certain medical criteria.

If you are a Medicare recipient, you are entitled to the Hospice Medicare Benefit, which generally covers all hospice services at 100 percent, excluding room, board and transportation. In the event that you do not have Medicare or insurance, the Halifax Health - Hospice team can explore other possibilities such as applying for Hospice Medicaid. To receive Medicaid, patients must financially qualify for this program through the local Department of Children & Families and may be required to make a co-payment. If you already have Medicaid, the State of Florida will require a new application be made for Hospice Medicaid.

Many commercial insurance policies pay for hospice services, but each plan varies in deductibles, co-payments and limitations. With your permission and direction, we will assist you in verifying your insurance coverage or assist you in initiating Medicaid application paperwork.

Through the generosity of many contributors, we are able to offer funding for Halifax Health - Hospice patients who have no other source of payment. To be eligible for this, it will be necessary for our staff to obtain financial information from you or your family. We are here to make this time in your life as peaceful, comfortable and stress-free as it can possibly be, so please feel free to call us with any other questions.

HOSPICE Enclara – YOUR PHARMACY

Welcome to Hospice Enclara, the pharmacy service provider for your Halifax Health - Hospice program. Hospice Enclara is a pharmacy designed to meet your special needs.

Why am I using Hospice Enclara ?

Hospice Enclara has the special medicines you may need. We are part of your Halifax Health - Hospice team and we only take care of people being served by hospice programs. The Hospice Enclara pharmacist may call you to talk about your medicines and is also available to answer your questions.

How will Hospice Enclara know which medicines I need?

Your Halifax Health - Hospice nurse will call the pharmacist about your medication needs.

What if I have a question about my medicine?

The Pharmacists at Hospice Enclara are available to talk to you about your medicine at any time. You can either call your Halifax Health - Hospice nurse or the pharmacy (Enclara) toll free at 1.888.362.5272, press option "4" and then press option "0" for connection to a pharmacist.

How will I get a new supply of medicines?

Because of your changing needs, the amount of medicine sent to you will be small. When you only have enough medicine in your home to last two or three days, please alert your nurse so he or she can contact us. Your nurse will need your social security number and prescription number to request refills of your medicine.

How will I get medicine that I need right away?

Your nurse will make arrangements with Hospice Enclara to get you the medicines you need when you need them. A pharmacy in your area may provide the first few doses of a medicine for you. The local pharmacy may deliver or you may need to pick up your medicine or have someone pick it up for you. All medicine from the Hospice Enclara pharmacy will be delivered to your door by a national courier.

How will I know when my medicine will arrive?

Your Halifax Health - Hospice nurse will be able to tell you when your medicine is scheduled to arrive. The Hospice Enclara staff will always be able to look up your prescription request and report to you the status of your medicine.

Will Halifax Health - Hospice pay for all my medicines?

Payment for your Halifax Health - Hospice services, whether through Medicare, private insurance, Medicaid or other sources, will include the cost of all medicines related to your terminal illness and those medicines your medical team feels necessary for your comfort.

Am I able to order medicine not covered by the hospice benefit?

It is possible for Hospice Enclara to help you get your other medicines. However, it is best for you to get your non-hospice medicines from your regular pharmacy.

What is a Hospice Enclara Comfort Pack?

Your nurse may have told you about a Hospice Enclara Comfort Pak. This is a sealed box with a few doses of medicines that you may need later. The box is sealed when it is sent to you by the pharmacy. Please do not open this box. Place the entire box in your refrigerator. If you need medicine from this box, your Halifax Health - Hospice nurse will tell you to open it. Call your Halifax Health - Hospice nurse or the pharmacy if you have any questions about the Hospice Enclara Comfort Pak.

Is there a charge for delivery of medicine?

Your medicine from Enclara will be delivered to you via FedEx.

What if I need medicine when the pharmacy is closed?

A pharmacist is always available. a Halifax Health - Hospice nurse will call the pharmacist in an emergency. If you have an emergency, we will make arrangements for you to get the medicines you need. Planning ahead is important. Please try to avoid an emergency by keeping your medicine supply up to date.

Is there a special way to dispose of medicines that are left over?

Yes, the Halifax Health - Hospice nurse will speak to you and your family about proper disposal of medicine that is no longer needed.

What if I am not satisfied with services or have a delivery problem?

Please call your Halifax Health - Hospice nurse. We will make every effort to address any concerns you may have.

REMEMBER: Please check your medicines, and have your Halifax Health - Hospice nurse call the pharmacy.

ALTERNATE CARE SETTINGS – WHEN HOME IS NO LONGER AN OPTION

Although care giving can be rewarding and challenging, there may come a time to consider the need for more care than can be provided at home. Halifax Health - Hospice has many alternatives for you to consider. We can provide care in a number of different settings such as an assisted living facility, a nursing home, or one of our Halifax Health - Hospice facilities. Planning for these changes will require assistance from your Halifax Health - Hospice social worker and other team members.

Halifax Health - Hospice Care Centers

Halifax Health - Hospice Inpatient Care Centers offer a warm, homey atmosphere and a caring place for terminally ill patients who require a higher level of care than is possible in their present location. All patient rooms are private and feature state-of-the-art beds and equipment to ensure that you or your loved one receives care of the highest quality. All care is provided by a team of highly trained professionals. Inpatient Care Centers combine the compassionate care Halifax Health - Hospice is known for with a unique, home-like environment designed to meet the special needs of terminally ill patients and their families. The care centers are generally considered short-stay facilities where patients reside for days or weeks rather than months. If a patient's symptoms are controlled and he or she no longer meets inpatient eligibility criteria, Halifax Health - Hospice will assist with transferring the patient back home or to your choice of an alternate care facility.

ALF/Nursing Home

Residents of assisted living facilities (ALFs) and nursing homes often have lived in the same facility for some time and consider the staff to be their extended family. Halifax Health - Hospice will provide services wherever a person lives. Ideally, patients should be able to remain in their current living situation unless it is their choice to change the arrangement. Halifax Health - Hospice works with all of the nursing homes and facilities in our area to support aging in a familiar place.

Your Halifax Health - Hospice **team is available to assist you and your loved one with decisions when remaining at home may not be feasible.**

Medical Emergency:

- To avoid long emergency room visits, call Halifax Health - Hospice first. An on-call nurse is available after office hours to answer questions and make home visits if needed. Many emergencies may be handled by CALLING HALIFAX HEALTH - HOSPICE FIRST.
- Please arrange ambulance or other transportation through a Halifax Health - Hospice nurse, as the patient may be responsible for the cost if not authorized by Halifax Health - Hospice. Ambulances for Medicare and Medicaid patients are paid for when it is needed for the comfort and management of the hospice-related illness. This must be part of your plan of care. Be aware that you may be responsible for the ambulance bill if the transport is not authorized by Halifax Health - Hospice.

General Safety:

- Avoid leaving objects on steps. Use handrails on stairs. Ensure that handrails are well secured.
- Be aware of coffee tables and foot stools to avoid tripping over them.
- Be sure bath mats are non-skid and there are treads in the tub or shower to prevent slips.
- Avoid wet floors – clean up all spills immediately.
- Adequate lighting will help prevent accidents.
  - Keep a lamp near the bed so you will not have to get up in the dark.
  - Keep a night light in the bathroom.
  - Keep hallways and steps well lit.
  - Keep a flashlight handy in case of power failure.
- Household pets should be kept from underfoot as much as possible.
- Because of Florida's frequent power outages, keep a flashlight and portable radio with extra batteries on hand.
- Place extension cords beneath furniture and rugs. Fasten them securely to the wall or floor, making pathways clear of loose cords.
- Replace any frayed electrical cords.
- Do not overload electrical cords. Check the rating labels on cords and appliances to make sure you're not overloading.
- Do not use multiple-outlet adapters.
- Disconnect electrical equipment that is not in use.
- Report any potential hazards to Halifax Health - Hospice.

Personal Safety:

- Wash hands often with antibacterial soap. This is especially important before and after giving care to the patient, preparing food, and after using the bathroom.
- The patient should avoid wearing socks, smooth-soled shoes, or slippers on uncarpeted floors.
- If the patient lives alone, ask a neighbor, friend or family member to check on him or her each day.
- Encourage the patient to take his/her time and do things slowly. Be safe! Hurrying increases the chance of an accident.
- To avoid dizziness, the patient should get out of bed or up from the chair slowly, waiting and making sure that he/she is not dizzy before moving away from the chair or bed.
- Keep an updated list of the patient's medications for emergency situations.
- Keep a telephone accessible to the patient in the event of an incident that renders him/her unable to move. If the patient does not have a phone, Halifax Health - Hospice will help make arrangements so that there is the ability to call Halifax Health - Hospice or to call for help.
- Place the Halifax Health - Hospice phone sticker on the patient's phone, along with other emergency phone numbers.
- Secure loose rugs, runners and mats to the floor with double-sided adhesive tape or rubber matting.
- Tack down carpet edges.
- Repair, replace or remove torn, worn or frayed carpeting.

Fire Safety:

- **DO NOT SMOKE WHEN OXYGEN IS IN USE!**
- If medical condition permits, turn off oxygen and remove mask/nasal cannula if people are going to smoke. (There should be no oxygen within 25 feet of an open flame).
- If the patient smokes in bed, someone must stay with him/her.
- Make sure that exits are free of clutter or furniture.
- Keep a fire extinguisher charged and handy, and know how to use it.
- Keep keys near doors that are locked with dead bolts.
- Install a battery-operated smoke detector on every level of the home. If you need assistance, call your local fire department. They have community programs to provide/install smoke detectors for those in need.
- Check smoke detector batteries every six months; a good time would be when you change the clocks in the spring and fall.

- Use space heaters according to manufacturer's instructions. Keep them away from clutter, papers, curtains, etc.
- Keep flammable liquids outside of the home in approved safety containers.
- Have the home's electrical system checked if there are signs of a wiring problem, like an appliance shorting out.
- Keep all electrical appliances in working order.
- Keep extensions cords away from sinks and water.

Fire Safety Plan:

- Have an evacuation plan in the event of a fire.
- Know at least two ways out of every room.
- Anyone needing help should be evacuated first.
- If the patient can't walk or get into a wheelchair, use the bottom bed sheet to lift the patient to the floor. The patient can then be pulled on the sheet to safety. (Remember to support the patient's head).
- If you must exit through smoke, crawl along the floor.
- Before escaping through a closed door, touch it before opening. If it is hot, use another way out.
- Choose a spot outside the home where everyone can meet after evacuation.
- Once out, **STAY OUT.**
- Call 9-1-1 after everyone is safely outside.

INFECTION CONTROL

The following information will help protect the patient and family members from contracting an infection.

General Information:

- All persons are potentially infectious.
- Patients are more susceptible to infections because they are not well.
- It would be better if visitors who have a cold or other illness wait to visit the patient until they have recovered.
- Hand washing is the single most important barrier to preventing the transmission of an infection. Use an alcohol-based hand gel or running water and soap for at least 10 seconds before and after touching the patient, dressings, or body fluids such as urine, etc.
- Wearing gloves when coming in contact with the patient can protect both you and the patient.

Infection Precautions:

- If the patient has an infection that requires specific precautions, your nurse will provide information about the infection and how to protect yourself.
- Your nurse will provide any protective equipment such as gloves or gowns.
- If you or a visitor has a cold, or if the patient is coughing or sneezing and cannot cover his/her face, wear a mask when you are around the patient. Halifax Health - Hospice will provide you with masks.

Biomedical Waste:

- Biomedical waste is any solid or liquid waste that is contaminated with blood or body fluids, excluding any of the following unless they contain blood: feces, nasal drainage, saliva, spit, tears, urine and vomit.
- Biomedical waste should be kept separate from other waste in the patient's home.
- Your nurse will set up biomedical waste containers, for example, red plastic containers for needles and red plastic bags for other types of waste.
- Filled red bags must be sealed in the home by tying the top and placed in a second red bag and tied to prevent leakage. Call Halifax Health - Hospice for pick-up.
- Red needle containers are sealed when they are full and may not be reopened.
- All biomedical waste must remain in the house or garage until it is picked up by Halifax Health - Hospice. **Do not put Red Bags out for regular garbage pickup.**
- Prevent children and pets from getting into biomedical waste. In the event that Halifax Health - Hospice services cease for any reason, and you continue to have biomedical waste, your Halifax Health - Hospice team will provide a resource to contact for removal of waste.

FUNERAL PLANNING

An important part of this journey may include decisions regarding final arrangements. Many people see this as an extension of will and estate planning. If you are the patient, your family will usually appreciate knowing your preferences, and this generally helps relieve them of making some of the necessary, and at times, difficult choices. These are important decisions and a time of special sharing.

Families often ask, "How can we talk about this?" One way is to begin with, "This is hard for me, but I want to carry out your wishes. I need to know what you want me to do." It is not always an easy topic, but it is definitely a worthwhile one. The following are some of the things you may want to consider.

- When thinking about final arrangements, important decisions include:
  - Type of memorial service desired
  - Burial vs. cremation
  - Cost
- Selecting a funeral home is an important decision. If possible, try to begin that process early. When selecting a funeral home, start by looking in the phone book yellow pages under "Funeral Homes." Another option may be to obtain recommendations from family, friends or clergy.
- Gathering family information such as names to be listed in obituaries and military discharge papers can be done by a close relative. This will save the caregiver from looking for information just hours after the death has taken place.
- Handling financial matters, which may include wills, life insurance, or bank accounts, is very important if the patient has been the main person responsible for family finances.
- If your loved one resides in a nursing facility, it is important to be aware that nursing facilities generally assign their residents a specific funeral home if the resident or their family has not decided on their own funeral home. This may not be a funeral home of your choosing and this may cause you additional expense. It is important that you make your choices known.
- Once a funeral home has been selected, call the funeral home and ask questions. Also, notify your Halifax Health - Hospice staff that you have made a decision.
- Our chaplains are available to perform or assist you in preparing for a memorial service. Our chapel is available as a memorial service venue.
- Making final arrangements can be a very difficult task. Your Halifax Health - Hospice social worker or spiritual counselor can help you throughout this process.

BEREAVEMENT SERVICES

Halifax Health - Hospice provides an extensive bereavement program that includes specialized counselors and volunteers to assist the survivors of Halifax Health - Hospice patients for up to 13 months and sometimes longer. These services are available to the community at large and not limited to Halifax Health - Hospice families.

New Beginnings

New Beginnings is a support group for individuals who need understanding and help in coping with the death of a loved one. Groups begin at four intervals throughout the year. By offering mutual support and friendship in small, informal groups, members can regain a level of emotional health and begin to participate in life's experiences again.

Reflections

This informal social and informational group addresses practical issues such as nutrition and budgeting. Participants meet to obtain information about community activities and services, and to socialize with others who are experiencing similar circumstances.

Lawrence E. Whelan - BeginAgain Children's Grief Center

Halifax Health - Hospice's BeginAgain Children's Grief Centers are a resource for children from 4 to 18 years old, for whom the loss of a loved one can be a life-altering experience. The program operates from the **Lawrence E. Whelan Children's Grief Centers** in Daytona Beach and DeLand. Art, music, drama, group activities, discussions and meaningful ceremonies are utilized to assist children in expressing their grief. The program includes **Camp BeginAgain**, a weekend retreat for young people ages 6 to 17 who have recently lost a loved one. The camp combines recreational and sharing activities while creating special bonds among campers who are experiencing similar emotions. Campers share in grief support groups and learn how to cope with emotions and to discover positive ways to remember their loved ones.

Individual and Family Counseling

Individual support is available for anyone wanting one-on-one counseling. Bereavement counselors work privately with families and individuals who are having difficulty dealing with their loss.

Bereavement Volunteers

Specially trained bereavement volunteers work with the Halifax Health - Hospice's chaplains and counselors to provide emotional comfort. They offer visits, telephone calls, cards, participate in support groups, and provide consolation during special days and events.

Community Memorial Services

Community memorial services are held to honor and remember patients who have died. Family and friends of those being honored, along with staff and volunteers, are invited to attend and share their experiences and memories. The services are non-sectarian in nature and are designed to be meaningful for people of all faiths and philosophies.

Caregiver's Guide

ESPECIALLY FOR THE CAREGIVER

In your new role as the caregiver of a person with a serious illness, you are giving the gift of yourself. It is so very important that you continue to take care of yourself as a caregiver. It is also important to reach out to others. Friends, relatives, and the Halifax Health - Hospice team will be there to help. This is a difficult undertaking, which can be physically challenging and at times exhausting. Without help, the tasks may become too much.

Each person's experience is unique. There is no right or wrong way. No other event in one's life will bring more emotions to the surface. Sometimes it is painful to hear the fears and worries of your loved one. You may feel confused about your own feelings because there are so many emotions involved, including love, fear, guilt and frustration among others. At times you may even feel resentful or angry because care-giving can be time consuming and physically taxing.

Every individual and family group has their own personality, coping mechanisms, ways of being and ways of interacting with one another. These do not change significantly because someone becomes ill. Family tension, conflict or differences may actually intensify and the picture-perfect idea of the family pulling together to help in a crisis will not necessarily happen.

The type of relationship you and your loved one had prior to the illness is another factor that affects the care-giving experience. The relationship may have been close, loving, and supportive but the stress of serious illness can create tension between the ill person, the caregiver, and the family.

All of these factors influence your ability to cope with your day-to-day care-giving tasks and the emotions that go along with them. It is very important to remember that there is no "perfect caregiver." Most caregivers report having feelings that they are not doing an adequate job of care-giving and feel angry, resentful, guilty and helpless at times. These emotions are natural and to be expected. It will be easier to cope if you confide in someone with whom you can be open about your true feelings without fear of judgment. This could be a friend, family member, counselor, or Halifax Health - Hospice staff member. Attending a support group can also help you meet others in a similar situation, share information and ideas, and allow you a break from your care-giving responsibilities. Your Halifax Health - Hospice staff can help you locate groups and resources.

It is very important for you to take care of yourself. Many caregivers become so absorbed in meeting their loved one's needs that they forget their own. Here are some tips on how to take care of yourself.

1. Ask friends to sit with your loved one periodically so you can do something for yourself or take care of necessary errands.
2. Exercise – Walk, stretch your arms and legs for 20 to 30 minutes several times a week. It's a good way to release stress and boost your energy.

3. Eat a balanced diet – Look at your eating habits over the last three days. Take time to sit down when you eat. You'll digest food better if you can relax.

4. Do not deny yourself pleasures – But try not to use too much caffeine, tobacco, or alcohol as they will ultimately drain your energy.

5. Rest and sleep are important – Sleep for an adequate amount of time each day, and treat yourself to a nap when you need it.

6. Accept help when it is offered – But also think about what you really need and then let people know exactly how they can help.

All caregivers begin with the intention that they will be the best caregiver possible and see their loved one through this phase of their life. There may come a time when you will face the reality that you just cannot continue any longer. You may not be well yourself or you may feel overwhelmed. There are resources that your Halifax Health - Hospice social worker can discuss with you. It is also very important to be honest when perhaps you are becoming exhausted. It is best to be able to plan ahead for some relief or a change in arrangements. Your Halifax Health - Hospice staff members are available at all times to help you.

It is important to seek help if you experience overwhelming feelings of anger, helplessness, depression, or any of the following problems: inability to sleep or eat, continuous irritability, severe mood swings, anxiety, thoughts of harming yourself or your loved one, or continuous lack of energy and motivation. These are "warning signs" of severe depression and should not be ignored. Contact your physician to arrange for a full medical exam and tell him or her about the "warning signs" you have been experiencing. Then contact someone on your Halifax Health - Hospice team. The social worker is available to help you work through your feelings and develop new skills to deal with them.

BATHING AND BEDMAKING

The ability to maintain our own personal hygiene is something most of us take for granted. But for a hospice patient, it may be difficult or impossible. As the caregiver, you can provide the patient with a much-appreciated measure of comfort by helping him or her to shower or bathe. This guide will help you explore various ways to help a hospice patient with bathing and hygiene needs.

Shower or Tub Bath

1. See if the patient is strong enough to stand long enough to take a shower.
2. Gather needed items such as soap, washcloth, and towel.
3. Turn on the shower and adjust the water temperature before the patient enters the shower.
4. Make sure there is a non-slip mat in the shower.
5. Assist the patient in the shower if necessary; a stall shower is usually easier since there is not a large rim to step over.
6. A shower chair may make it easier for the patient, but a simple white plastic lawn chair can work in its place. A tub bath requires the patient to be able to safely lower into and rise out of the tub. Talk with your Halifax Health - Hospice team about the patient's ability to take a tub bath.

The Partial Bath/Chair Bath

1. Talk with your Halifax Health - Hospice team about how much activity the patient can safely tolerate. A Halifax Health - Hospice aide may be needed to help with bathing.
2. A partial bath may only be needed on the days the Halifax Health - Hospice aide does not visit.
3. A partial bath can be given while the patient is still in bed or sitting up in a chair.
4. Gather needed items such as soap, washcloth, towel, wash basin, shaving supplies, and mouth care supplies, such as toothpaste or mouth wash.
5. Do mouth care first, then remove those items from the bathing area. (Talk to your Halifax Health - Hospice care team about getting a table that fits over the bed.)
6. Place basin with bath water (be sure to check water temperature) within easy reach for the patient; generally patients can wash their own face and hands.
7. For the chair bath, assist the patient to stand to wash private areas and assist with towel drying as needed.

Shaving

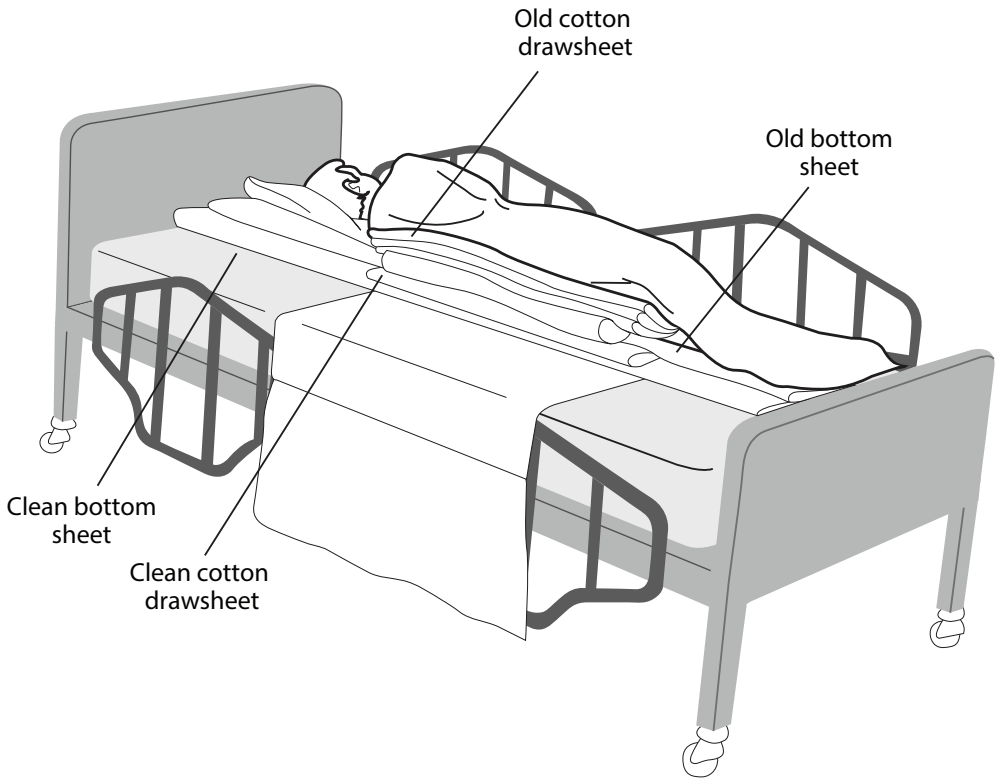
If a male patient can shave himself, place items within easy reach. If a patient is taking medications that could cause bleeding, such as Coumadin, talk with your Halifax Health - Hospice team. The patient may need to use an electric razor instead.

The Bed Bath

1. Offer the bedpan or urinal before bathing.
2. Gather necessary supplies, including soap, washcloth, towels, and clean bed linens.
3. Raise the bed to a comfortable level for you and put on gloves. (Your Halifax Health - Hospice team can supply gloves.)
4. Lower the head of the bed to a level that is comfortable for the patient; ideally the head of the bed should be flat. (The patient can have one pillow.)
5. Moisten a washcloth and gently wipe the eyes first, using an inner-corner to outer-corner motion.
6. If the patient is able to wash with soap, wash face, ears, and neck.
7. If the patient is able to move independently in the bed, have the patient move close to you.
8. Place a towel under the arm lengthwise and wash the arm, shoulder and armpit. Rinse and dry this area and repeat this process on the other arm area. Make sure the patient is covered as much as possible to prevent chilling and unnecessary exposure.
9. Place the towel over the chest lengthwise and raise part of it to wash the chest. Wash one side at a time to limit exposure time and prevent chilling.
10. The patient's breasts are not exposed during the bath. A bath towel is placed horizontally over the chest area. The towel is lifted slightly to reach under to wash the breast and chest.
11. Move the towel to the abdomen and wash this area, one side at a time; rinse and dry each area. Place a clean gown on the patient at this time.
12. Next place the towel under one leg lengthwise. Wash this area, and encourage the patient to move the extremity independently if possible. If the patient is unable to move extremities independently, this is a good time to gently exercise the arms and legs. Ask your Halifax Health - Hospice nurse to show you the proper technique for passive range of motion to the extremities.
13. If you are able, you may place each foot in the washbasin one at a time. If not, wash the foot by placing the towel under it, then wash, rinse and dry each foot.
14. Turn the patient to one side and place the towel on the bed along the patient's back. A blanket should cover the patient's front for warmth and privacy. Wash the back from neck to buttocks with long, firm, continuous strokes.
15. Change the water, then wash the perineal (private) area. The bed can be changed at this time. (See the following information on making an occupied bed.)

Making an Occupied Bed

1. The patient should be on their side and comfortably close to the bed rail. Have the patient hold on to the bed rail for support. Support the patient's head with one pillow if able.
2. Loosen the corners of the bottom sheet at the top and bottom of the bed; if a lift sheet is used, loosen this as well. Move the sheets towards the center of the bed, and gently tuck them close to the patient. Leave the top sheet in place to cover the patient and prevent chilling.
3. Place the top and bottom corners of a clean sheet (use a fitted bottom sheet) on the bed and move them toward the center of the bed.
4. Turn the patient over to the other side of the bed, remove the dirty sheets and pull the clean sheet through (lift sheet included).
5. Ask the patient to hold on to the top of a clean cover sheet and gently pull the dirty cover sheet out. Change any soiled blankets at this time.
6. If a second pillow is used, change the pillowcase of one and place this under the patient's head at this time, then change the other pillow case.
7. If the patient's needs increase or become overwhelming for you, talk to your Halifax Health - Hospice team about getting a hospice aide or increasing the aide's visits.



BLADDER MANAGEMENT

Urine is a liquid composed primarily of water and body waste materials. It is important to provide the patient with liquids so that the body continues to remove waste and maintain a good urine output. Hospice patients may lose the ability to control urination, which is called incontinence. Others may have difficulty making it to the restroom in time for various reasons. In other cases, an infection in the bladder can cause discomfort and the need to use the restroom frequently, which can be tiring.

The inability to control or manage one's own urination is a source of embarrassment, anxiety and discomfort for patients. It interferes with the ability to leave the home and participate in enjoyable activities. As a caregiver, you can help to minimize the unpleasantness of incontinence and other urinary problems.

What to look for

1. Urine should be yellow and clear. Urine that is cloudy, dark in color, or has a bad odor could be the sign of a problem. When the patient is drinking very little or not at all, urine will become darker and can look the color of tea.
2. Discomfort or pain in the lower part of the abdomen.
3. The need to use the toilet often followed by the inability to produce more than a small amount of urine.
4. Urine leaks that occur when sitting still, walking to the restroom, coughing or changing position.
5. Inability to urinate at all.

What to do

1. **Contact the primary care nurse for all of the above issues.**
2. Ask your nurse for a bedpan or bedside commode.
3. Consider whether the patient would be willing to try adult briefs.
4. A Foley Catheter is a tube that is placed into the bladder, then drains into a bag, eliminating both the inability to urinate and occurrences of leaking urine (incontinence). Talk with your nurse regarding preferences.
5. Consider using pads that will protect the bedding.

Call your Halifax Health - Hospice **Nurse with any and all questions.**

FOLEY CATHETER CARE

A Foley Catheter is a tube that is placed in the bladder to drain urine into a drainage bag. It can be used to address two problems: incontinence, which is a leaking of urine that cannot be controlled, and retention, a condition making it difficult or impossible to urinate. There are various ways to cope with these problems. Ask the nurse to explain those choices to your loved one so that he/she can decide if a Foley Catheter is the right choice.

Care of the Foley Catheter

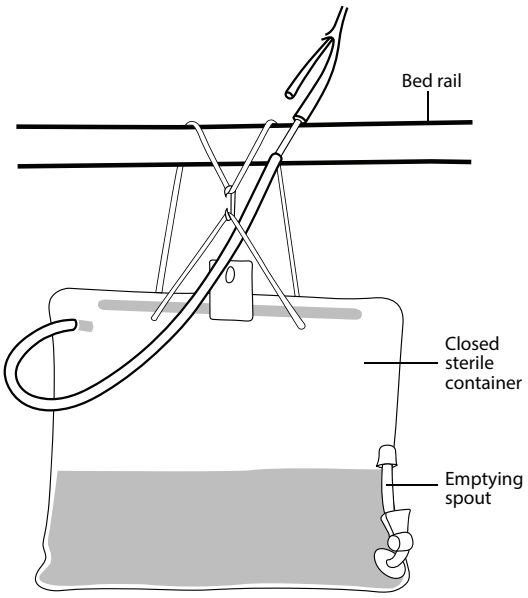
1. Wash hands before and after catheter care.
2. Provide catheter care at least daily.
3. Wear gloves when handling the catheter. (Your nurse or nursing assistant can bring gloves to the home.)
4. Gently separate the labia (female) or pull back the foreskin (male) and wash with comfortably warm soap and water.
5. Wash the area gently with a washcloth and use another wet wash cloth to remove any remaining soap. If an area is heavily soiled, use several washcloths so as not to contaminate the catheter tip. Wash in one direction (front to back for a female).
6. Avoid tugging or pulling on the tube while cleansing.
7. Be sure to replace the foreskin on a male once catheter care is done.
8. If the catheter tube becomes dislodged at any time, call your Halifax Health - Hospice nurse. Catheter insertion should only be done by a nurse or a doctor.
9. Please read the section on "What to look for."

Placement of the Drainage Bag

1. The drainage bag should be placed lower than the body or urine will not drain into the bag.
2. The bag should not be placed on the floor; it can sit on a stool or hang in a pail.
3. While using a hospital bed, hang the drainage bag on the bed frame where it will not be trapped if the bed is lowered or raised. Do not hang the bag on a side rail.
4. When using a wheelchair, hang the bag on the chair frame.
5. When sitting in a recliner or other household chair, hang the bag in a clean, new wastebasket lined with plastic. Place the bag inside the wastebasket and attach to the rim. You can also lay the bag on a low stool.

6. When walking around the house or leaving the home for outings, ask the nurse for a leg bag. It is a smaller bag with straps that wrap around the thigh. It is worn out of sight. This type of drainage bag must be emptied more often.

Emptying the Drainage Bag



1. Wash your hands with soap and water before and after handling the drainage bag.
2. Select a container in which to empty the drainage bag and mark the container For Urine Only so that it is not inadvertently used for another purpose.
3. Empty the bedside drainage bag each morning and any time the bag is more than half full. When using a leg bag, empty the bag every two hours or when it is half full.
4. Place the container you will use to drain the bag on the floor near the bag, laying plastic underneath to protect the floor or rug.
5. Remove the short tubing on the bottom of the bag and hold it over the container.
6. Release the clamp on the tubing and drain the urine into the container.
7. Avoid touching the end of the tubing or allowing the tubing to touch the container while emptying the bag.
8. Re-clamp the tubing.
9. Clean the end of the tube with a cotton ball and 70 percent alcohol and replace in the base of the bag.

Changing from Bedside Drainage Bag to Leg Bag

1. Wash your hands with soap and water. Empty the bag. Leg bags are worn during the day and replaced with a bedside bag at night. Wearing a leg bag in bed will prevent proper drainage. However, if lying down for short time (30 minutes or less) there is no need to change bags.
2. Clamp the catheter. If there is no clamp, you may use a clothespin or bend the catheter back on itself and wrap with an elastic band.
3. Clean the connection with 70 percent alcohol using three separate cotton balls.
4. Connect the drainage bag (leg bag or bedside) and unclamp the catheter.
5. Always cover the bedside bag tubing end with a cap when not in use. Before reconnecting, cleanse the tip of the tubing with 70 percent alcohol prior to connecting the catheter.

Cleaning the Leg Bag

1. Rinse the bag with cold water, then wash with warm, soapy water and then rinse again with cold water.
2. Rinse the bag with vinegar solution (1 cup vinegar to 2 quarts of water). This reduces odor.
3. Hang the bag from a shower rod to dry.

The Foley Catheter tube provides relief from the unpleasantness of incontinence or the discomfort of retention. However, it is not natural to have tubes in the body. There is the possibility of infection or injury due to pulling on the catheter. It is important to observe the urine in the bag and be aware of some symptoms that should be reported to your nurse.

What to look for

1. No urine in the bag.
2. Color of urine is darker than usual.
3. Urine is cloudy.
4. Less urine and darker in color.
5. Low back pain.
6. Urine leakage around the catheter.
7. Blood in the urine.
8. Particles (sediment) in the urine.
9. Fever of 101 degrees Fahrenheit or above.
10. Chills.
11. Catheter has come out. (There is a small balloon on the tip of the catheter, which may cause bleeding if the catheter is pulled out.)
12. Pain and fullness in the lower belly.

What to do

1. Provide six to eight (8 oz.) glasses of fluid each day.
2. Whenever there is no urine in the bag, check for kinked tubing first and then for fullness in the lower belly. If the person is not able to tell the caregiver how they are feeling, restlessness may be a signal that there is a problem. Notify your primary care nurse right away.
3. If the urine changes color, becomes cloudy or has particles or anything unusual in it, notify your primary care nurse.
4. Pain in the lower abdomen, low back, chills or fever should be reported immediately.
5. If the catheter is leaking, has come out, or is not draining, notify the primary care nurse.
6. If the person is confused and tends to tug on the catheter, tuck the bed clothes around them, keeping the tubing covered.

Flushing (irrigating) a Foley Catheter

Flushing the catheter may be ordered by the doctor if the catheter is not draining. The nurse will teach you how to flush the catheter and provide the equipment you will need.

1. Wash your hands with soapy water and put on a pair of rubber gloves.
2. Place something waterproof under the catheter, such as a sheet of plastic covered with a towel.
3. Using the sterile solution the nurse provided, pour about 1/2 cup into the container provided.
4. Keep the cover on the tip of the syringe and in the tray until you are ready to fill the syringe.
5. Remove the tip, place into the solution container, squeeze the bulb and pull up the solution into the syringe. Replace the tip.
6. Disconnect the catheter from the tubing, place the tip of the tubing into an opened alcohol pad packet and squeeze the packet around the tubing. Do not lay the end of the catheter down.
7. Remove the cap on the syringe, insert the syringe into the catheter and gently squeeze the bulb until all of the solution has been expelled. Pinch the catheter tube back on itself and remove the syringe. Sit the syringe in the tray, bulb-end down.
8. Pick up the tubing, shake the alcohol packet off and connect to the catheter. Then release the catheter. Urine should flow through the tubing. If it does not, notify your primary care nurse.
9. Empty the remainder of the solution (if any) from the container.
10. Wash the syringe with soapy water and rinse with cold water. Place the tip back onto the syringe and replace in tray.

Contact your Halifax Health - Hospice **nurse for help with any of the above.**

EXTERNAL CATHETER CARE

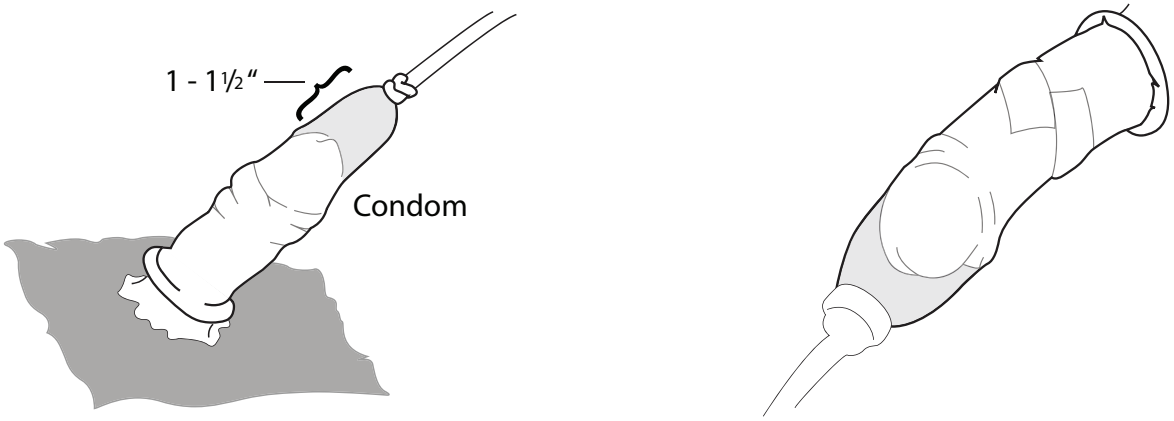
An external catheter is used only with male patients. This type of catheter may also be referred to as a Texas catheter or condom catheter. Your Halifax Health - Hospice nurse will demonstrate the application and care of the catheter. However, there may be times when the catheter becomes dislodged or falls off. Reapplication of the external catheter may need to be done by the caregiver in the home.

Application of the External Catheter

1. Wash hands.
2. Place a protective pad under the patient to keep bed linens clean and dry.
3. Arrange necessary supplies within easy reach; the over-bed table is usually a convenient place.
4. Open the kit and lay out items for easy access.
5. Wear gloves. (Your Halifax Health - Hospice team will leave gloves in the home.)
6. Hold the penis in place and gently roll the condom onto the penis.
7. Leave a one-inch space between the penis and the end of the catheter.
8. Secure the condom with the adhesive strip by applying the strip in a spiral so as not to constrict the penis.
9. Attach the condom to the drainage tubing.
10. Attach the drainage bag to the bed frame, NOT the bed rail.
11. Wash hands.

Empty the drainage bag using the same instructions for the Foley Catheter. See page 40.

Call your Halifax Health - Hospice **nurse with any questions.**



BOWEL MANAGEMENT

A bowel movement is the way in which the body gets rid of waste material. It's important to have a bowel movement at least once every three days. Everyone has a natural pattern of bowel movements, which usually does not change unless they are ill, severely dehydrated, eating out-of-the-ordinary foods or taking medications that affect the digestive tract. Mild or gradual decreases in the amount a person drinks should not cause sudden constipation.

Appetite has a great deal to do with the frequency and nature of bowel movements. If one's appetite has decreased or there are few foods that really appeal to the patient, they may have infrequent bowel movements that can be very hard in consistency and difficult to pass. This is what's known as constipation. Constipation can cause unnecessary discomfort and there is the possibility that it could eventually cause a blockage in the intestines. If three or more days have passed without a bowel movement, report this to your primary care nurse.

Some medications, and especially those for pain management, can cause constipation. However, there is no reason to avoid taking effective pain medications, as constipation can be managed using stool softeners and laxatives if necessary.

Frequent watery bowel movements, often accompanied by cramping, are known as diarrhea and can cause much discomfort. It is always important to consider all of the possible reasons for diarrhea, such as new medications, response to stool softeners or laxatives, illness, severe constipation, and others. Review these possibilities with your nurse.

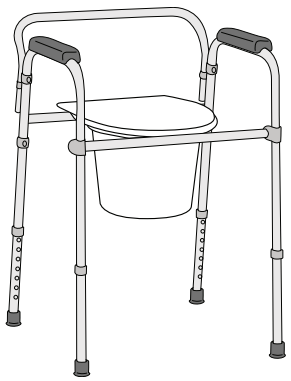
A change in bowel habits or difficulty controlling bowel movements can be embarrassing and frustrating for the patient and the caregiver. It is a loss of control that is very difficult to cope with.
An understanding and caring attitude from a caregiver can lessen the feeling of helplessness.

Call your Halifax Health - Hospice **nurse with any questions.**

BEDSIDE COMMODE

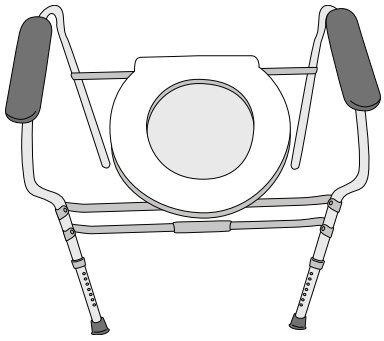
A bedside commode is a portable chair with a container beneath. It is designed to assist with toileting. It may be a stand-alone piece of equipment or an add-on placed over a standard toilet to provide support and safety. When your commode is delivered, the technician will adjust it to the proper height.

Bedside Commode



1. The commode is placed close to the patient who is having difficulty walking to the rest room.
2. When sitting or standing, push straight down on the commode arms to avoid tipping.
3. To avoid odors, keep a small amount of water and vinegar in the bucket. It will also be easier to empty the contents.
4. Empty the contents into the toilet after use. You should wear gloves and be careful not to splash contents when emptying. (Your nurse will provide you with gloves.)
5. Clean the contaminated areas of the commode with a solution of one part bleach to 10 parts water.
6. Inspect the rubber tips on the legs of the commode regularly for wear.

Over-Toilet Model



1. This device is similar to the commode but does not have a back. It should only be used over a toilet and can be adjusted in height.
2. The existing bathroom toilet lid and seat should be in the upright position before placing the commode over the toilet.
3. Exert pressure straight up and down when standing or sitting.
4. Clean the splashguard with the bleach solution mentioned above.
5. Inspect rubber tips on the commode chair legs regularly for wear.

There are various styles of commodes; your primary care nurse will suggest the proper one for your needs. If you experience difficulty with the operation of your commode, contact your primary care nurse.

Call your Halifax Health - Hospice **nurse with any questions.**

LIFTING AND MOVING A PATIENT SAFELY

As the patient gets weaker, he or she will need more help turning, sitting up and getting out of bed. The following are guidelines for moving patients when they are no longer able to move independently.

To help the patient sit up in bed and stand at bedside

1. Raise the head of the bed so the patient is in a sitting position.
2. Slide one arm under the patient's shoulders and the other under the thighs
3. Pull the patient's legs over the edge of the bed. At the same time, turn the patient a quarter turn as the legs go over the edge of the mattress.
4. Ask the patient to sit on the edge of the bed briefly to adjust to the position change.
5. Once the patient feels comfortable enough to stand, have patient stand at bedside.

Moving the patient up in bed

To help the patient move up in the bed, a "turn" sheet may be used. This technique requires two people.

1. Raise the level of the entire bed to a comfortable level for your back.
2. Lower the head of the bed as low as the patient can tolerate; ideally the head of the bed should be flat.
3. Move any pillow against the headboard if the patient can be without it.
4. Gently roll the edges of the turn sheet close to the patient's body. This requires a person on each side of the bed.
5. Ask the patient to cross their arms across their chest. Make sure the turn sheet is placed underneath the patient, near the shoulders and buttocks.
6. If possible, ask the patient to bend knees and push with his or her feet, head raised slightly off the bed.
7. Grasp the edges of the turn sheet near the shoulders and buttocks and gently move the patient toward the headboard, simultaneously.
8. Unroll the turn sheet and straighten any linen as needed. Place the pillow under the patient's head and elevate the head of the bed to a comfortable level.

To help the patient transfer to a chair or wheelchair

1. Place the chair or wheelchair at the head of the bed.
2. Be sure the bed is in its lowest position with the wheels locked.
3. Help the patient sit up at the edge of the bed. Feet should be touching the floor.
4. Face the patient. Use a transfer belt if needed.
5. Help the patient to a standing position by placing your hands under the arms and around the shoulder blades.
6. Ask the patient to push his or her fists into the mattress.
7. Brace your knees against the patient's knees and block the feet with your feet.
8. Straighten your knees as you pull the patient up. Have the patient support as much weight as possible.

9. Turn by moving your feet and having the patient do the same.
10. Have the patient grasp the armrest and lower slowly into the chair.

MOUTH CARE

People experience a dry mouth as the result of drinking less fluid or as a side effect of taking certain medications. Frequent mouth care helps resolve dryness and improves the taste of food and fluids. When the mouth is wet and moist, it contributes to a sense of well being for the patient.

What to look for

1. Red tongue or inside of the mouth
2. Chapped or very dry lips
3. Complaint of dry mouth
4. Loose dentures
5. Complaints of a sore mouth
6. White patches on the tongue or inside of the mouth

What to do

1. Daily Care

A. Remove dentures and clean them.

B. Clean the mouth using a soft toothbrush or disposable foam-covered stick.

C. Look at the gums to ensure that dentures are not causing irritation.

D. Keep lips moist with lip balm.

E. Artificial saliva may be helpful.

2. For a sore mouth, avoid:

A. Salty or tart foods

B. Crackers

C. Hard or crunchy foods that may cut or rub sore areas

D. Foods and drinks that are very hot or very cold

3. Mouth Care and Medications

A. Some medications dissolve in the mouth.

B. Clean the mouth before giving medications to avoid removing the medications.

Contact your Halifax Health – Hospice nurse if you should have any questions about dry mouth issues.

MEDICATION GUIDE

Administering medication is an important part of providing care for an ill person. Keeping a journal or log of medications given, including the times and dosages, helps your Halifax Health - Hospice care team make appropriate adjustments. Your Halifax Health - Hospice nurse can provide you with a medication record to keep track of medicines as you give them.

When you receive the patient's medications, read the label on the container. If the label is different than the information your nurse provided, do not use the medication. Call your nurse immediately.

Medication Guidelines

1. Keep a current list of all medications the patient is taking.
2. Include all over-the-counter medications on the list.
3. Note any changes in the behavior of the patient after taking medications.
4. Note effectiveness of pain medication, such as "pain not gone after two pain pills every six hours," and notify your Halifax Health - Hospice nurse if pain medication is not working.
5. Your Halifax Health - Hospice nurse will ask the patient to rate pain using a "pain scale." The scale that is used most frequently is a 0-10 scale. The way to ask about pain is: "Can you tell me how much pain you feel on a scale of 0-10, with zero being no pain at all and 10 being the worst pain you could imagine?"
6. A copy of the pain scale can be found in the "Symptom Guide" section of this book. Ask your Halifax Health - Hospice nurse about other ways to recognize pain if the person cannot respond to the 0-10 pain scale.
7. Note the time that pain medications are given.
8. Keep medications in one designated area so they are easy to find but safe from small children.
9. Keep medications in their original containers.
10. Follow label directions for proper storage. Suppositories need to be stored in the refrigerator.
11. Keep a thermometer on hand to check for any fever.
12. If the patient has been receiving injections, observe the injection site for any redness, swelling or pain. Notify your Halifax Health - Hospice nurse of any of these symptoms.
13. Review all medications with your Halifax Health - Hospice nurse on admission and then on a regular basis. Look at your medications weekly and let the nurse know when you have one week of medication left so more can be ordered.
14. Talk to your Halifax Health - Hospice nurse about which medications to keep on hand and which ones are OK to destroy while the nurse is present.

15. Don't give the patient medications that have been prescribed for other people.
16. Don't crush medications without talking to your Halifax Health - Hospice nurse first, as some medications are not meant to be crushed. A change in medication may be needed if the patient can't swallow that medication any longer.
17. Wet the mouth before giving medications.
18. Medications for nausea should be given with water one half hour to one hour before other medication. The patient should not eat until the medication has had time to start working.
19. Be sure the patient is in a sitting position to take medications. Use pillows if needed to prop up the head and shoulders or talk to your Halifax Health - Hospice nurse about getting a hospital bed.

Call your Halifax Health - Hospice **nurse if medications are not effective, behavior changes occur, medication is running out or the patient is having difficulty swallowing the medication.**

Caregiver Medication Record

Halifax Health Hospice
Licensed since 1979

Name: **Call your nurse as needed at 1.800.272.2717**

Drug Name and Dose	Time	Date	→	→	→	→	→	→
Bowel Movement		**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
		No	**No**	**No**	**No**	**No**	**No**	**No**

Medication Name - Write the name of the medication as it appears on the prescription label.
Dose - Write the amount of medication to be given.
Time - Write in all the possible times you would give the medication.
To record that a medication has been given - Place a check mark on the line that corresponds to the time the medication was given.
Bowel Movement - Please circle Yes or No.

CAREGIVER MEDICATION RECORD

HALIFAX HEALTH
HOSPICE
Licensed since 1979

Name: **Call your nurse as needed at 1.800.272.2717**

Drug Name and Dose	Time	Date	→	→	→	→	→	→
Bowel Movement		**Yes** **No**	**Yes** **No**	**Yes** **No**	**Yes** **No**	**Yes** **No**	**Yes** **No**	**Yes** **No**

Medication Name - Write the name of the medication as it appears on the prescription label.
Dose - Write the amount of medication to be given.
Time - Write in all the possible times you would give the medication.
To record that a medication has been given - Place a check mark on the line that corresponds to the time the medication was given.
Bowel Movement - Please circle Yes or No.

NUTRITION AND HYDRATION

Meaningful life experiences often are tied to meal times. We may share a meal with our loved ones, gather for family dinners, or celebrate holidays over traditional dishes. Unfortunately, many hospice patients experience a decrease in appetite and thirst. The patient may be disturbed by the smell of food, may feel "too full" or just not have the energy to eat. Caregivers sometimes feel helpless because their loved one is not eating or drinking an adequate amount.

Some reasons for a loss in appetite

- The disease process
- Pain
- Constipation
- Weakness and fatigue
- Nausea and vomiting
- Medication side effects such as those from narcotics
- Sores in the mouth

How to help

1. Serve meals in a relaxed, comfortable, pleasant atmosphere.
2. When feasible, eat in the room with the patient.
3. Give mouth care prior to the meal to freshen the mouth.
4. Since the appetite tends to decrease as the day progresses, make the most out of breakfast and lunch.
5. Serve small, frequent meals or snacks.
6. Use soft foods and small bites if dentures can no longer be worn.
7. Place patient in a comfortable position for meals. Generally a sitting position is most comfortable and helps to avoid choking.
8. Gently encourage, but do not try to force someone to eat. The choice to eat is the patient's.
9. Use a cup with a handle, such as a toddler cup with handle and cover, to avoid embarrassing spills.

10. Give pain medication on a schedule to reduce discomfort before and during meals.
11. Use small amounts (large amounts may be overwhelming) of high-calorie milk shakes, ice cream, or dietary supplements between meals.
12. If nausea is a problem, your Halifax Health - Hospice nurse can talk to the doctor about providing medication that may reduce nausea before meals.

Call your Halifax Health - Hospice **nurse if the patient is beginning to show difficulty swallowing such as coughing, choking or holding food in the mouth.**

Adequate Hydration

1. When it comes to liquid intake, encourage "quality" liquids as well as quantity. High-calorie supplements such as Ensure or Carnation Instant Breakfast provide not only liquids but nutrition.
2. Liquids can be given in other forms such as Jell-O, pudding or ice cream.
3. Straws or medicine droppers can be used to give liquids to patients who are weak or unable to hold a cup.
4. Avoid liquids just before or during meals as this may create a sense of fullness.
5. Patients can be kept comfortable with sips of water or ice chips if they are able to safely swallow.
6. Your Halifax Health - Hospice nurse may need to supply you with a feeding syringe.
7. Giving fluids through the veins is generally a short-term solution. The risk of over-hydration may cause uncomfortable symptoms such as swelling of the hands and feet. Excess fluid build-up in the body could lead to breathing problems as well.
8. Talk to your Halifax Health - Hospice nurse and doctor about your concerns regarding adequate hydration and nutrition.
9. Remember, when the patient is dying, the need for food and fluids greatly decreases. This is natural.

Call your Halifax Health - Hospice **nurse if the patient is beginning to show difficulty swallowing such as coughing or choking when drinking fluids.**

SKIN CARE

Good skin care helps to prevent skin breakdown and bedsores and provides comfort. Skin breakdown often occurs over bony areas of the body. When a person is bed-bound and does not move around very much, the blood supply is poor in the skin with the most weight on it. Breakdown also can occur as a result of sitting in a chair for extended periods of time. This often occurs on the heels, hips, lower back, buttocks, elbows, and even the ears. Skin also may break down due to moisture, body weight, or friction, such as being pulled over the sheet.

What to look for

1. Reddened skin
2. Broken skin
3. Torn skin

What to do to prevent skin breakdown

1. Change the person's position every few hours. If moving causes discomfort, make sure to give pain medication before repositioning.
2. Keep the skin clean and dry.
3. Check the skin daily and call the Halifax Health - Hospice nurse if you see any reddened areas, tears, or broken skin. Even with the best of care, breakdown can occur.
4. Sometimes, special mattress pads can help. Ask your Halifax Health - Hospice nurse if he or she would suggest using one.
5. If you find chafed skin:
   A. Expose the chafed skin to the air for drying.
   B. Lightly dust dry skin with powder (never put powder on wet skin).
   C. Use creams or ointments, such as A&D or a barrier cream from Halifax Health - Hospice, to help prevent skin irritation when incontinence (uncontrolled bowels or bladder) is an issue. If the incontinence continues, ask your Halifax Health - Hospice nurse if a urinary catheter is needed.

Always report any breakdown of the skin to your Halifax Health - Hospice **nurse. Should specialized care be required for a bedsore that worsens, your** Halifax Health - Hospice **nurse will show you how to care for the wound.**

TOILETING / ELIMINATION

As a person becomes weaker, it may become too difficult to walk to the bathroom unassisted. This loss of independence is particularly distressing as it makes the patient feel as if they are losing control.

There may come a time when a person is unable to control his or her bowels or bladder, also known as incontinence. This leads to frequent bed changes, soiled clothing, discomfort and embarrassment. There are various ways to manage incontinence. Please ask the nurse to offer suggestions. A bedpan, bedside commode or urinal may help.

Trying to have a bowel movement or urinate in the presence of others can also be uncomfortable. Provide as much privacy as possible. A matter-of-fact approach to providing care helps alleviate or minimize the sense of losing control.

Using the Bedside Commode

1. Help the patient get up from bed. (See "Lifting and Moving Safely" located in the "Caregiver's Guide" section of this manual.)
2. Provide as much privacy as possible while still keeping the person safe.
3. Place some water and a few drops of detergent in the bottom of the commode to ease cleanup.
4. Leave toilet tissue within reach.
5 Stay close by in case assistance with wiping, standing, and returning to bed is needed.
6. Keep hand sanitizer within reach.
7. Notify your Halifax Health - Hospice nurse of any changes in stool, such as constipation or diarrhea.

Using the Urinal (Male Patients)

1. Determine if the patient will stay in bed or stand.
2. Assist the patient to stand if necessary.
3. For bed use, the handle should be up to keep the urinal on the appropriate angle.
4. Tilt the bottom of the urinal down to prevent spills.
5. Rinse the urinal twice between uses.
6. Keep within reach.
7. Keep hand sanitizer within reach.

Using a Standard Bedpan

1. Make sure the person is covered for warmth and privacy.
2. Sprinkle powder on the edges of the bedpan.
3. If able, have the person lift up their body so you can slip the bedpan in place. The buttocks should rest on the rim of the bedpan.
4. If unable to lift their body, roll them onto their side. Note: There are times when spillage could occur and a waterproof bed pad under the bedpan is helpful.
5. Place the bedpan well under the person and gently roll them back onto the bedpan.
6. Elevate the head of the bed according to comfort.
7. Leave the room, as privacy helps. Identify a method to let you know when they are finished.
8. Once finished, hold down the side of the bedpan nearest to you and roll the person away from you, onto their side.
9. If the person was not able to clean themselves, clean them now. Baby wipes are helpful.
10. Clean your hands and help the patient clean theirs.

Fracture Bedpan

11. This style bedpan is angled with the lowest end providing a flat surface while the rest of the pan has a narrow edge with a handle. The lowest part of the bed pan goes under the buttocks.
12. Follow the instructions above.
13. Carefully remove the bedpan to avoid tearing skin.
14. This style of bedpan is easier to place and remove from between the legs because the edges are not wide.

Symptom Guide

BREATHING PROBLEMS

Shortness of Breath

Shortness of breath is the experience of struggling to take in enough air. It can be caused or made worse by mucous in the airways, tumors, removal of part of a lung, infection, lung damage, some chemotherapy drugs, radiation therapy to the lungs, allergies or being overweight. It also can be a direct symptom of illness such as emphysema or heart disease. The effect is that the body has to work very hard to move air in and out of the lungs, causing anxiety, which in turn causes the breathing rate to increase. Rapid breathing does not allow enough oxygen to move from the lungs into the bloodstream.

What to look for

1. Anxiety
2. The need to sit up very straight or lean over a table to breathe
3. Inability to lie down and breathe adequately
4. Changes in skin color to pale or bluish
5. Coughing
6. Confusion

What to do

1. Create an atmosphere of calm.
2. Raise the head of the bed or position pillows to raise the head.
3. Encourage slow, deep breathing.
4. Assist the person to sit up, lean forward slightly and rest his or her arms on the knees, chair arms or over the bed table.
5. Turn on a fan and position so the air is blowing gently on the cheeks or face.
6. Reduce the temperature in the home. The cooler the body is, the less demand for oxygen.
7. Apply a cool cloth to the face.
8. Avoid activities that cause or increase shortness of breath. Use rest periods during activity. Position chairs throughout the home on which to rest.
9. Use distractions like watching TV, listening to music or humor.

10. Help the person relax and reduce the feeling of shortness of breath by using progressive relaxation. Ask the social worker for techniques.

11. Pursed lip breathing can help:

    - Breath in through the nose
    - Keep the lips together while inhaling, then breathe out slowly between the lips. The extra time it takes to exhale helps the oxygen go into the bloodstream.

Medications and Oxygen

1. Medication to reduce anxiety may be ordered by the doctor. Follow the nurse's instruction regarding these medications.
2. Medications may be ordered to open the airway(s).
3. Oxygen is considered a medication and must be ordered by a physician. Oxygen may not help certain types of shortness of breath depending on the patient's medical condition.
4. Mouth breathing does not decrease the amount of oxygen received through the oxygen tubing.
5. **Too much oxygen may cause headaches, slurred speech and slow breathing. Do not adjust the oxygen without contacting the primary care nurse. Notify the nurse before connecting the last oxygen tank if not using a concentrator.**

Congestion

Congestion is caused by secretions (mucus) in the air passages. Frequently, a cough is present and the patient may cough up mucus that has a color to it. If there is no coughing, congestion may be indicated by a vibration felt when breathing.

What to look for

1. Productive coughing is bringing up mucous.
2. Mucous that is not white or clear should be reported to the nurse.
3. Difficulty lying flat
4. Fever

What to do

1. Encourage coughing and spitting out mucus. Keep a small sample for the nurse if it has any color.
2. Encourage fluids to keep mucus thin and easier to expel.
3. Do not provide milk products or fried foods as these make mucous thicker and more difficult to cough up.
4. When coughing is persistent, instruct the person to take three to four deep breaths in quick succession and then give a forceful cough(s).
5. Encourage a change in position at least every two hours if lying in bed.
6. Suction only as a last resort. It causes distress and is not a comfortable procedure.

Suctioning

1. Suctioning can cause coughing or gagging.
2. Suctioning oneself is less likely to cause the above.
3. Encourage coughing prior to inserting the tip of the suction wand or catheter.
4. Leave the suction device in the mouth for 8 to 10 seconds only while covering the vent. Be careful not to damage tissue by leaving the suction device in the same place for too long.
5. Dip the device in a glass of water to clear the tubing between suction attempts.
6. Allow a rest period between periods of suctioning.
7. Report the amount and color of the mucus to the nurse.
8. Keep water handy for the next suctioning.

Avoid

1. Tobacco smoke
2. Humidity
3. Pollen
4. Hot or cold temperatures

Contact your Halifax Health - Hospice nurse if your treatments and medications do not relieve the patient's respiratory symptoms.

CONFUSION, RESTLESSNESS AND AGITATION

Confusion is characterized by not being able to remember routine, everyday information, such as where you are, who the people around you are or what date it is. For hospice patients, this can happen occasionally or it can be constant. The reason for confusion is usually related to the disease, changes in the body or lack of interest in activities.

Restlessness is the inability to sleep or relax and is often the result of anxiety, pain or fear. It can be occasional or constant.

Agitation is excessive restlessness with increased mental and physical activity. At times, the person may actually strike out at those around him or her because he/she can no longer understand what is going on. It can be occasional or constant.

Causes for these symptoms can be the spread of cancer in the body, changes in electrolytes in the body, infection, inability to pass bodily waste, and decreased oxygen to the body tissues, especially the brain. In the case of advanced diseases, these causes cannot always be eliminated.

Coping with a loved one who is experiencing confusion, restlessness or agitation can be very trying for you as a caregiver. Your primary care nurse and doctor will do everything they can to minimize these symptoms.

What to look for

1. Short-term memory loss that progresses to instances where the patient cannot recall events.
2. Inability to rest or be still.
3. Insistence on doing an activity the person has not been able to do for some time, or lack of understanding when urged to stop. An example is a patient who can not walk, yet constantly attempts to get out of bed.
4. The person thinks you are someone else or are there to harm him or her.
5. Repetitively doing the same activity, such as constantly swinging legs over the side of the bed.
6. Any new symptoms after beginning a new medication or dose change.

What to do

1. Provide a calm setting, reduce noise and avoid too much stimulation, such as multiple visitors at once.
2. Offer distraction such as quiet music, TV or radio.
3. Increase or decrease the light in the room.
4. Involve the person in chats. Provide links to reality such as TV, a calendar and a clock.
5. If attempts to bring the person back to reality are not successful, take a more passive approach, such as nodding and not disagreeing while gently guiding them to do what you wish.
6. If the patient is fearful, try to find out the source of the fear.
7. Explain everything you are going to do before proceeding. This should have a calming effect.
8. Massages and warm baths are very soothing and may promote relaxation.
9. Develop a routine for toileting, eating etc. There is comfort in familiarity, which may reduce stress-related restlessness.
10. Safety is always an issue. Leave the side rails on the bed down and the commode or chair next to the bed if the patient tends to climb over the rails. You may even want to consider placing a mattress on the floor to break falls.
11. Provide walking and exercise if possible.
12. There are medications that reduce feelings of anxiety and restlessness, and they may be tried if other measures are not working well.

Contact your Halifax Health - Hospice nurse if the above symptoms are unmanageable.

CONSTIPATION

Constipation is the lack of having bowel movements. It is a symptom that can be managed. Without adequate management, a person can experience discomfort, pain, nausea and vomiting.

What to look for

1. Three days or more without a bowel movement
2. Hard bowel movements that the patient has difficulty expelling
3. Abdominal cramping without a bowel movement
4. No bowel movement for several days followed by passing small amounts of liquids. This usually means hard stool is blocking the rectum and liquid stool is seeping around the blockage, also known as impaction.
5. Decreased food or different types of food and fluid intake
6. Decreased activity
7. Prescribed pain medications. Constipation may be a side effect.

What to do

1. Refer to the Standard Laxative Protocol.
2. Provide fruit, vegetables and fiber daily.
3. Provide fluids such as water and apple juice. Record the amount of fluid taken for two days.
4. Keep a record of bowel movements and show it to the nurse when he or she visits. Note if bowel movements were very small or hard.
5. Avoid foods that constipate, such as cheese, peanut butter and bananas, or any foods that seem to have caused constipation in the past.
6. Ask the nurse for a bedpan or bedside commode if getting the patient into the bathroom is a problem.
7. Let the nurse know if there has not been a bowel movement for 48 hours (if that is unusual) and in any case where there has been none for 72 hours.
8. If stool softeners and laxatives have not relieved the constipation, it may be necessary for the patient to have an enema.

Giving an Enema

1. The nurse will tell you what type of enema to get.
2. Protect the bed with waterproof material. A plastic shower curtain liner or heavy-duty garbage bag under the sheet works well.
3. Gather your supplies: disposable waterproof material, bedpan or bedside commode (use the bathroom if the patient is able), toilet tissue, gloves, wash cloths and a basin of warm soapy water or baby wipes, and the enema.
4. Fill a basin or bathroom sink with warm water and place the enema bottle in the water. (Cold enema liquid can cause discomfort.)
5. Place the disposable waterproof pad under the hips; use two if the pads are small.
6. Have the patient lie on his or her left side with right knee bent. Place a pillow under the bent knee if it is uncomfortable to lie in this position. (This is the natural direction for the enema to drain into the bowel.)
7. Put on disposable rubber gloves.
8. Remove the cap from the enema bottle.
9. Ask the patient to breathe slowly and deeply through the mouth.
10. Insert the tip of the enema bottle into the rectum up to the cap and squeeze slowly and gently. If enema begins to run out of the rectum, remove the enema bottle, wait for a few minutes and try again.
11. Ask the patient to squeeze their rectum and hold the liquid for at least five minutes before you remove the enema bottle tip. If the patient cannot retain the enema, a second one might be necessary. For someone who is unable to get out of bed and is in a weakened state, have the bedpan next to the patient for quick use.
12. If the patient is able to get up to a commode or the bathroom, provide assistance.
13. When the patient has had a bowel movement, have him clean the rectal area with a baby wipe or washcloth and wash hands. Remove your gloves and wash your hands.
14. Make a note of the nature of the bowel movement, including the amount and whether it was soft, normal, or hard.
15. If there is no bowel movement after the enema, notify the nurse.

Note: If the movement is hard or dry, there may have been some irritation resulting in bleeding. There should not be a lot of bleeding and it should stop within a couple of minutes. If bleeding continues or seems excessive, call the nurse.

If you have any questions about constipation, please ask your Halifax Health - Hospice nurse.

STANDARD LAXATIVE PROTOCOL

Bowel function is affected by many things, including diet, activity, and medications. Even if a patient has never had a problem with constipation, he or she may begin to have difficulty due to these changes. If the patient is taking a pain medication regularly or does not have a bowel movement at least every three days, he/she may need to take a laxative or stool softener. Please do not wait until constipation is a problem. If the patient is taking a prescription pain medication, please follow the instructions below to help maintain good bowel function.

1. Provide two Senna S tablets every night at bedtime.
2. If the patient does not have a bowel movement within 48 hours, add two tablespoons of Milk of Magnesia at bedtime.
3. If the patient does not have a bowel movement the next day, call your Halifax Health - Hospice nurse.
4. Once bowel movements are occurring approximately once a day, continue taking two Senna S tablets every night.
5. Any time there is no bowel movement for two days, take two tablespoons of Milk of Magnesia at night on the second day, along with the Senna S tablets.
6. Always call your Halifax Health - Hospice nurse if there is no bowel movement for three days.

If patient complains of abdominal pain or experiences nausea and/or vomiting, please contact your Halifax Health - Hospice nurse before using laxatives.

DIARRHEA

Loose or watery bowel movements, known as diarrhea, can be very uncomfortable. Inability to control the bowels (incontinence) can also be very distressing.

What to look for

1. Forceful liquid stool
2. Cramping
3. Decrease in amount eaten and no change in laxative
4. Just began taking a stool softener, laxative or both
5. A new medication
6. Eating only fruits and vegetables
7. Stool with red blood, black color, or unusual odor. Call your nurse and save the bowel movement for examination.

What to do

1. Have the patient drink more fluids but avoid coffee or tea with caffeine and soft drinks.
2. Avoid foods that stimulate the bowels such as fruit, fruit juice, greens, milk/milkshakes, nuts, corn, etc.
3. If diarrhea lasts more than two hours, provide only fluids and avoid either very hot or very cold liquids.
4. Drink plenty of fluids.
5. Clean the rectal area well after each diarrhea bout as it can quickly become irritated. Baby wipes with aloe are soothing.
6. Notify your primary care nurse if diarrhea does not subside in 24 hours or less.

Contact your Halifax Health - Hospice nurse when you have any questions about diarrhea.

FEVER

There are numerous reasons for a person to have a fever. The usual reason is an infection in either the lungs or the bladder. It is not always necessary to treat a fever, as it is the body's natural way to fight infection. If a fever is suspected, use a thermometer of your choice to check the temperature. Fevers often occur at night or in conjunction with nausea and vomiting.

What to look for

1. Reddened face, hot skin, sweating.
2. A cough or productive cough (coughs up mucus that is not clear.)
3. Shallow breathing.
4. Decreased intake of fluids.
5. Staying in bed more or sleeping more.
6. Decreased urine, dark or cloudy urine, change in urine odor.
7. An open wound with drainage.

What to do

1. Notify your nurse of the fever.
2. Offer medicine for fever as instructed (Tylenol tablets, caplets, suppositories or generic acetaminophen)
3. Remove bed covers and heavy clothing.
4. Bath with cool or lukewarm water if tolerated. (Usually for a fever greater than 101°)
5. Change any damp clothing. Perspiring generally means the temperature is going down.
6. Offer fluids often.

AVOID giving aspirin or anti-inflammatory medications such as Advil or ibuprofen unless your nurse or doctor has recommended it.

Call your Halifax Health - Hospice nurse to report a fever.

SWELLING

Fluid retention is the build-up of fluid in tissues. The reasons could be either illness or inability to move around, especially walk. There could be weight gain, swelling in the face, hands, arms, feet, legs, stomach or back if bedbound and a feeling of fullness.

Fluid retention may be a side effect of a medication (like steroids), blockage of circulation, or changes in electrolytes in the body. Diseases of the heart may cause swelling in the feet and legs. Certain illnesses involving the liver can cause swelling in the abdomen (ascites) which can then cause swelling in the legs. Circulation back to the heart is not good as a result of pressure in the abdomen.

What to look for

1. Puffiness in the feet, ankles, hands, face.
2. Gradual expansion of the abdomen.
3. Urinating less often or producing dark-color urine despite drinking fluids.
4. Shoes, slippers, pants or belt feel tight.

What to do

1. For foot or leg swelling, put the legs and feet up preferably higher than the heart as much as possible. Raise hands and arms higher than the heart on pillows if they are swollen.
2. Weigh and report any weight gain to the nurse.
3. Use lotion on swollen skin to keep it soft and free of cracks.
4. Avoid injury to swollen areas of the patient's body – use socks, avoid tight shoes.
5. Try moving affected arms or legs in easy exercises. This will help improve circulation and move fluid away from the area. The person can do this for him/herself or if it is too tiring, another person can move the arms or legs. If it causes discomfort, stop.
6. The doctor may order medications that will help decrease the swelling. They are usually taken in tablet form but can also be given by injection. They do not always work, depending on the cause of the swelling.
7. Some of the medications (called diuretics) cause the body to lose potassium (Lasix, Bumex, Zaroxolyn). Potassium tablets may be ordered to take along with the diuretic.
8. For swelling in the abdomen, offer the patient small frequent meals high in protein and calories. Smaller meals will be more tolerable and will not create such a feeling of fullness.

9. Diuretics rarely help abdominal swelling although the doctor may prescribe them if swelling is just beginning.

10. Abdominal swelling can cause trouble breathing from upward pressure on the diaphragm when lying down. Elevate the head of the bed to relieve the pressure. Turning a fan on will help as well.

Contact your Halifax Health - Hospice nurse if the patient is having trouble breathing, increased pain, nausea and vomiting, swelling, weight gain, or an increase in the size of the abdomen.

INABILITY TO SLEEP

Insomnia is not being able to fall asleep or stay asleep. It can be caused by many different factors such as symptoms that are not managed, fearfulness, sleeping too much in the daytime, and anxiety.

Before looking at medications, it is best to consider symptoms that could cause trouble with sleeping.

What to look for

1. Shortness of breath or a cough.
2. Bowel and bladder issues including constipation, inability to urinate, fear of urinating in one's sleep.
3. Pain, discomfort, fever, nausea or painful swelling of legs, arms or abdomen.
4. Fear that no one will hear if help is needed, fear of dying in the middle of the night, or fear of dying while asleep.

What to do

1. For shortness of breath, contact your primary care nurse to evaluate if oxygen is needed. Oxygen does not always help. Follow the suggestions on help with breathing under the Symptom Guide section of this guide related to Breathing Problems.
2. Use the Laxative Protocol under the Symptom Guide section of this guide related to Standard Laxative Protocol, if the patient is constipated. If it has been three days since the last bowel movement, contact your Halifax Health - Hospice nurse.
3. Keep the commode close to the bed in case frequent urination is a problem. If no urine has been passed in the last 12 hours and the person is drinking fluids, contact Halifax Health - Hospice.
4. Use adult briefs or pad the bed with waterproof material under the bottom sheet.
5. Assure the patient that it is all right to awaken you for help during the night or if he/she is fearful. A baby monitor or walkie-talkie may be helpful.
6. Ask if pain is controlled and use a system to rate the pain like a scale of 1 to 10 utilizing the Wong-Baker FACES Pain Rating Scale or the PAINAD (for non-verbal patients). Talk with the primary care nurse about the current pain management program. If pain is causing wakefulness at night, it may be time to change medication.
7. Avoid heavy covers and use a fan if sweating at night occurs. A warm sponge bath and bed change helps.

Contact your Halifax Health - Hospice nurse with questions about insomnia.

LOSS OF APPETITE

Loss of appetite is associated with advanced disease. It might be due to the effects of the disease, changes in taste, nausea/vomiting, some medications, changes in metabolism, and symptoms like fatigue, pain, depression, anxiety and grief. Sometimes the sight or smell of food will cause nausea. Loss of appetite can lead to weight loss. Some measures may improve appetite.

What to look for

1. Feelings of fullness.
2. Food may be requested but when it arrives there is no desire to eat it.
3. The sight of the food causes nausea.
4. Eating may be followed by nausea and vomiting. Some people will attempt to eat to please others.

What to do

1. Provide preferred foods.
2. Provide small meals five to six times a day.
3. Provide high-protein foods like cheese, yogurt, eggs, and pudding.
4. Add powdered milk to foods to increase protein intake.
5. Use supplements: Carnation Instant Breakfast, Ensure, or Boost.
6. Allow the person to eat only what they can.
7. Avoid high-fat foods.
8. Encourage patient to chew the food slowly.
9. Avoid gas forming foods: cabbage, broccoli, and carbonated liquids like soda or beer.
10. The doctor may order a medication to stimulate appetite. This may or may not be effective. If it does help, there will be a time when it is no longer effective.

Contact your Halifax Health - Hospice nurse if the patient is unable to take solid or liquid foods, medication is not working, or if the patient experiences side effects such as dizziness when standing up.

NAUSEA AND VOMITING

At times, hospice patients may experience nausea, vomiting or a combination of the two. There are various causes for this including certain medications, chemotherapy, infection, cancer, motion, constipation, alcohol, coughing, large amounts of fluid in the abdomen and radiation therapy to the chest, stomach, abdomen or spine. Depending on the patient and the cause, the nausea and vomiting may be mild or they may be severe enough to interfere with the patient's quality of life. There are, however, many ways to manage these symptoms.

What to look for

1. Determine if the nausea and/or vomiting is/are related to the illness specifically.
2. Determine if medicine is being taken on an empty stomach.
3. Find out if a new pain medicine or any new medicine has been introduced. Write down when the nausea begins after taking the medicine.
4. Be aware that the odor and sight of certain foods may cause nausea.

What to do

1. The doctor may order anti-nausea medication. These medications may be taken by mouth, rectum, or injection. Have the patient take medication on a regular schedule, preferably 45 minutes prior to eating.
2. If certain medications seem to cause nausea, report it to the doctor. Read the information that comes with medications and be sure they are taken with food if recommended.
3. Eliminate bad or nauseating odors.
4. Avoid constipation.
5. Avoid cooking strong-smelling foods unless the area is well ventilated.
6. Make sure patient brushes teeth and tongue often during the day.
7. Avoid foods that cause nausea.
8. Have the patient sip cool, clear fluids.
9. Help the patient rest and relax.
10. Avoid too many sweets, fatty foods, dairy products, and acidic foods such as citrus, fruits, juice, and vinegar.

11. If nausea only occurs in the morning, provide a few crackers or a slice of toast 20 to 30 minutes before regular medicines are taken.
12. Schedule rest periods before and after meals.
13. Use distractions such as watching TV, listening to music or participating in a favorite activity.

Diet

1. Foods that are unlikely to cause nausea include grapes, toast, crackers, ginger ale, cola, dry popcorn and baked potatoes.
2. Avoid providing favorite foods when the person is nauseated.
3. Try foods at room temperature or cold.
4. Provide one to two quarts of fluids daily, and offer fluids like Gatorade, which replace lost electrolytes.
5. Try popsicles, Jell-O, or frozen Kool-aid.
6. Offer small meals more often.

Call your primary care nurse if:

1. The patient is experiencing nausea and vomiting.
2. The patient is unable to take anti-nausea medicine.
3. The patient's anti-nausea medicine is not lessening or eliminating the symptoms.
4. The patient vomits more than twice a day.
5. Nausea and vomiting lasts more than two days or keeps the patient from doing things that are important to him/her.
6. Urine is dark yellow and/or the patient is not urinating as often as normally.
7. There is weight loss of more than two pounds a day.
8. The patient feels light-headed, dizzy or mixed up.
9. The vomited material looks like coffee grounds.

PAIN MANAGEMENT

Pain is common with advanced disease and affects all aspects of a person's life: physical, emotional, spiritual, and social. Some people feel it is a sign of weakness to feel or discuss pain; others may feel that increased pain means the disease is worsening. Whatever the reason, many patients do not want to admit how much pain they are experiencing. Because the main goal of hospice care is to provide for the person's comfort, it is extremely important that patients be encouraged to talk openly about their pain. Effective pain management allows a person to enjoy activities they might otherwise miss.

Pain may range from sporadic discomfort to constant, excruciating pain. It may be caused by the disease, the treatment of the disease, arthritis, lack of oxygen to the heart and lungs or other conditions. Pain can make it difficult for a person to carry on with everyday activities such as bathing, sleeping, eating and enjoying time with family and friends. It may distress loved ones and caregivers.

Whenever Halifax Health - Hospice staff visit the home, they will ask the patient if he or she is comfortable. Usually, we will ask the patient to rate the pain on a scale of 0 to 10, with 0 indicating no pain at all and 10 indicating the worst pain imaginable. We may show pictures to correlate with the scale if it is difficult for the patient to talk. It is best if patients can tell us where the pain is located, what it feels like, how often they experience the pain, if the current medication provides pain relief and for how long. This will help Halifax Health - Hospice staff to recommend the right medication or combination of medications to relieve the pain. It is not always possible to eliminate pain, but in most cases the pain can be lessened so the patient feels more comfortable.

A word about pain medications. To get adequate pain relief, many hospice patients require medications in the morphine family. Some people fear that they will become addicted to such medication and therefore they try not to take it or want to take less than prescribed. However, it is important to take the medication as prescribed by the doctor and as instructed by the Halifax Health - Hospice nurse.

Addiction is not a problem with hospice patients. If the pain goes away, the medication can be easily decreased. It is also important not to worry about becoming "immune" or tolerant to the medication as the doses can be increased when necessary.

Medications

1. Different medications are ordered for different types of pain.
2. Medications the doctor might order include over-the-counter medications (such as Tylenol, ibuprofen), or prescription medications such as opioids (morphine, Oxycodone, Dilaudid), antidepressants (Elavil, Pamelor), anti-convulsants (Tegretol, Neurontin), and corticosteroids (Prednisone, Decadron).
3. The medications ordered are based on the person's reports of pain.

4. More than one medication may be ordered to control pain. Read the labels carefully. If the directions, name of the medication or amount of medication is different from the information provided by your Halifax Health - Hospice nurse, do not give the medication. Call your Halifax Health - Hospice nurse immediately.
5. Give pain medication at the first sign of pain.
6. It is best to provide medications as the Halifax Health - Hospice nurse has instructed.
7. It may take some time to find the right medication or combination of medications to control or reduce pain.
8. If movement causes pain, give pain medication before any activity like bathing or riding in the car.
9. When pain is frequent, the doctor might recommend around the clock medication to help keep pain under control.
10. Medication regimen may include taking a long-acting or sustained released form of medicine. There will also be an immediate-release medicine to be administered when the patient experiences additional pain.
11. Pain medication may be taken by mouth, in suppository form (by rectum), through injections or with patches applied to the skin.
12. If the person cannot tell you if they are in pain, look for signs such as frowning, moaning, restlessness, protecting a part of the body, reluctance to move, short rapid breathing, stiffness or tenseness in the body and pulling away when touched or moved.
13. Keep a record of when pain medication is given and when it is due again. This is especially important if more than one person is giving the medication.

Pain Emergency

Sudden, severe pain may be a frightening experience for both patient and caregiver. It may happen in the evening or late at night. Give the prescribed amount of medicine for breakthrough pain. This is the medication that can be given every four hours. **If pain is not relieved within one to two hours, call Halifax Health - Hospice.** The nurse can make suggestions for added control and comfort measures.

Suggestions to Limit Side Effects of Medications

1. **Dry Mouth** – Give fluids, hard candy, gum or artificial saliva.
2. **Constipation** – Use the bowel protocol provided by your Halifax Health - Hospice nurse. Call the nurse if there is no bowel movement for three days while using the bowel protocol.
3. **Nausea and Vomiting** – Note if these occur when medicine is taken. Call your nurse so a change in medication can be discussed with the doctor.
4. **Drowsiness** – Usually improves within one to three days of starting or increasing the dose. If there has been difficulty sleeping due to pain, the body will catch up on lost sleep as part of the process of regaining comfort.
5. **Increased Heart Rate** – May slow within a few days of starting medicine or changing the dose.

Taking Medicines by Mouth

1. Give pills with enough liquid. Unless otherwise instructed, pills may be taken with water, milk, juice or soda. Taking a few sips of liquid to moisten the mouth may help the patient swallow and prevent pills from sticking. Provide enough liquid to ensure the pill has been completely swallowed.
2. Some large tablets can be crushed or cut and placed in a small amount of juice, pudding, ice cream or applesauce. Note: this may cause the food or fluid to taste bitter or unpalatable. **Make sure to ask your nurse about any time-released medications. These tablets should not be crushed or cut.**
3. Capsules are difficult for some people to swallow. Some capsules may be opened and sprinkled on food and fluids. **Check with your nurse before opening any capsules.**
4. Learn the names of medicines and the reasons they are prescribed. The doctor or Halifax Health - Hospice nurse can answer any questions.
5. Administer medicines at the time intervals indicated and the amount prescribed. The Halifax Health - Hospice nurse can help you make a schedule to follow.
6. Do not stop providing medicine unless instructed by your Halifax Health - Hospice nurse or doctor.
7. Keep each medication in its original container.
8. Keep all medications in a safe place and **out of the reach of children**.
9. Do not allow anyone else to take the patient's medications. They have been specifically prescribed for the patient and may be harmful to others.

Helping a Person In Pain

1. When in pain, people often like to have someone nearby, be touched, or have their hand held.
2. Limiting visitors may be helpful.
3. Dim lights and keep the room temperature comfortable. Let the patient rest and sleep as much as possible.
4. Encourage slow, deep breathing and relaxing as the medicine begins to work. Closing the eyes and listening to soft music can help.
5. Some people find that a cold ice pack, heating pad, massage, music, humor or rest can help relieve pain.

Call Your Halifax Health - Hospice Nurse If:

1. The patient indicates the pain has changed, feels different, hurts more, medication isn't working, or hurts in a different place.
2. The medication label does not match what your nurse has conveyed to you.
3. There are any concerns or you do not understand instructions.
4. Medicine cannot be taken as ordered.
5. The person is having difficulty swallowing.
6. The person chooses not to take the medication as ordered.
7. There are any side effects from the medication.
8. You have any questions at all.

Additional Pain Relief Techniques

Distraction is a method of relief that depends on the patient's ability to focus on some kind of entertainment such as listening to the radio, writing, reading, or even daydreaming. This takes the person's mind off his or her health concerns.

Meditation is a conscious effort to place the body and mind in a state of relaxation. Prayer may work for some and guided imagery may help others. The patient can learn these techniques through reading, listening to tapes/CDs or assistance from caregivers or Halifax Health - Hospice staff.

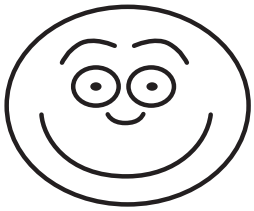
Hydrotherapy can be as simple as a relaxing bath or warm shower. Bath salts may be added to the water, as can Epsom salts, which are equally effective and non-scented. Adding baby oil to the water may help relieve itchy or dry skin. One-half cup of baking soda added to the water will also lessen itching.

Wong-Baker FACES Pain Rating Scale

Halifax Health Hospice
Licensed since 1979

No Pain

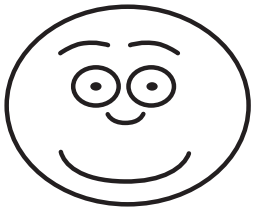
0



1

Mild Pain, Annoying

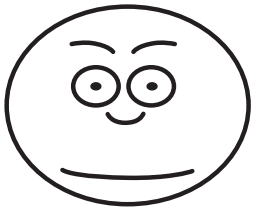
2



Nagging, Uncomfortable, Troublesome

3

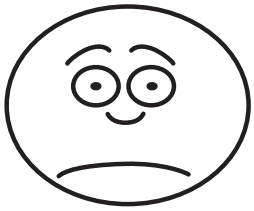
4



5

Distressing, Miserable

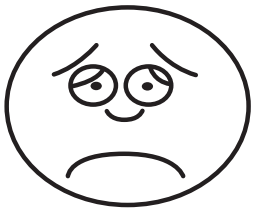
6



7

Intense, Dreadful, Horrible

8



9

Worst Pain Possible, Unbearable, Excruciating

10

EQUIPMENT

PROCESS AND DELIVERY

Halifax Health - Hospice, in cooperation with a local medical equipment company, will provide you with the appropriate medical equipment to assist you with mobility, independence and comfort.

Upon delivery, instuctions will be given on the proper use of the equipment. Please do not hesitate to ask questions during the demonstration. If any questions arise later, please call Halifax Health - Hospice at 1.800.272.2717 and we will be happy to assist you.

HOSPITAL BED

Semi-electric beds are provided to assist with comfort and body position for the person and make it easier for the caregiver to provide care. The height of the bed makes many tasks more comfortable for the caregiver.

Operating Instructions for Semi-Electric Beds

1. The wheel locks located at each end of the bed should be locked.
2. The bed has a hand control with four buttons that operate the head and foot sections. Arrows indicate the direction the bed part will move.
3. Push only one button at a time. Pushing two buttons at a time could damage the bed or stop the bed from functioning.
4. There is a crank at the foot of the bed to raise the height of the entire bed.
5. In the event of a power failure, a hand crank can be found in the springs under the mattress. The crank will fit into the appropriate motor sockets at the foot of the bed to raise the head and foot in the event of a power failure.
6. Raise the foot of the bed prior to raising the head to prevent the patient from sliding toward the end of the bed.
7. The entire bed can be set slightly higher when you need to help the patient out of bed and slightly lower when you need to help the patient back into bed.

8. The bed will have side rails for safety and to aid in turning the patient. To raise the side rails, pull up on the rail until it locks into place. To lower the rail, use one hand to pull out the button on the bottom side of the rail while using the other hand to slowly ease the rail down. Repeat at each end of the side rail.
9. An over-bed table can be provided with the hospital bed. To raise or lower the table, use one hand to pull up on the lever and the other to apply pressure up or down to adjust the height to the patient's liking. Never push down on the side of the table opposite the lever, or the table will tip over.
10. An overhead trapeze may be used to assist the patient in transferring out of bed or adjusting body position while in bed. When not in use, slip the trapeze over the top of the frame so it is out of the way.

Precautions

1. Always plug the bed into a grounded wall outlet.
2. Make sure the two locking wheels at each end of the bed are locked.
3. The patient should always have help when getting in or out of bed.
4. The bed should be at least one foot away from any walls.
5. Move items such as the over-bed table away from the bed before lowering or raising the bed.
6. Never place objects under the bed.
7. Keep the hand-control cord out of the way when raising or lowering the bed.
8. Do not attempt to disassemble the bed.
9. Be alert to any unusual noises during the operation of the bed.
10. Do not plug the bed into an outlet that is being used to power other major appliances, and do not use extension cords to plug in the bed.
11. Do not tie patient restraints to the side rails.

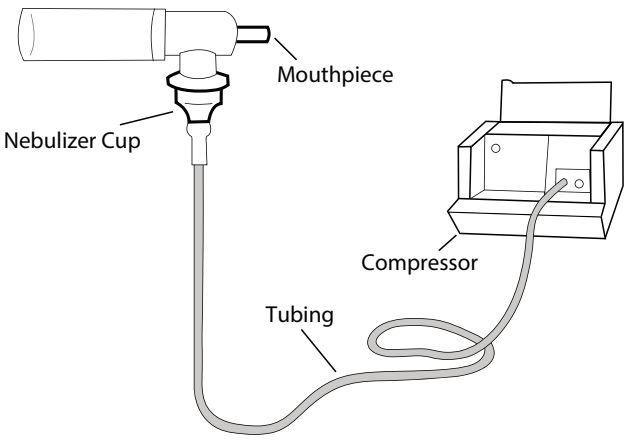
If you experience difficulty operating the hospital bed, contact your primary care nurse.

NEBULIZER COMPRESSOR

Some respiratory symptoms may be relieved by inhaling an aerosol medication into the lungs, using a device called a nebulizer. Your primary care nurse will explain the type of medication, show you how to measure the appropriate amount, and review the length of time for the treatment.

Operating Instructions

1. Place the nebulizer on a flat surface near the user so the controls are within reach.
2. Turn the on/off switch to ON.
3. Remove the mouthpiece and tubing from the storage compartment.
4. Attach one end of the tubing to the compressor outlet, and connect the other end to the nebulizer cup.
5. Open the nebulizer assembly by turning the medication cup to disconnect and fill with the prescribed medication.
6. Attach the cup back to the assembly, place the mouthpiece into the mouth and have the patient breathe through the mouth until the medication is gone.
7. When the treatment is complete, turn the switch to OFF.



Maintenance and Cleaning

1. Remove the nebulizer assembly and mouthpiece from the machine and wash in hot water with mild detergent. Rinse thoroughly in hot water for three minutes after each use.
2. Soak the nebulizer assembly and mouthpiece in a solution of one part vinegar to three parts water for thirty minutes each day.
3. Rinse the nebulizer assembly and mouthpiece for three minutes and air dry.
4. Wipe the tubing regularly with a damp cloth to keep it dust-free.
5. Wipe the machine with a damp cloth regularly.
6. Remove the small, round filter next to the on/off switch and clean with soap and water once a month or more frequently if discolored. Rinse and dry thoroughly before placing in the machine.

Precautions

1. Do not plug the machine into an outlet used by any other major appliance.
2. Extension cords may only be used if they are at least 18-gauge and no more than 25 feet long.
3. Always unplug the machine after using.
4. Do not use the machine while bathing or near water.
5. Do not place the machine in water for any reason.
6. Be careful to keep the machine's air vents clear of blockage. Avoid placing the machine on bedding while it is in use.
7. Do not operate inside an oxygen tent.

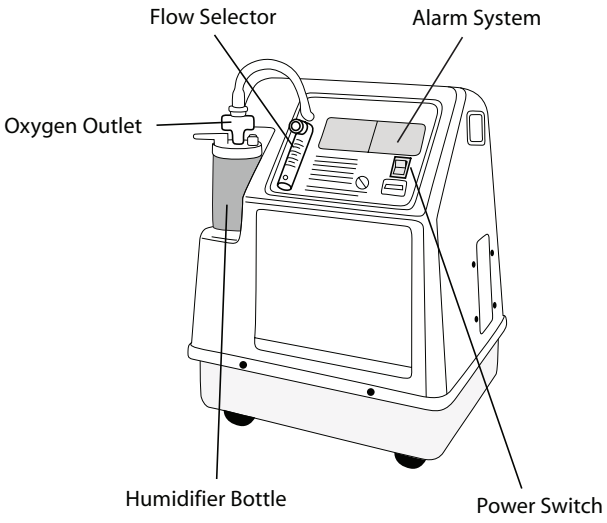
If you have difficulty operating the nebulizer or need service or supplies, contact your primary care nurse.

OXYGEN EQUIPMENT

If illness requires the use of oxygen equipment, Halifax Health - Hospice,, in cooperation with a local partner company, will provide the appropriate equipment. Upon delivery, instructions will be given on how to use the equipment. Please ask questions at that time.

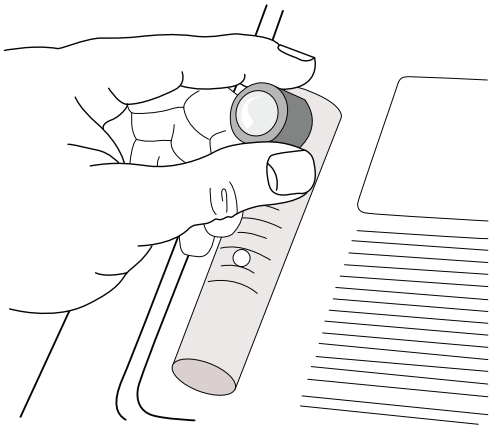
Oxygen Concentrator

An oxygen concentrator is an electric machine that draws air from the room, separates the oxygen from the other gasses, concentrates the oxygen and delivers it through tubing to a nasal cannula (prongs that go into the nose) or a mask. Your doctor will order the appropriate amount of oxygen and that will be the setting on the machine. **The setting should only changed at the recommendation of the nurse or doctor.** When the machine is delivered, there will also be tanks of oxygen to keep on hand in case of power failure.



Operating Instructions

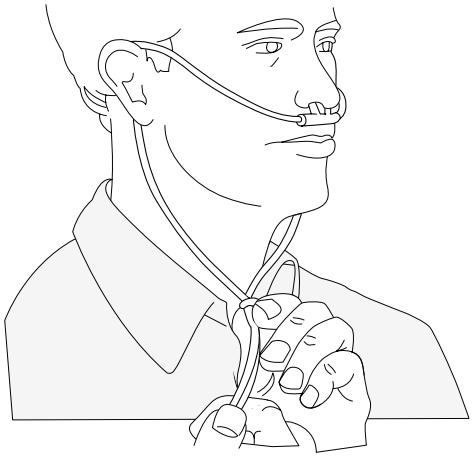
1. Plug the machine directly into a grounded electrical wall outlet. **Do not use an extension cord.**
2. Turn the on/off switch to the ON position.
3. Adjust the flow-adjustment knob until the silver ball in the meter reaches the level ordered by your doctor or nurse. The ball should rest in the middle of the line indicating the prescribed flow rate.
4. Attach the tubing from the facemask or nasal cannula (prongs that fit into the nose) to the oxygen outlet on the machine. If a humidifier bottle is being used, attach the tubing to the humidifier bottle.



Using a flowmeter liter control knob to adjust the oxygen flow rate

5. Nasal Cannula – turn the cannula until the two prongs curve upward and place into the nostrils. Slide the tubing over and behind each ear. Adjust the tubing under the chin by sliding the adjuster upward. Avoid adjusting too tightly. Check the ears for any redness or soreness.
6. Mask – place the mask over the nose and mouth. Slide the elastic strap over the head and position it above the ears.

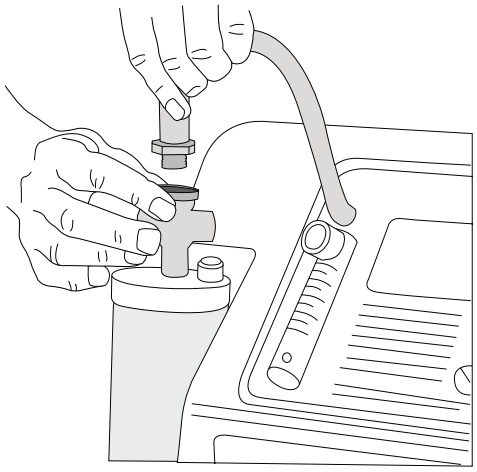
7. When the flow rate is greater than two liters per minute, a humidifier bottle is generally recommended. Attach a filled bottle to the threaded outlet tube on the concentrator. Center the threaded cap on the bottle under the threaded outlet tube and turn the cap on the humidifier bottle until it is screwed tightly onto the outlet.
8. Additional oxygen tubing may be needed so the patient can move about the house. The equipment technician will add the proper amount of tubing.
9. To turn off the concentrator, turn the on/off switch to the OFF position.



Adjust the tubing to fit comfortably under the chin

Maintenance and Cleaning

1. Remove and clean the filter(s) on the outside of the concentrator once a week. Wash in warm, soapy water using a non-lotion detergent or dishwashing liquid.
2. Rinse the filter thoroughly with warm water and gently squeeze excess water from the filter. Pat dry with a towel and replace filter(s) by pushing into the filter slot.
3. Refill the humidifier bottle daily. Turn off the concentrator. Wash your hands, then unscrew the bottle from the lid. Discard any remaining water. Rinse the bottle under a strong stream of warm water for three minutes and shake off excess water. Refill the bottle with distilled water to the "fill" line on the bottle. Overfilling will cause water to collect in the oxygen tubing. Screw the bottle back onto the lid until tight and turn the concentrator back on. If the water in the bottle is bubbling, the bottle is tight.



Attaching a filled humidifier bottle

4. Clean the humidifier bottle once a week with a mixture of one part water and one part vinegar. Soak for 30 minutes and then thoroughly rinse for three minutes in warm running tap water.
5. Remove the nasal prongs daily and clean with a clean damp cloth.
6. Discard and replace the nasal cannula every two weeks, humidifier bottle once a month, and oxygen tubing every three months.

Concentrator Alarms

1. The concentrator will sound an alarm if there is a power outage or the equipment fails. If you hear the alarm, turn off concentrator, connect to the backup system and call your nurse.

2. In the meantime, check that the power cord is plugged into the outlet. If it is not, simply plug it back in.

3. Check other appliances, fuses and circuit breakers to see if there has been a power failure.

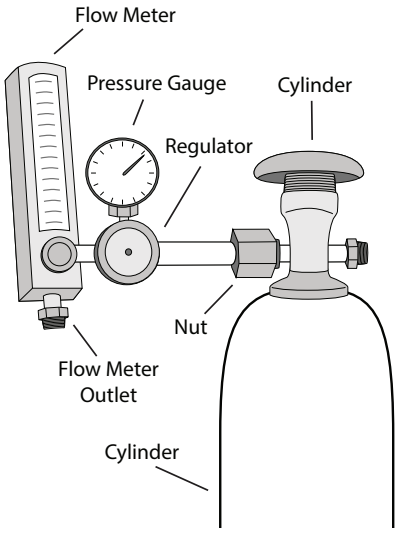
Oxygen is safe to use when proper instructions are followed. If there is difficulty with the operation of the equipment or service is required, contact your primary care nurse immediately.

Portable Oxygen Cylinders

Portable oxygen cylinders and/or larger tanks are provided as a backup to the oxygen concentrator or for oxygen use when the patient is away from home. Cylinders are pressurized and care is necessary when operating, storing or transporting. Cylinders will be delivered in a cart or stand with a regulator attached. As with the concentrator, use only the liter flow recommended by the doctor or primary care nurse.

Operating Instructions

1. Either by hand or using the attached wrench, slowly turn the small handle at the top of the cylinder counterclockwise
   one-quarter turn.



2. Check the pressure gauge on the regulator. A full tank should register 2,000 lbs. The cylinder must be turned on to read the amount of oxygen pressure.

3. Adjust the liter flow gauge to the amount ordered by the doctor or primary care nurse.

4. Attach the tubing from the nasal cannula to the nipple on the regulator outlet.

5. Apply the cannula with nasal prongs and adjust for comfort.

6. To turn off the cylinder, use the handle or wrench and turn clockwise until tight. Oxygen will still flow until the excess leaks from the shut-off valve.

7. When changing the regulator from one cylinder to another, grasp the T-shaped handle, turn counterclockwise and lift from the cylinder.

8. Attach the regulator by slipping it over the post valve of the cylinder and align the pegs inside the regulator with the holes in the post valve of the cylinder. Tighten the "T" handle of the regulator by turning it clockwise firmly. If the "T" handle is not secure or the regulator washer is not in place, there will be a loud hissing noise indicating that oxygen is escaping. **This does not represent a danger.** Just turn the cylinder valve off and check the position of the regulator for proper alignment. Be sure the washer is present and then retighten the "T" handle firmly.

Cleaning

1. Wipe cylinder and regulator with a damp cloth only.

2. Never use wax, cleaning spray or polish.

Transporting Cylinders in A Vehicle

1. Do not smoke in the vehicle.

2. Securely fasten the cylinders in the back of the vehicle with a seat belt.

3. Do not transport or store cylinders in the trunk.

4. Keep at least one window partly open.

5. Do not store oxygen in any area where the temperature could reach 120° Fahrenheit.

6. Always remove cylinders from your car after returning home. Never store cylinders in a vehicle.

It is important to check the pressure gauge of your cylinder regularly to avoid running out of oxygen. It is suggested that you keep at least four hours of oxygen on hand in case of power failure. The following charts will assist in determining when to request more oxygen cylinders from Halifax Health - Hospice. Please contact your primary care nurse at least one day in advance if you require replacement cylinders or service.

Fire Safety:

1. DO NOT SMOKE WHEN OXYGEN IS IN USE.

2. If medical condition permits, turn off oxygen and remove mask / nasal cannula if people are going to smoke. (There should be no oxygen within 25 feet of an open flame).

3. If the patient smokes in bed, someone must stay with him / her.

"E" Cylinder Flow Chart (Approximate)

Gauge Reading	Hours at 1 liter	Hours at 2 liters	Hours at 3 liters	Hours at 4 liters	Hours at 5 liters	Hours at 6 liters
2,000 lbs.	10	5	3.5	2.6	2	1.7
1,500 lbs.	6	3	2.2	1.5	1	.75
1,000 lbs.	4	2.5	1.5	1	.7	.4
500 lbs.	2	1.25	.75	.5	.25	.10

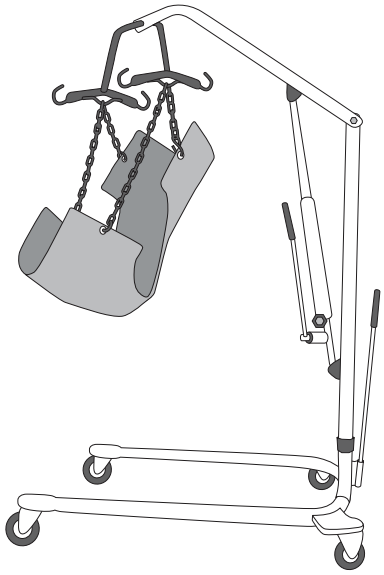
"D" Cylinder Flow Chart (Approximate)

Gauge Reading	Hours at 1 liter	Hours at 2 liters	Hours at 3 liters	Hours at 4 liters	Hours at 5 liters	Hours at 6 liters
2,000 lbs.	4	2	1.3	1	.45	.4
1,500 lbs.	3	1.5	1	.45	.36	.3
1,000 lbs.	2	1	.4	.3	.24	.2
500 lbs.	1	.3	.2	.15	.12	.10

PATIENT LIFT

Patient lifts are specially designed to help you safely transfer the patient from a hospital bed to a wheelchair or commode with minimized physical strain on both patient and caregiver. They are not meant for transporting patients. A patient lift comes with a sling and chains and has several parts: the base, base shifter handle, hydraulic pump, pump control valve, steering handle and spreader bar. You should not attempt to use this device alone or without instruction and supervision from your primary care nurse.

Operating Instructions



1. We recommend that two people be available to operate the patient lift.
2. To place the sling under the patient, roll the patient to one side of the bed. Fold one half of the sling, accordion style, in the center of the bed with the other half of the sling flat on the bed. Roll the patient over the folded half of the sling and onto the sling. Pull the folded half of the sling until is it flat on the bed. Roll the patient onto his/her back. Your primary care nurse will demonstrate the proper technique.
3. The top of the sling should be positioned slightly above the armpit level of the patient. The bottom of the sling should be a few inches above the back of the knees.
4. Attach the chains to the sling. One chain should be attached to the two holes on one side of the sling, the other to the opposite side of the sling. The short end of the chain should be attached to the back of the sling with the longer end of the chain attached to the lower end. Place the "S" hooks through the holes of the metal bar in the sling with the open end of the "S" hook away from the patient.
5. Before hooking the patient to the lift, the base must be opened to its widest position. Place one hand on the shifter handle and the other hand on the steering handle for support. Pull the shifter handle toward you to unlock it and move the shifter handle to the right to spread the base. The shifter handle must lock into the notch on the far right.
6. Always have the bed in the lowest position. Using the steering handle, move the lift under the bed to the side of the patient.
7. To lower the height of the lift bar so the chains reach the spreader bar, release the spreader bar by opening the pump control valve. Lower the lift bar and close the pump control valve. Attach the chains to the spreader bar.

8. Move the pump handle up and down slowly to raise the lift until the patient is high enough to clear the bed. The device will support the patient's weight.

9. When the patient is clear of the bed, swing the patient's feet off the bed toward the lift pump, facing you.

10. Move the patient away from the bed using the steering handle.

11. Open the control valve slowly, lowering the patient so his/her feet rest on or over the base of the lift, straddling the mast. Close the control valve.

12. Push the lift with both hands and guide it around to the location you are transferring to, such as a wheelchair.

13. The patient should be elevated enough to clear the chair, wheelchair or commode. Guide the patient over the chair and lower the lift by opening the pump control valve.

14. Lower the sling onto the chair. Close the pump control valve.

15. To transfer the patient back to bed, recheck the sling and chairs for proper attachment. Lift the patient by moving the pump handle up and down.

16. Once clear of the chair surface, use the steering handles to move the patient away from the chair and back to the bed.

17. Move the base of the lift under the bed and lower the patient onto the bed by releasing the pump control valve. Remove the sling by rolling the patient to one side, and fold the free edge of the sling, accordion-style, to the center. Roll the patient over the folded part of the sling and remove from the opposite side.

Precautions

1. Do not move the patient in a lift over any great distance or to a different room. It is only intended for transfer from one resting place to another.

2. Do not use any plastic-backed incontinence pad in the sling.

3. Do not roll the patient in the lift over uneven surfaces, including carpet or loose rugs.

Cleaning

1. Use a damp cloth with a small amount of detergent if needed.

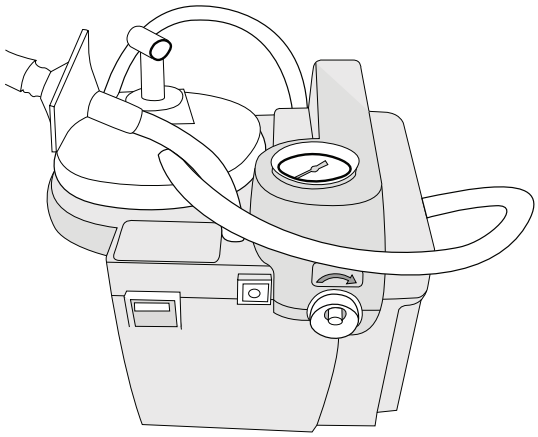
2. Remove the metal bars from the sling before washing in hot water.

Call your Halifax Health - Hospice nurse if you experience difficulty with the lift or need service.

SUCTION MACHINE

A suction machine is an electrical device run by a compressor that creates a vacuum called "suction." While there are various types of suction machines, they all have the same basic parts: a regulator knob that allows you to set the pressure and a pressure gauge that tells you the amount of suction. Basic suction equipment typically includes a soft catheter and a plastic wand-shaped suction device called a Yankauer. There is also a more permanent form of suction known as gastric suction, which requires that a tube be surgically implanted into the stomach. Your primary care nurse will order the correct machine for your use. Do not operate the suction machine without instruction from your primary care nurse.

Operation



1. Place the suction machine on a firm, flat surface close to the patient.
2. Plug the suction machine into a grounded electrical outlet.
3. Supplies include tubing from the machine to the canister and tubing from the canister that connects to your suction device.
4. Make sure all tubing is secured tightly to the machine.
5. Wash your hands and put on gloves.
6. Turn on the suction machine by turning the on/off switch to ON. Place your thumb over the end of the suction tubing and check the amount of the pressure on the pressure gauge. Make adjustments if necessary by turning the regulator knob to establish the level of pressure prescribed by your primary care nurse. Remove thumb.
7. Attach either a Yankauer or catheter as indicated by your nurse.
8. YOUR PRIMARY CARE NURSE WILL INSTRUCT YOU IN THE USE OF THE CATHETER AND YANKAUER.
9. Perform suctioning according to instructions by the nurse.
10. Turn off the suction machine by turning the on/off switch to OFF.
11. Discontinue suction when the fluid reaches the "full" line or 1000ml as marked on the canister.

Changing the Suction Canister

1. Wash your hands and put on gloves.
2. Remove tubing from the suction canister. Remove the canister from the machine and place on a firm surface, being careful not to spill contents.
3. Place caps over holes where the tubing was removed (should be attached to the lid).
4. Remove top of canister and empty contents into the toilet. Rinse canister with warm water, wash with soapy water and rinse again.
5. Wash your hands.
6. Place a new canister (or cleaned canister) in the suction machine and reconnect the tubing, making sure everything fits securely.

Precautions

1. Do not use an extension cord with the suction machine.
2. Do not plug the suction machine into an outlet with other appliances.
3. Never allow the canister to fill above the maximum fill line. Over-filling can cause serious damage to the machine.
4. Do not submerge the machine in water and do not use if it is damp or wet.
5. Do not place the suction machine on the floor.

Cleaning

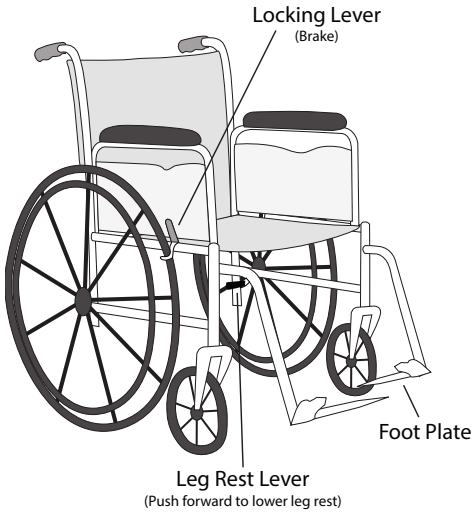
1. Wipe the outside of the machine with a clean, damp cloth.
2. Remove the suction tubing from the canister daily and rinse the catheter or Yankauer and tubing for three minutes under warm, running water.
3. Soak the catheter or Yankauer and tubing weekly in a solution of one part vinegar and one part water for 15 minutes. Discard the vinegar solution and rinse for three minutes in warm running water.
4. Replace the Yankauer and tubing every two weeks. Your primary care nurse will recommend the length of time to use the catheter.

Call your Halifax Health - Hospice nurse if you need assistance or service for your suction machine.

WHEELCHAIR

Wheelchairs are provided to increase the patient's mobility, independence and comfort. It is important to follow all operating instructions for safety. Halifax Health - Hospice will recommend a suitable wheelchair based on the patient's height, weight and needs.

Operating Instructions



1. Someone else should always be present when the person is transferring to, from or operating a wheelchair.
2. Before entering or exiting the wheelchair, the locking lever should be pushed forward until the lock snaps into place.
3. To collapse the wheelchair, pull the foot plates upward, then lift up under the center edge of the seat upholstery.
4. To unfold the wheelchair, tilt it slightly to one side to raise the wheels on the opposite side off the floor, then push down on the seat rails.
5. Before transferring a person into the wheelchair, it is best to remove the foot plates. Fold each one upright, apply the release mechanism, swing the foot plate to the side of the chair and lift it off the hinge. This will allow the chair to be placed closer to a bed or chair and makes the chair lighter to transport.
6. To replace the foot plates, put them in the swing-away position on the pins. Swing each one forward until it locks into place. Push the foot plates down.
7. The length of the foot rest should be adjusted so the patient's thigh rests on the seat with even pressure on the buttocks. The feet should rest with light pressure on the foot plate. At least two inches clearance is needed between the floor and the foot rest.
8. An elevating leg rest allows the leg to rest in various upright positions. To elevate, pull up on the leg rest and it should lock into place. To lower the leg rest, apply slight pressure to it and release the elevating mechanism.
9. To remove the arm rest, push on the button in front of it and pull upward. To replace it, align it in the front and rear sockets and push down. Make sure it locks into place.
10. The tipping levers (extensions of the frame at the rear of the wheelchair) allow for safer maneuvering on curbs or uneven surfaces. Apply pressure to the levers with your foot while pushing down on the handles to gently guide the front wheels over the unlevel surface.
11. To transport the wheelchair in a car, remove the leg rests, fold the chair, tip it backward and place the front wheels into the car. Lift up on the handgrips and push the wheelchair forward into the car.

Precautions for Patient and Caregiver

1. Avoid leaning forward in the seat of the wheelchair to reach items or reach down between the knees.
2. Avoid leaning over the back of the chair or in any direction that causes an extreme shift in weight.
3. Do not use the wheelchair locks to stop a moving wheelchair.
4. Avoid tilting the wheelchair without assistance.
5. Avoid using the wheelchair on an escalator.
6. Avoid attempts to independently ride over curbs or obstacles.
7. Do not lift the wheelchair by any of its removable parts.
8. Avoid standing on the foot rest or frame of the chair.
9. Avoid stepping onto the foot rest when transferring in or out of the chair.
10. Avoid attempts to move up or down on an incline that is wet, oily or iced.
11. Do not transport the wheelchair in a moving vehicle while the user is in the wheelchair.
12. When using a wheelchair in an elevator, back the wheelchair into the elevator. When exiting, turn the wheelchair around and back out.

Inspections

1. Handgrips should be tight and secure.
2. Wheelchair locks should lock the wheels securely.
3. Look for missing tips and caps. The rubber on the wheels should be secure.

Wheelchairs come in many sizes, heights and different levels of functionality. Your Halifax Health - Hospice nurse will suggest the proper one for your use. If you have any problems with your wheelchair, contact your Halifax Health - Hospice Nurse.

WALKER AND CANE

Appropriate equipment is based on the support and stability needed. The primary care nurse will assist in identifying the correct walker or cane. When the equipment is delivered, a technician will adjust the equipment for the proper height. Please use the equipment as your doctor, primary care nurse, or therapist has instructed for the patient's safety.

Precautions

1. The patient should never attempt to use a walker or cane on stairs without approval and instructions from the primary care nurse, therapist, or doctor.
2. Taking small steps helps maintain balance.
3. Clear away all rugs that are not secured to the floor.
4. Pay attention to areas that could cause safety hazards such as doorway thresholds and uneven surfaces.
5. For safety, someone should be on hand the first time a patient uses the equipment.

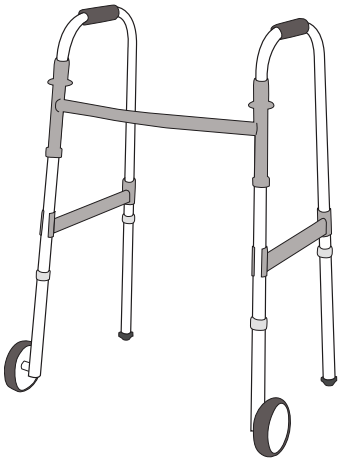
Maintenance

1. Check the rubber tips and replace when worn or damaged.
2. Check handgrips and replace if torn or loose.
3. Check that the height adjustment is secure.

Adjustments

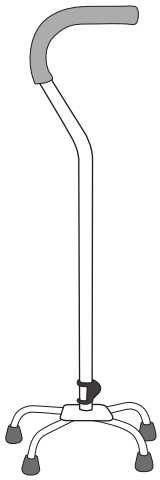
1. The patient's elbow should be bent at a 20- to 30-degree angle if the height adjustment is correct.
2. The patient should avoid attempts to stand if it cannot be done safely. If able to stand safely, stand up straight with the arms relaxed by the sides. The height of the grip will be adjusted so that the hand grip is just above the wrist.
3. After the height is adjusted, check to ensure that the adjustment mechanism is securely locked.

Walker Use



1. The patient should follow slightly behind the walker. Stepping all the way to the front of the walker could cause loss of balance.
2. The walker should be lifted and placed so that the rear legs of the walker are a few inches ahead of the patient. The patient should step forward so his or her legs are even with the rear legs of the walker.
3. Short steps are safer than long steps.
4. Folding walkers have various mechanisms to open and close them. A Halifax Health - Hospice staff member will instruct you on the patient's particular model. Once open, the walker should be locked into place.

Cane Use



1. Canes should be used in the hand opposite the weaker leg.
2. The patient should move the cane and the affected leg forward at the same time while bearing weight on the stronger leg. He or she should lean on the cane for support and move the stronger leg forward.
3. Quad canes have one flat side and one side that extends outward. The flat side should face the leg/foot. The same cane can be used on either side by turning the cane so the flat side is next to the leg.
4. The patient should always take short steps to maintain balance.

Halifax Health - Hospice provides standard walkers, as they are the safest. But there are many accessories available for walkers such as wheels, platforms, baskets and bags. There are also various styles of walkers, including those with a seat and/or brakes. If you have questions about the cane, walker or other equipment, or service is required, contact your Halifax Health - Hospice nurse.

Preparing for Death

SIGNS OF APPROACHING DEATH

Your team and supporters from the Halifax Health-Hospice understand and support your desire to help your loved one to approach death in familiar surroundings. We also realize that this period may be a very difficult one for you and your family. This information is intended to help you understand and **feel confident** that you understand the symptoms and changes you may observe as your loved one approaches the final stages of life. Not all of these symptoms will appear at the same time, and some may never appear. Your Halifax Health - Hospice staff is always available to answer your questions, provide support and to serve you. We encourage you to call whenever you need us.

The members of your Halifax Health - Hospice care team want you to know what to expect and how to respond in ways that will help your loved one accomplish this natural transition with support and understanding. This is the GREATEST GIFT OF LOVE you have to offer your loved one.

The physical and emotional signs and symptoms listed below will help you understand the natural stages your loved one is going through and how you can respond appropriately. Just as everyone's living experience is unique, so is everyone's process of dying. There is no order in which symptoms appear. Sometimes a number of symptoms occur over a period of hours or days, and even when many signs are present, there is still no way to predict the amount of time before death will occur. Some people exhibit some of the changes and then for no particular reason, their condition may begin to improve somewhat. These roller coaster changes are very difficult for families and may be physically and emotionally exhausting.

Emotional Changes

Withdrawal: A person may gradually stop enjoying activities they previously enjoyed. They may stop watching television, listening to the radio, reading or listening to music. They may not wish to see visitors or may only continue to see a certain few. This is bound to make some visitors feel badly, so it will be important to explain that this is natural and has nothing to do with them personally. This period can sometimes seem like depression, so it is always appropriate to have your counselor talk with your loved one. Some people will simply close their eyes and not talk. The patient may be okay with you sitting near them, but may not want to engage in conversation. Everyone reacts differently and some patients never experience withdrawal. This is part of the "letting go" process that indicates less concern with surroundings and relationships. Remember, this is a natural process and is not directed at caregivers, family or friends.

Sadness: Your loved one may become sad and tearful about the prospect of leaving loved ones just as the family is experiencing the same feelings. At times, the person will grieve the loss of his/her own life and lost opportunities to spend special times with loved ones. Your counselor can help you and your loved one find meaning even in this phase of life.

Fearfulness: Fear of the unknown is the greatest and most unmanageable emotion. No one can actually explain what happens as the body dies. We can see events from an outside perspective but we cannot begin to explain what it feels like to die. We can manage symptoms so people are comfortable and do everything possible to ensure that someone is present with them at the time of their dying. This experience can be scary for a caregiver as well. Halifax Health - Hospice is always there to answer questions and support you.

Anger: Not everyone is ready or prepared to die. If your loved one lashes out at you over little things, he/she could be having great difficulty with the concept of dying. Please try not to take it personally. You may feel the same way at times. Your hospice team can help in this situation.

Anxiety: Unresolved or unfinished personal issues may be one of several things that cause a loved one to become anxious. Sitting with them, gently stroking them and allowing them to talk are some of the things that can be calming to them. Talking about a favorite experience, reading something comforting or playing a favorite song may also help in reassuring the person that it is okay to "let go." Speak in a quiet, natural way to let your loved one know they are not alone.

Confusion/Vision Experiences: As the body is preparing to separate from this world, so is the mind. A person may seem confused or speak in rambling words or symbols. They may stare at what seems like nothing and insist that a favorite family member who died in the past is right there in the room talking to them. They may reach out to this person. There might be talk of "going home," "planning a journey," or "getting in line."

We cannot enter this other world, but we can share by listening to everything they say. It is best to allow them to be in their moment and not attempt to bring them back to your real world as they usually can no longer perceive it. Affirm their experience. If they seem to be frightened, explain that it is not unusual and sit with them to reduce anxiety. This is a precious time to share with your loved one. Watch for clues: does the rambling speech have a message, does their vision bring a smile or look of wonder, does the body seem to relax, do they speak of beauty and light? You can ask them what they see: is it beautiful or peaceful, did the people there tell you anything?

These are not hallucinations, which tend to be frightening and may include visions of bugs or feelings of persecution.

Giving Permission and Saying Good-Bye: Sometimes the dying person will try to hold on to life, even though it may prolong their discomfort. It is believed that they need to be sure that those who are going to be left behind will be all right. Giving permission to your loved one to "let go" can be very difficult for you. When the person is ready to die and you are ready to let go, it is time to say "good-bye." Your ability to give him/her assurance that it is okay is very important for their transition. It can be very comforting to hold your loved one in your arms or hold their hand and say everything you need to say. It may be as simple as saying, "I love you." Tears are a natural part of saying good-bye. They do not have to be hidden from your loved one or anyone else. Tears express your love and help you to let go. Even though your loved one may not be able to speak to you or may not appear to hear you, assume that they do. You may even be surprised with a tear or slight squeeze of the hand.

Physical Changes

Coolness/Skin Color: The person's arms and legs may become increasingly cool to the touch and at the same time, the color of the skin may change. This is a natural process that means that the circulation of blood is slowing and decreasing to the extremities and is being reserved for the vital organs. You can keep your loved one warm by covering them with an extra blanket. Even though you can feel the coolness, many people deny feeling cold, so it is best to ask them before adding blankets.

Skin color may become pale, yellow or bluish around the lips, ears, and nails. Splotches or areas of reddish-blue or purple (mottling) may develop on the extremities and move closer to the body as time progresses.

Increased Sleeping: The person may spend an increasing amount of time sleeping and appear to not respond to your touch or voice. They may be difficult to arouse from sleep. Changes in the body's metabolism cause this normal process to occur. Plan to spend time with them during periods when he/she seems more alert and awake. Speak directly to your loved one as you normally would if he/she appears uncommunicative. Even if the patient appears to be sleeping, tell visitors and other family members to assume he/she can hear what is being said. Nothing should be said that would distress the patient should the conversation be overheard. NEVER assume the person cannot hear. Research and our experiences have shown that hearing is the last sense to be lost.

Restlessness: The person may make restless or repetitive motions such as pulling at the bed linens and clothing or trying to get out of bed. This often happens and is due to the decrease in oxygen circulation to the brain. Do not interfere or try to restrain such motions. If safety is a concern, sit with your loved one and read to them or play soothing music. Lightly massaging them can be a great comfort and will let them know they are not alone. If touching or massaging seems to increase restlessness, then discontinue what you are doing. These techniques may help, but if your loved one becomes increasingly restless, please contact your primary care nurse, who will contact the doctor about further treatment.

Confusion or Disorientation: Your loved one may seem to be confused about time, place and the identities of people surrounding him/her. This may include close and familiar people. Identify yourself by name before you speak to him/her so they will know who you are. Explain everything you are going to do for them before you do it. This is not the time to ask them if they know who you are as it may create increased anxiety. Speak softly, clearly and truthfully when you need to communicate something important or when they have asked you a direct question. Although watching this normal occurrence may be difficult for you, being truthful will help the patient, who is usually unconcerned about these changes.

Loss of Bladder and Bowel Control: The person may lose control of bladder and/or bowel functions as the muscles in that area begin to relax. Urine output normally decreases and may become a dark tea-color due to the gradual decreased fluid intake and decreased circulation through the kidneys. Talk to your nurse about ways to protect the bed from soiling and keep your loved one clean and comfortable.

Decreased Food and Fluid Intake: You will notice a gradual decrease in appetite and thirst. The person will want little or no food or fluids. The body is naturally slowing down, and that includes the digestive tract so there is a feeling of fullness rather than hunger. Most patients feel overwhelmed by the sight of food and will deny hunger. The body begins to naturally conserve energy so it is very important

not to force the person to eat or drink. Many patients will try to eat to please their caregivers and may become uncomfortable or experience nausea and/or vomiting. It requires energy to digest food. It is best to provide anything the patient requests in very small amounts. They may always have a second portion if desired.

It is important to determine if the person is able to swallow as this is another change that people might experience as the body begins to relax. Sit the patient up and provide a small amount of fluid until you are sure they can swallow without coughing. When providing food, look into the mouth to ensure the person can chew and swallow food adequately. Use foods with a consistency that the person can tolerate.

Your loved one will adjust to decreased fluid intake but could experience a dry mouth. Provide small amounts of ice chips, frozen popsicles, or juice, and refresh frequently. Cleaning the mouth so it remains fresh is very important. Ask your nurse for toothettes (a small sponge on a stick) to clean and refresh the mouth.

Dehydration: Dehydration occurs naturally due to decreased oral intake of fluids, decreased digestive system and kidney function, and loss of moisture through the skin and lungs. While the thought of your loved one not eating or drinking very much is upsetting, it is helpful to understand that the body functions in a wonderful balancing act and is constantly changing to keep all organs and tissues working well. Less urine output decreases the need for a bedpan or Foley catheter. There is less chance of congestion in the lungs and fewer secretions to be swallowed, which lessens the incidence of breathing difficulties (dyspnea) and coughing or choking. Nausea and vomiting decrease because there is less fluid in the digestive tract. Swelling (edema) that may be located around tumors or on the arms and legs will reduce. Many people are actually more comfortable as a result of these changes and it is important to let this happen naturally. A sudden addition of fluids, such as IV fluids, could actually overwhelm the body and cause fluid overload.

The primary discomfort that hospice patients experience is a dry mouth. Frequent mouth care and small amounts of desired fluids will help. There are artificial saliva substitutes that may help, or ice chips may be used if the patient can swallow. Vaseline may be used for dry lips **UNLESS THE PATIENT IS USING OXYGEN.** If using oxygen, use a non-petroleum based lip balm. Avoid lemon glycerin swabs as they can actually promote dryness. You can make a soothing preparation with water and a small amount of alcohol-free mouthwash to gently swab the inside of the mouth with a moistened toothette.

Breathing Changes: Your loved one's regular breathing pattern may change as death approaches. The pace or rate may increase, decrease or alternate. An irregular pattern of shallow breaths followed by a period of time with no breathing (apnea) may occur. Apnea can last anywhere from a few seconds to a minute before the patient resumes breathing again. Your loved one may also experience periods of rapid, shallow, pant-like breathing. These and other various patterns are very common and indicate decreased circulation of oxygen. These patterns are not uncomfortable for your loved one. Slightly elevating the head or perhaps turning the person on his/her side may be helpful.

Congestion: Your loved one may develop a "gurgling" sound from his/her chest. The sound may become very loud and may be distressing for you to hear. Although the sounds are disturbing, this congestion may not cause the patient any distress. This change is due to the patient's inability to cough or swallow normal secretions. Gently turn the person's head to one side or raise the head of the bed. On occasion, turning the person on their side may help. Some people call this gurgling sound the "death rattle." It does not indicate the onset of pain, pneumonia or distress of any kind.
If you or your loved one find this distressing, please notify your nurse.

Vital Signs: When your nurse visits, she/he will always take your loved one's blood pressure, pulse, and respiration. Blood pressure can tell us if the heart is working efficiently. A lower than normal blood pressure indicates the heart may be failing. If it continues to drop, it is an indication that death is nearing. The pulse can tell us if the heart is beating normally or is weaker. The heart beats more rapidly when it is weak because it cannot move enough blood through the body. Respiration can tell us if the lungs are working well. Breathing rapidly tells us that the lungs are not working effectively. When a person is declining, changes in these readings will occur. The blood pressure may be lower, the breathing rate may be much higher or much lower, and the pulse may be rapid or slow, weak or absent in the wrists or feet. We do not routinely take a person's temperature but will do so if you request it. The patient's temperature may go up, but drenching sweats can occur even without an elevation in temperature.

How will I know when death has occurred?

Although you may be prepared for the dying process, you may not be prepared for the actual moment of death. It may be helpful for you and your family to think about and discuss what you would do if you were the one present at the moment of death.

The signs of death include not breathing, no heartbeat, no response from the person, and enlarged pupils of the eyes. At this time you may experience many emotions. When you feel you are able, please call Halifax Health - Hospice and then stay off the phone until the nurse returns your call. Halifax Health - Hospice will send a team member to your home.

She/he will help you notify family if you wish. When you are ready, they will call the doctor, the funeral home and make arrangements for medical equipment to be removed from your home. Your loved one's body does not have to be removed until you are ready. If you would like to prepare the body by bathing and or dressing, a nurse will help you.

You do not have to dial 911 or call the police in the State of Florida because Halifax Health - Hospice is providing services.

Your Halifax Health - Hospice staff member will remain with you until the funeral home staff come to take your loved one to the funeral home. At that time, the funeral home will set a time with you to make further arrangements.

Halifax Health - Hospice staff will assist you to destroy medications that are no longer needed.

The equipment company may call to arrange a time to pick up the equipment.

If your loved one lives in a nursing home or assisted living facility, the nursing home will notify Halifax Health - Hospice. Halifax Health - Hospice will notify you. If you would like to go to the nursing home to see your loved one, let the Halifax Health - Hospice nurse know. The nursing home staff will clean and prepare the body.

We at Halifax Health - Hospice would like to be present to provide information and support when your loved one dies. However, if you feel this is a private time and would prefer that we do not visit, please let us know.

GRIEF

Grieving usually begins soon after the diagnosis of a life-limiting illness. The person who is ill, their friends, family and significant others grieve for the changes that are taking place within the body, for the loss of ability to do the things they once enjoyed and for the shortened time they have with one another.

Grief is natural. It is our human response to change or loss. It is painful. Everyone experiences grief in their own unique way. There is no right or wrong way to grieve just as there is no specific length of time after which you should "get on with life." The pain of grief moves through the body, mind and soul differently for each person.

Some of the thoughts people have are:

"Why me, why now?"

"Where is God?"

"It can't be true."

"I don't want to talk to anyone."

"Why can't things just be the way they were?"

"My heart hurts."

"I can't think."

"If the doctors and nurses had just done their job!"

"I can't cry." or "I can't stop crying."

"Why can't I say what I feel?"

"I can't believe this is happening."

"I'm so empty, so numb."

"Is God punishing me?"

"Where did I go wrong?"

"I don't know what to do."

"Someone should be able to fix this."

"When will the pain go away?"

"I hate what this is doing to me."

"What do I feel?"

"I'm so tired."

"I keep getting a cold."

"I don't know what to do with myself."

"If only I had or if only I hadn't."

"I feel so lost, I can't stop thinking about him/her."

Sometimes you don't know why you feel empty, hurt or sad. **If at any time you feel terribly sad or feel that you cannot go on, call your** Halifax Health - Hospice **team immediately.** Sometimes it helps just to say the feeling out loud to yourself and know that you have these feelings, and it is not unusual. Talk with someone. Call your Halifax Health - Hospice social worker, chaplain or bereavement counselor and say, "Help me understand these feelings."

The emotions of grief are powerful and sometimes frightening. Talk and cry with someone. Crying helps move the feelings through the body. Tears are normal and precious.

Halifax Health - Hospice **can be a resource for you and your family after the death of a loved one. Bereavement services are available for individuals, families and in group sessions. There are also specialized groups for children.**

Children grieve differently than adults. Their grieving depends on their developmental stage and their capacity to understand death and its permanence. They may believe that they caused the person to die because they were angry once and might have said, "I wish you were dead." They move in and out of sadness and anger and may seem as if they are not affected by the death at all. Children require specialized assistance that includes spending time with other children who have had similar experiences.

Bereavement services include:

› Individual counseling

› Group counseling

› Family counseling

› Grief support groups (day and evening)

› Holiday-season support groups

› Education and information about grief

› Children's Grief Center

› Camp BeginAgain - a specialized camp environment for children that includes bereavement activities side-by-side with typical camping activities

HALIFAX HEALTH
HOSPICE

Licensed since 1979

Your Opinion Matters

It is an honor to be chosen as your hospice provider and to support both you and your loved one during this meaningful time in your lives. At Halifax Health Hospice, we are dedicated to delivering expert, compassionate care to you and your family. Our goal is to provide the highest quality of hospice services, tailored to your unique needs.

If you have any questions or concerns at any stage of the hospice journey, please don't hesitate to discuss them with any member of your healthcare team. Should you encounter any challenges or issues with our care, please let us know right away so we can address them promptly and ensure that we meet your needs.

We are deeply committed to excelling in the care we provide, and your feedback is invaluable in this process. At the end of our time together, we encourage you to complete a survey called the Consumer Assessment of Healthcare Providers and Systems (CAHPS), which helps us understand the quality of services provided. You will receive the survey either by standard mail or electronically.

We understand this may be a difficult time, but your input will help us improve and continue to provide exceptional care. Your feedback truly matters to us!

For more information about the survey, please visit the following websites:

- https://www.hospicecahpssurvey.org/
- https://www.cms.gov/medicare/quality/hospice/cahpsr-hospice-survey