Patient and Family Care Guides

Hospice Information Booklet



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Nursing services

Professional

Registered nurses at Centrica[™] Care Navigators are part of a highly qualified professional interdisciplinary team. They are experienced and knowledgeable about pain and symptom control and caring for the needs of the seriously ill. The nurses, under the direction of the attending physician, will evaluate your loved one's condition and answer questions on a regular basis. Your nurse will also keep your attending physician updated.

Adaptable

Our nursing services are flexible and adaptable. Your nurse will set up a schedule with you based on your needs and visit once a week, at a minimum. You can always increase or decrease the frequency of the visits or request an extra visit as needed.

Available 24 hours a day

Available Services

Caregiver Tips

Our nurses are available to assist you 24 hours a day, including weekends and holidays. They wear a pager at all times and are familiar with your medical history and medications. Our answering service will take your name, telephone number and message before paging the nurse. The nurse will respond to your call as promptly as possible. If you have not received a call back from the nurse within 20 minutes, please call the answering service again. If you need a visit from the nurse, be sure to ask.

If you reside at our hospice site, skilled nursing is available on-site 24 hours a day.

Hospice aides

Experienced

Our hospice aides are experienced employees who have completed our hospice training and clinical competency program, along with state CENA (Competency-Evaluated Nurse Aide) certification requirements. Their role is to help provide your loved one with personal care, under the supervision of the hospice nurse, and to provide light housekeeping as necessary and desired by you and your loved one. Light housekeeping tasks include:

- Wiping counter tops and sinks.
- Washing less than a sink-full of dishes.
- Assisting with starting or finishing a load of laundry.
- Light vacuuming of the patient's room.
- Helping to prepare a light meal.
- Empty trash from patient's room.
- Sweeping kitchen floor.

Adaptable

The hospice aide will come to your home to meet your needs. You can set up the schedule that is best for you with the aide and your hospice nurse. The days you are scheduled for a visit, the hospice aide will call in the morning or the afternoon before to schedule a time for the visit.

If you reside at our hospice site, hospice aides are on-site and available 24 hours a day.



Forms Social work support

The hospice social worker is available to provide emotional support to you and your loved ones and to help coordinate community resources as needed. Initially, the social worker will meet to get to know you, your goals and wishes while receiving hospice care. Together, you can establish a visit schedule that meets your needs.

You maintain control of what you want to share about yourself and your life. The journey you are on is a difficult one. Allowing someone to help may make that journey a little easier.

How can your social worker help?

- Support you in maintaining independence for as long as possible.
- Facilitate a family meeting if requested to allow you or your loved ones to discuss changes and needs.
- Identify additional options and provide information for caregiving when you and your family need extra support.
- Available Services

Caregiver Tips

- Provide information and facilitate discussions on the importance of advance directives to ensure your healthcare wishes are carried out.
- Offer space and opportunities for you to say what you want to family members and friends while there is still time.
- Talk with you about your wishes regarding funeral arrangements.
- Provide referrals and resources for drawing up wills, guardianships and other legal concerns.
- Obtain information and assist with applications for financial assistance and with basic needs, such as utilities, food, insurance and funeral costs.
- Acquire information about community resources, such as life alert buttons, private duty aides, transportation resources and Meals-on-Wheels.
- Support you and your family throughout your grief process, providing emotional support and a compassionate presence.
- Provide referrals to our music therapy and volunteer services.
- Follow up with your loved ones after death to provide support and referral to our grief support services.

There may be other areas and concerns you would like to discuss with your social worker. We want to provide you with the care and support you feel you and your family need most.

Chaplain services

Our chaplains support you and your family in your spiritual journey

- Honoring what gives your life meaning and purpose.
- Exploring the nurturing and/or healing of relationships.
- Facilitating connection to faith community.



Rose Arbor Place

Home away from home

At times during a serious illness, staying at home may not be the best choice. When complex conditions require constant care, Rose Arbor Place provides the comforts of home for patients and families – plus the expert management of symptoms by physicians, registered nurses, nurse practitioners, counselors and others, 24 hours a day.

Designed as "cottages," spacious private rooms serve as peaceful gathering places for family and loved ones, where medical care can be administered and dignity maintained. Each room is equipped to allow family members to stay overnight and participate in patient care. Other amenities include family gathering areas, whirlpool for patient skin care and visitor shower facilities.

Rose Arbor Place is located at 5473 Croyden Avenue, Kalamazoo, MI 49009

For details, call 269.345.0273 and ask for our brochure. Or visit CentricaCare.org to learn more.

Available Services

Grief support

We offer many types of grief support services:

We understand that individuals and families grieve in different ways. For many people, the grieving process may begin long before an actual death occurs. Our grief support groups are available to anyone in the community as well.

- **Individual grief support counseling** Professional grief counseling is offered to each household following the loss of a loved one. Appointments in our office are offered at periodic intervals for 13 months after death. These visits focus on how individuals are coping with loss and provide education and support as needed. In addition, volunteers are available for companionship, emotional support and practical assistance.
- Grief support groups and workshops We offer a variety of grief support groups and workshops tailored to specific age groups and shared circumstances, meeting on a regularly scheduled basis.
- Caregiver Tips
- **Communication** Periodic mailings are sent out during the 13 months following the death of a loved one. These mailings provide opportunities to reflect on life without your loved one and offer information on coping with loss and other grief issues.
- **Referrals** We refer families to community resources and programs as needed. Information also is available about other grief support groups in the community.

For details and meeting schedules, call 269.345.0273 and ask for our brochures. Or visit **CentricaCare.org** to learn more.



Forms Volunteer services

Volunteers are an essential part of our interdisciplinary team at Centrica Care Navigators. Each volunteer has cleared a background check and received in-depth training, as well as ongoing supervision and continuing education. Volunteers provide reports of all visits to the hospice team. They typically visit 2 to 4 times a month providing a comforting, supportive presence for you and your family.

Volunteer services include (but are not limited to):

- Respite visits so tired caregivers can take a break.
- Companionship.
- Writing letters, memoirs and Story Catcher (recording life stories/history).
- Sharing a good book, cards and other games, or a hobby.
- Running an errand for you.
- Available Services

Helping with light housekeeping, such as tidying a room, vacuuming, doing a load of laundry or washing up dishes after a meal.

• Pet therapy.

Your social worker will discuss areas in which a volunteer may be helpful. At any point during your care, you may ask your social worker for a volunteer. We will work with you to identify how best we can help based on the skills and availability of our volunteers.

While volunteers provide a wide variety of assistance, please be aware that volunteers are never allowed to administer medications or nursing care; to feed or bathe your loved one; or to assist with toileting; moving or lifting him or her. Your social worker will help you arrange for this help from another member of the interdisciplinary team. These limitations are in place to protect you, your loved one and the volunteer.

Tips for caregivers

Caregiver Tips

These guidelines on general care are designed to help you care more confidently for your loved one at home. If your loved one is at our hospice site, you can be as involved in his or her care as you would like to be. Please remember that each person's illness progresses differently, and your loved one may or may not experience the changes mentioned. The goal of this information is to prepare you for what might happen in the future and equip you to respond to your loved one's needs.

- Speak slowly and clearly.
- Reassure your loved one that he or she is not alone.
- Do not leave him or her alone for prolonged periods.
- Do not be afraid to touch your loved one. Your touch assures him or her that you care.
- Allow your loved one to sleep as much as he or she wants.
- Help plan rest periods to save energy for important things.

Home Safety

- Always lock the wheels on the bed or wheelchair before transferring your loved one to prevent injury.
- If your loved one is weak, provide assistance on his or her weakest side. Do not force assistance if it is not needed.



CAREGIVER TIPS CONT.

- When helping your loved one out of bed, have him or her sit on the edge of the bed for a minute to prevent dizziness.
 - Do not smoke around oxygen tanks or equipment.
 - If your loved one is using oxygen, register with your utility company as a priority electrical user.
 - Slips, trips and falls:
 - Ensure walkways are clear of any cords or clutter.
 - If you have area rugs, make sure you are using anti-slip pads or carpet tape to secure the rugs in place.
 - Place night lights in dimly lit areas to increase visibility.
 - Install a smoke and CO₂ alarm if you do not have one.
 - In case of an emergency, make sure you have:
 - o Flashlights
- Available Services
- o Battery-powered radio
- o Nonperishable foods and bottled water
- o Medications and medical items
- o A list of emergency numbers

Breathing

- If your loved one is having trouble breathing, raise the head of the bed or prop him or her up with pillows. Call your hospice nurse.
- Encourage your loved one to breathe slowly and calmly.
- Open a window or turn on a fan to promote air circulation.
- If oxygen has been ordered, make sure it is on and functioning. Make sure the tubing is not kinked, pinched or pulled apart.

Elimination

- As your loved one takes in fewer fluids, urine amounts also decrease. Urine may become darker and more concentrated.
- If your loved one is unable to control his or her bladder or is unable to urinate, a catheter may be placed for comfort. Consult with your hospice nurse.
- Many medications, including pain medications, may cause constipation.
- Your loved one should have a bowel movement every 2 to 3 days, even if he or she is not eating much.
- A good bowel program will decrease discomfort; ask your hospice nurse about it.
- Call your hospice nurse if there has been no bowel movement in 3 days or if your loved one is having 6 to 8 loose stools a day.
- Call your hospice nurse if you notice blood in the stool or urine.

Emotions

- Allow time to talk about feelings. Try to recognize that these feelings are real.
- Anger is common. Remember, it is usually not directed at you personally.
- Frustration is also common and may lead to anger and irritability. Acknowledge these feelings.
- A low lamp or night light may help decrease fear and anxiety at night.



- Your loved one is losing control over many aspects of his or her life and may try to regain control in other ways. Though the issues may seem insignificant to others, this control is very important. Allow control over issues that will not harm your loved one or others.
 - Your hospice social worker is there to discuss these issues with you and to offer suggestions.

Mental changes

- Confusion or changes in personality may occur as your loved one's disease progresses or as a side effect of medications. Inform your hospice nurse of any changes that you see.
- Attempt to orient your loved one by using calendars, pictures, etc. Keep him or her involved in day-to-day activities.
- If your loved one becomes frightened, let him or her know that you are there and that you care.
- If your loved one doesn't always seem to know who you are, remember that this is not meant to hurt your feelings; it is probably very frustrating for him or her as well.
- Your loved one may have near-death experiences that appear to be hallucinations.
- Available Services

Caregiver Tips

- Let your loved one know that you believe him or her. You do not want him or her to stop sharing or to feel isolated.
- If your loved one becomes comatose (unconscious), do not assume that he or she cannot hear you. Continue to comfort and talk to your loved one.

Nausea and vomiting

- Offer clear liquids.
- Dry toast, soda crackers or ice chips may help decrease nausea.
- Do not force foods or fluids. This can increase discomfort.
- Remove offensive odors, sights and sounds. A quiet, calm environment is relaxing and helpful.
- When food is desired, offer a bland diet. Avoid spicy, sweet, greasy and fatty foods.
- Offer small portions. Encourage your loved one to eat slowly.
- Try to avoid favorite foods when nauseated. They may become associated with the nauseated feeling and may not be tolerated when the nausea is gone.
- If anti-nausea medications are ordered, try them. It may help to give them regularly around the clock, or 1/2 to 1 hour before meals, to control nausea.
- Contact your hospice nurse if nausea and vomiting become a problem.

Nutrition

- Allow your loved one to eat as much or as little as he or she wants. Forcing food or fluids increases discomfort.
- Offer crushed ice and liquids often. Sips of water or ice chips can keep your loved one comfortable.
- Offer liquids that have some consistency, such as milkshakes, applesauce and soups. These are easier to swallow.
- Offer liquids with meals to moisten food and help with swallowing.
- Try soft, easy-to-eat foods.
- Offer high-calorie supplements.
- Add dry milk powder to casseroles, mashed potatoes, macaroni and cheese, etc. to increase calories and protein. Do not offer milk if your loved one has respiratory problems this can cause extra mucus.



 Offer tart items, such as lemon drops. If pain is a problem, try giving pain medications before meals. Ask your hospice nurse for additional suggestions. Do not force your loved one to eat. It is important to remember that food does not cure a disease. You have not failed if he or she will not eat. Your loved one is not dying from not eating. Not eating is part of the dying process Pain Don't assume that your loved one has no pain or that it is not as severe as he or she says. Pain is whatever a person perceives it to be. Everyone's tolerance for pain is different. Taking pain medications on a regular, around-the-clock schedule can control pain better. If a pain medication is taken before pain is intolerable, it will give better relief with a smaller dose and have fewer side effects. If your loved one is taking only enough medication to control pain, he or she will not become addicted. Poin can be affected by anxiety, stress, frustration, fear, fatigue and depression. Avoid giving your loved one alcohol as it increases the sedative effects of some medications. Repositioning frequently can add to comfort. Do no tgive over-the-counter medications without checking with your doctor or hospice nurse. Try alternative methods of pain control, such as relaxation, imagery or distraction. Always explain what you are going to do before you do it. Gloves should be worn when direct contact with bodily fluids is anticipated. Wash hands before putting gloves on and after removing them. Offer mouth care every 2 to 3 hours, especially if your loved one is not eating: Brush teeth with a soft toothbrush, rinse with water. Avoid	Forms	 If your loved one can't swallow, do not force foods or fluids.
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 Neep skin clean and ary. 		 Skin care Keep skin clean and dry.
 Add moisturizing soap to bath water to help relieve dry skin or request special liquid soap from hospice. 		• Add moisturizing soap to bath water to help relieve dry skin or request special liquid soap
 Use lotion to help prevent cracking and sores and to keep skin soft. 		
 Turn your loved one frequently to change pressure points, turning about every two hours. Even small changes in position can relieve pressure areas. 		• Turn your loved one frequently to change pressure points, turning about every two hours.

CENTRICA

CAREGIVER TIPS CONT.

- Use a draw sheet to help with turning. Ask your hospice nurse or hospice aide to show you how to do this.
 - Keep sheets clean and as wrinkle-free as possible.
 - Avoid heating pads or electric blankets as these can easily cause burns.
 - Use a foam egg crate mattress or air mattress on the bed to help reduce areas of pressure.
 - Avoid leaving soaked clothing or bed linen in contact with skin.
 - Avoid leaving your loved one in urine or stool. Waterproof, disposable pads are available to protect bed linens and make cleaning up easier. Discard soiled items properly.
 - Always wash your hands well before and after changing dressings to help prevent infection.

Let your hospice nurse know about open sores. The nurse or hospice aide can teach you to care for these.

Available Services

Facing the food issue

A dilemma for patients and families

As an illness progresses, your loved one may have more difficulty eating and drinking. When this happens, some families may want their loved one to go on IV fluids and feeding tubes. This may seem like a logical choice; however, at the later stages of an illness, food and water can cause more discomfort.

Discomfort that may be caused by eating:

- Diarrhea
- Nausea
- Vomiting
- Constipation or impaction

Discomfort that may be caused by drinking:

Caregiver Tips

- Congestion
- Confusion

Coughing

• Shortness Of Breath

- Nausea
- Vomiting
- Urinary retention
- Edema (swelling)

Providing your loved one with the choice to eat or drink during this time can help decrease any emotional and/or physical discomfort. The family can provide their loved one with ice chips and, if necessary, can administer mouth care as frequently as every two hours. It is important to respect nonverbal signs that your loved one does not wish for food or fluids. These nonverbal signs may include coughing, pursed lips, clenched jaw or turning the head away. With the exception of mouth care, fluids or food should never be given to an unresponsive person.

What you may see as death approaches

Many families have not experienced first-hand the natural stages a person may go through during the final weeks and days of life. Your loved one may experience some or all of these symptoms in the weeks and days before death.

- Decreased desire for food and drink
- Sleeping more
- Loss of control of bladder and bowels
- Increased confusion
- Congestion, especially in the back of the throat
- Available Services
- Restless mind/body
 - Body becoming cooler

• Changes in breathing

• No response to communication

For more details on what to expect during the final weeks and days of life – and what you can do to help make your loved one more comfortable – call 269.345.0273 and ask for our brochure titled, "When Death is Near."

How to obtain medications

It is important that you tell your nurse about all medications your loved one is currently taking. Centrica Care Navigators provides all medications related to your hospice diagnosis. Your nurse will monitor medications and place orders as needed and they will be delivered to your home. Some medications your loved one may need will not be related to his or her hospice diagnosis and will require prior authorization before your pharmacy can refill them. We will complete and submit the prior authorizations for you. If you need a medication immediately, please notify your hospice nurse.

Caregiver Tips

Controlled substances

Symptoms can quickly change in hospice patients due to breathing difficulties, pain, nausea or anxiety. Opioid drugs can play a key role in reducing suffering for those at the end of life.

Today, there is an increased focus on opioid use. Michigan lawmakers require that all drug prescribers, including those working in hospice, talk with patients about opioid risks and complete an "Opioid Start Talking Form" before prescribing controlled substance drugs. Opioids are commonly used by hospice patients. Your hospice nurse will answer any questions you may have, including worries about opioid addiction or how these medications should be properly disposed of when no longer needed.

There are risks with any drug you take. Controlled substance drugs are safe when used as directed and often are the best choice for comfort care.





Caregiver Tips

Cardiopulmonary resuscitation

Cardiopulmonary resuscitation (CPR) starts when a person stops breathing and/or the heart stops. It may include mouth-to-mouth breathing, chest compressions, defibrillation (shocking the heart), putting a tube in the airway and injecting medicine. Paramedics or Emergency Medical Technicians usually perform CPR and must begin within minutes after breathing/heart function has stopped. If CPR starts after a delay of 4 minutes, the risk of permanent brain injuries increases.

Centrica Care Navigators does not recommend the decision for CPR with seriously ill people who are at the end of their life because:

- CPR has a very low success rate.
- CPR can be painful and can increase suffering.
- CPR can be traumatic for family and loved ones to watch.
- CPR is not comfort care it takes away the possibility of a natural death.

The goals of hospice care are to help the individual be in control of his or her care, be free of pain and suffering, and experience well-being in familiar surroundings during the last stage of life. If you agree to allow a natural death, when that time comes, all your caregiver needs to do is call hospice and a nurse will respond. No other medical intervention will be initiated.



Forms 🖁

If you do want CPR

We understand that talking about CPR may be difficult and that some hospice patients may want to try CPR, even though success would be very rare. If you choose to have CPR, we will honor and respect your decision. At the first sign of breathing and heart function stopping, the caregiver should call 911. An ambulance with emergency staff will respond to the call. Please call hospice as soon as possible to notify your nurse of this change in condition.

Home emergency preparedness

The following precautions are recommended by Centrica Care Navigators to follow when emergency conditions require action. They are not all-inclusive and are presented here as guidelines. You may find that other precautions/actions become necessary during an actual emergency.

In case of fire

Available Services

Caregiver Tips

Make sure everyone understands the escape routes and knows about a meeting place.
 Explain that if they have to escape a fire, they will need to use certain techniques to be safe.

- Respond promptly. In a fire, seconds count.
- Take nothing. Do not pause to get dressed or take valuables. There isn't time.
- Crawl under smoke. In a fire, there may be superheated air near the ceiling, a thick layer of deadly smoke in the upper part of the room or hallway, and possibly heavy toxic gases near the floor. To survive, you should crawl under the smoke, keeping your head in a safety zone about 12 to 36 inches off the floor.
- A closed door can stop the spread of gas, heat and smoke feel doors before opening.
 Before opening any door, feel it with the back of your hand. If you feel heat, do not open the door. Use another way out.
- Know two ways out of each room. If your first way is blocked by smoke or fire, use your second way out.
- Don't use elevators. If you live in an apartment building, don't use the elevator in a fire. It may take you to the fire floor.
- Go immediately to your meeting place. This is the best way to make sure everybody is out.
 Do not go back inside for any reason. Call 911 if a family member is trapped; a trained fire fighter with protective clothing has the best chance of rescuing them.
- o After evacuation, call Centrica Care Navigators.

Floods

Precautions before the flood

- 1. When a flood alert or warning is issued, store drinking water.
- 2. Turn off all unnecessary electrical appliances.
- 3. Do not touch any electrical appliance unless it is dry.
- 4. Open basement windows to equalize water pressure on the walls and foundation.
- 5. Move patient to upper floor or to other designated areas.
- 6. Move all essential equipment and supplies to safe areas.

After the flood

- 1. Do not use any open flame devices until the home has been inspected for possible gas leaks.
- 2. Watch for and avoid live electrical wires.



Forms 3. Do not turn on any electrical appliance until it has been inspected.

4. Do not use any food supplies that have come in contact with floodwaters.

Flash floods

- 1. Remember: Flash floods can happen without warning.
- 2. Gather supplies in case you have to leave immediately.
- 3. When a flash flood warning is issued, take immediate action.
- 4. Protect your loved one, as well as yourself, to the best of your ability.
- 5. Contact Centrica Care Navigators with evacuation plan or need.

Tornado

- 1. Go to a safe room, basement or storm cellar. If there is no basement, get to a small, interior room on the lowest level.
- 2. Stay away from windows, doors and outside walls.
- 3. Take additional cover by shielding your head and neck with your arms and putting materials such as furniture and blankets around you.

Winter storm

- 1. Have extra food and medical supplies, including medications, on hand during a winter storm warning.
- 2. Stay off the roads.
- 3. Stay indoors and dress warmly. Wear several layers of loose, lightweight warm clothing.
- 4. Prepare for power outages. If you experience a power outage, refer to the power outage section (page 26) on what to do. If without power for a prolonged period of time, the following can occur:
 - **Frostbite** causes loss of feeling and color around the face, fingers and toes. Signs include numbness, white or grayish-yellow skin, and firm or waxy skin.
 - Hypothermia is an unusually low body temperature. A temperature below 95 degrees is an emergency. Signs include shivering, exhaustion, confusion, fumbling hands, memory loss, slurred speech and drowsiness.
- 5. If you are experiencing any signs of frostbite or hypothermia, contact Centrica Care Navigators.

Power outage

- 1. Keep freezers and refrigerators closed.
- 2. Only use generators outdoors and away from windows.
- 3. Do not use a gas stove to heat your home.
- 4. Disconnect appliances and electronics to avoid damage from electrical surges.
- 5. Contact Centrica Care Navigators if you are out of power for a prolonged amount of time. Call Centrica Care Navigators for immediate oxygen needs.
- 6. If safe, go to an alternate location for heat or cooling. Then contact Centrica Care Navigators.

Extreme heat

- 1. Try to keep your home cool by covering windows with drapes or shades.
- 2. Wear loose, lightweight, light-colored clothing.
- 3. Drink plenty of fluids to stay hydrated.



Available Services

Caregiver Tips

- Forms 4. Signs of heat cramps include muscle pains or spasms in the stomach, arms or legs.
 - 5. Signs of heat exhaustion include heavy sweating, paleness, muscle cramps, tiredness, weakness, dizziness, headache, nausea or vomiting, and fainting.
 - 6. Signs of heat stroke include extremely high body temperature (above 103 degrees) indicated by an oral thermometer; red, hot and dry skin with no sweat; rapid, strong pulse; dizziness; confusion; and unconsciousness.
 - 7. If you are experiencing any signs of heat cramps, exhaustion or stroke, contact Centrica Care Navigators.

Thunderstorm, lightning or hail

- 1. When thunder roars, go indoors.
- 2. Move from outdoors into a building or car.
- 3. Pay attention to alerts and warnings.
- 4. Unplug appliances.
- 5. Avoid running water or using landline phones; electricity can travel through plumbing and phone lines.
- 6. Secure loose outdoor items (chairs, umbrella and miscellaneous yard tools).

Community resources

You may have physical problems brought on by an emotional reaction. The physical problems are real; take steps to remedy them. Contact your physician if needed. Our social workers are also available to help. In addition, you are encouraged to call 2-1-1, a free program connecting you with service providers in your area. A variety of community resources may be available to help you with additional support services, including:

- Healthcare
- Medical equipment

Emergency services

- Home-delivered meals
- Transportation
- Financial and legal services

Caregiver Tips

Available Services

• Emergency alert systems

For a list of resources available in your area and their phone numbers, visit **CentricaCare.org**.

