Rainbow
Hospice Care

Phone: 920-674-6255
www.RainbowCommunityCare.org

Rainbow
Community Care
At your side with compassion,
commitment and comfort

Rainbow Hospice Care is a program of Rainbow Community Care, an organization dedicated to improving the overall health of the communities we serve in rural southern Wisconsin.

Rainbow Hospice Care

Rainbow Hospice Care, Inc. (RHC) is committed to providing exceptional and compassionate care and services. Prompt response to your needs is important to us.

- **Phone: 920-674-6255**
- **Toll-free: 888-493-8276**
- **Fax: 920-674-5288**
- **Alternate Phone: 877-499-5750**

Use the numbers listed above to ensure you receive a timely response. Staff cell phones and voice mail are not monitored after hours or on days off. You may not receive a response when calling staff cell phones directly. Please note that staff phone numbers may display as out of state or restricted numbers on caller ID.

If you find that you are unable to reach Rainbow Hospice using the numbers above, you can contact us on our emergency line at 877-499-5750 anytime.

Your primary care team will strive to manage and anticipate your needs during their routine visits to make your care experience the best possible. You can reach us at the number above anytime.

What you can expect from Rainbow

1. Contacting your team:
   You can call us anytime you have questions. If you have a specific question for your team, it is best to contact them during their normal working hours 8am – 4:30 pm. Your team members may not always be working, but there are always staff members available to assist you. A nurse is available 24/7, if you have questions or need a visit.

2. Timely Visits:
   Your hospice team will coordinate routine visits that are mutually beneficial for you and the team member's schedule, as much as possible. Team members will try to accommodate special time requests when feasible. Specific requests may require numerous staff members to meet your

request consistently. Early morning or late evening visits may not always be possible.

3. Anticipating Your Needs:

   We want you to have the help you need, when you need it, even when we are not there. We prepare patients and caregivers through education and by making tools available in the home (medications, supplies, equipment) in anticipation of needs. Education is provided on what to expect, how to provide care, and how to use medication, equipment, and supplies. By having these tools available in the home ahead of time, you have the help you need when symptoms arise. For example, comfort medication or oxygen can be available in the home, in anticipation of urgent symptom management situations. The nurse can then instruct you, over the phone, to use one or more of these to help relieve the symptoms quickly.

4. Contacting Rainbow during Evenings, Weekends, Holidays and in an Emergency:

   Our staff share the responsibility of answering our phones during evenings, weekends, holidays, and emergencies. We are available 24/7.

   It can be stressful working with unfamiliar staff. Rest assured, your primary care team will carefully document your care needs and goals in your electronic medical record. Other care staff can easily access your plan of care to ensure your care needs are met even when your primary care team is not available.

   We have staff dedicated to answering your calls around the clock. When you call you may be asked a series of questions including: your name, the patient’s name, and your call back number. If you need to speak with a nurse, you will either be connected directly to the nurse or the nurse will call you back. Our goal is to return all calls within 15 minutes. If you don’t hear from us within 15 minutes, please call again. Rainbow Hospice has staff available to respond to your calls as promptly as possible.

5. Timely Arrival:

   Nurses will make visits anytime there is a need. Visits will be made as soon as possible, usually within 1 hour for urgent needs and the same day for non-urgent needs. If a visit is needed, the nurse will ask you a variety of questions to best determine how to triage your needs with the needs of other patients. A Nurse can provide phone support, as needed, while waiting for the visit nurse to arrive.
   Staff will keep you informed of arrival time and any delays, if applicable.
   Emergencies:

During emergency situations, such as severe weather or disasters, we will contact you as soon as feasible to inform you of necessary changes in communication or visits plans.

6. Preparing you for when we are not there:

   Your team will strive to keep you prepared for what to expect/need along the way. We want you to have all the medication, supplies and equipment you need to feel confident and prepared until our next visit. Our staff works hard to make sure you don't run out of medication or supplies before our next visit. Staff members will check your medication and supplies with routine visits.

7. Documentation and Plan of Care with Visits and Calls

   RHC staff documents visits and call information in your electronic medical record to provide your individualized care. A Plan of Care is specific to each patient. Your Plan of Care is accessed securely using smart phones, tablets and laptops. Staff access your Plan of Care and document securely using these devices.

8. Calling at the time of death

   Your care team will help you prepare for your loved one's death and instruct you on what to do if you suspect your loved one has passed away. When a loved one passes, you can take any time you need to say your goodbyes. Call Rainbow Hospice Care when you suspect your loved one has passed away. The nurse will discuss your preferences regarding visit time. When you are ready, the nurse will make a visit and guide you through the next steps.

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Caregiver Training

Rainbow
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Personal Care

Personal care is the management of hygiene, including bathing, shampooing, and shaving, dressing and brushing teeth.

Caregivers provide support to someone who needs help. It doesn't matter how many hours per week are spent providing support. Caring for a family member or friend is not easy, nor is it something most of us are prepared to do. Learning about being a caregiver may help you provide the care your friend or loved one needs.

Caregiving often comes with new responsibilities and unfamiliar tasks. To learn more about caregiving, the decisions you may need to make, enhancing your loved one's quality of life and where you can go for help and support, talk with your hospice team.

In this section, you will find detailed information about providing care. You will find additional information throughout this handbook, including instructions for safely moving the patient.

Rainbow Hospice Care provides caregiving videos on important topics.

Visit our website at http://www.rainbowcommunitycare.org to watch the videos.

Bathing

Most patients, especially bed bound patients, find a bath refreshing and comforting. A bath can be given any time of the day or night, depending on patient preference and/or a time convenient for the patient and caregiver. Rainbow Hospice Care provides some supplies for bathing such as a bath basin. Everyday bathing and personal care items are not supplied by hospice (shampoo, body wash, wet wipes, powder, lotion, and deodorant).

A few things you will need:

Basin of warm water, soap, wash cloth, towels and a light blanket to prevent chills.

Suggestions:

- Give the patient pain medication about one hour before their bath if movement causes pain.
- Close the doors and drapes to provide privacy and to prevent chilly drafts.
- If the patient is in a hospital bed, raise it to prevent back strain from bending.
- To avoid chills, cover the patient with a light blanket and only expose a small area at a time.
- If a complete bath is too tiring for the patient, try to wash the face, hands, back, underarms and private parts daily.
- Ask the patient if you are applying too much or too little pressure with washing.
- Make sure to dry between all skin folds to prevent breakdown.

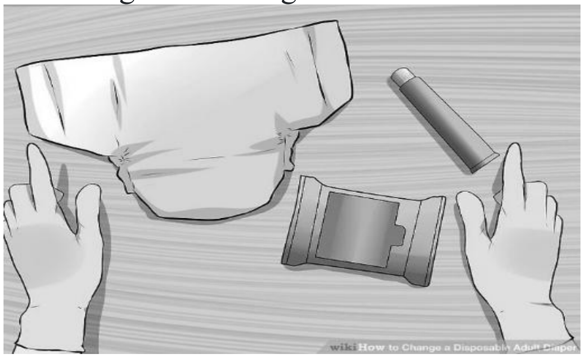
Begin bathing with the patient's face and work down toward the feet. The buttocks and private parts should be bathed last. Wash between the patient's legs from the front to the back. Rinse well and dry gently with a towel. A skin barrier cream such as Desitin or A&D ointment may be used if bowel or urine control is a problem.

A lotion backrub can be given after bathing to promote comfort and to support skin health

Step by Step directions for giving a bed bath.

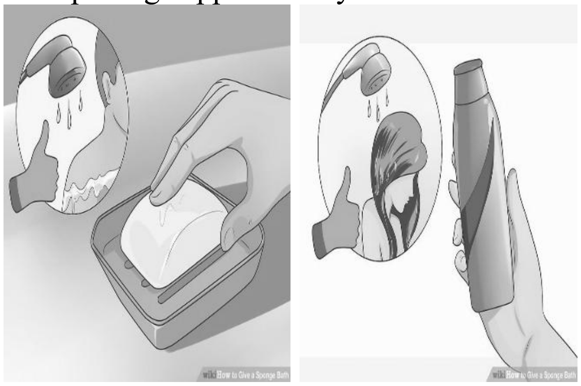
1. Wash your hands. Put on disposable gloves.

2. Collect your supplies.
   - Two basins with warm water
   - Wash clothes / Towels
   - Disposable gloves
   - Soap / Shampoo
   - Bag for soiled clothing / bedding
   - Change of clothing

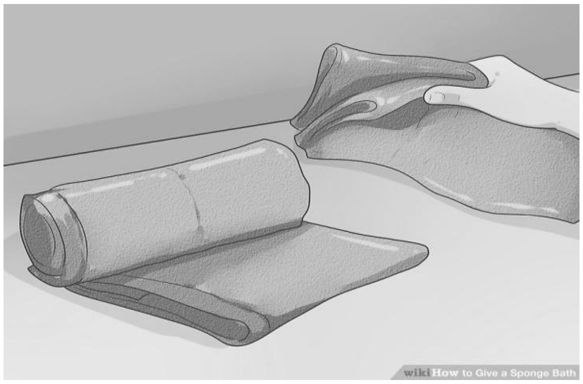


3. Fill two basins or washtubs with warm water. One is used for washing, and the other for rinsing. Make sure the water is comfortable to the touch, but not too hot.

4. Choose a soap that's easy to rinse away. Get shampooing supplies ready.



5. Have a stack of clean towels and washcloths ready. At minimum, you'll need three large towels and two washcloths.



6. Place two towels under the patient. This will prevent the bed from getting wet and keep the patient comfortable during the process.

7. Cover the patient with a clean sheet or towel. This will ensure the patient stays warm during the bath as well as provide some privacy.


wikiHow to Give a Sponge Bath

8. Remove the patient's clothes.


wikiHow to Give a Sponge Bath

9. First, apply soap or soapy water to the patient's skin. Scrub it gently with a washcloth to remove dirt and bacteria, then place the washcloth in the soapy basin. Dip a second washcloth into the rinsing basin and use it to rinse away the soap. Pat the area dry with a towel.


wikiHow to Give a Sponge Bath

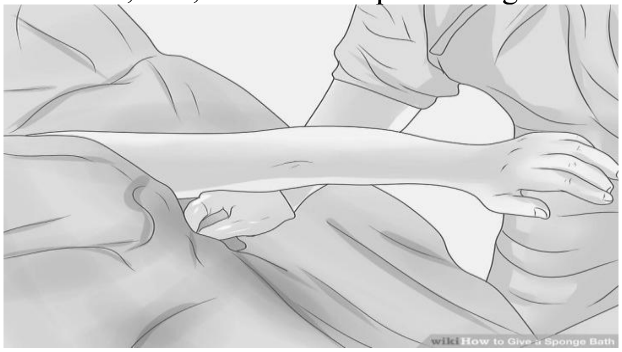
10. Start with the patient's face. Gently wash the patient's face, ears, and neck.


wikiHow to Give a Sponge Bath

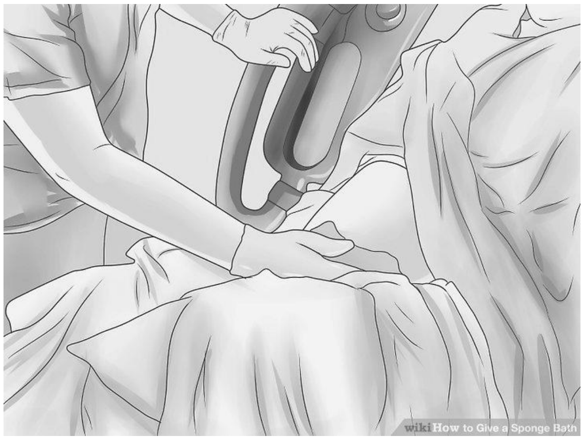
11. Wash the patient's hair. Gently lift their head into the shampooing basin. Wet the hair by pouring water over the patient's head, taking care not to get it in their eyes. Apply shampoo, then rinse it away. Pat the hair dry with a towel.


wikiHow to Give a Sponge Bath

12. Wash the patient's left arm and shoulder. Fold over the sheet on the left side of the body down to the hip. Place a towel beneath the exposed arm. Wash and rinse the patient's shoulder, underarm, arm, and hand. Repeat for right side.

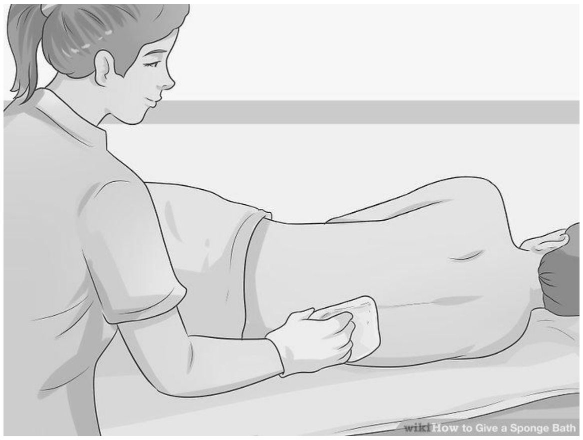

wikiHow to Give a Sponge Bath

13. Wash the patient's torso. Fold the sheet down to the waist and gently wash and rinse the chest, stomach, and sides. Be sure to wash carefully among any folds in the patient's skin since bacteria tends to get trapped there. Dry the torso carefully, especially among the folds.


wikiHow to Give a Sponge Bath

14. Wash the patient's legs. Next wash one leg and then the other. Then wash the feet and toes.

15. Pour the water out of the basin and re-fill with warm, fresh water. Help your loved one roll onto their side so you can wash their backside. Using a new washcloth, clean the genital area.


wikiHow to Give a Sponge Bath

16. Apply body lotion to protect your loved one’s skin. Don’t put the lotion in an area that can become damp like where the skin folds.

17. Help your loved one redress, then put away your supplies and wash your hands.

Skin Care

It is important to provide routine skin care to keep the skin in good condition. Even with frequent skin care, patients can develop skin breakdown or sores. Pressure sores (also called bedsores) can occur with patients at the end of life. There are many factors that contribute to this skin condition. Patients who have limited mobility or who are confined to bed are at a higher risk for skin breakdown.

What you can do to prevent skin breakdown:

- Assist or encourage the patient to reposition frequently. Every two hours is a good rule of thumb. Patients may have discomfort with repositioning. Medication or other interventions may help to reduce discomfort. Even small changes in position can be helpful, such as elevating the legs or reclining.

- When in bed, repositioning a patient every couple of hours helps to keep the skin in good condition.

- Patients are positioned in bed on right or left side and back rotating through the different positions every couple of hours. Use pillows to support the patient in a side-lying position. Use pillows under knees and calves to raise heels off of the bed when lying on back.

- Provide pain medication as needed so that movement is easier.

- Keep the skin clean and dry.

- Keep the bed linens dry and wrinkle free.

- Skin over boney areas such as the heels, ankles, bottom, and hips is the most prone to skin breakdown. Avoid these areas when applying lotion and do not apply any degree of massage to these areas.

- Apply lotion around areas of pressure once or twice a day.

- Even with the best care, skin breakdown may occur. Let your nurse know if you see any new skin concerns. Your nurse will suggest ways to protect and treat skin conditions.

Mouth Care

Things You Need:

- Soft toothbrush or mouth swab.
- Toothpaste.
- Cool water.
- Small bowl or basin.
- Mouth wash (non-alcohol).
- Dry cloth.

Things to Remember:

- Don’t put toothbrush near the back of the mouth as this can cause gagging.
- If person is lying flat, use the mouth swabs rather than a toothbrush and liquids to prevent the feeling of choking/gagging.
- If mouth sores develop, ask your nurse for advice and help.

How to do Mouth Care:

If the patient is able to do this independently, this is preferable.

If assistance is needed, raise the head and trunk to a half-sitting position to prevent feelings of choking and place a towel under the chin. Give a sip of water to moisten the mouth. Brush teeth and gums gently with toothpaste, trying to remove all food. The patient can then spit into the bowl or basin and rinse with cool water, followed by a mouthwash rinse. Try to do this at least twice daily. If the patient has dentures, continue to follow cleaning routines. After eating, remove and clean dentures. Gently clean the patient’s mouth as mentioned above.

If the patient has difficulty swallowing, use a mouth swab. Moisten the swab and wring out most of the moisture. Swab around the mouth including between cheek and upper and lower gum, under tongue, roof of mouth and tongue surface. As a patient loses weight, dentures may no longer fit properly and continued use can result in mouth sores. If refitting by a dentist is not possible, the dentures should be left out. Mouth swabs are usually the preferred method of cleansing the mouth near the end of life. They are an effective and gentle way of providing oral cares without causing discomfort.

Care of Lips:

After completing mouth care, apply a moisturizer such as lip balm or Vaseline to the lips and corners of the mouth to prevent cracking. Reapply the moisturizer throughout the day as needed.

As the end of life nears, a dry mouth is quite common. Offer gentle oral cares.

Changing a Depend in Bed

Patients need assistance with incontinence care and proving personal cares to prevent infection and skin breakdown. It is important to protect their privacy and maintain dignity during this vulnerable time. Follow the steps in this section to assist the patient with turning in bed. Refer to the skin care page for additional information on how to keep the skin in good condition.

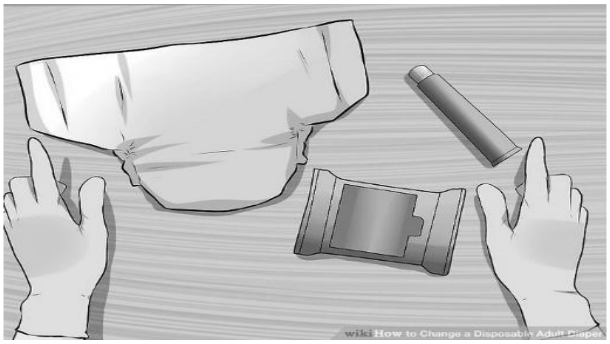
- Make sure you close curtains, draw blinds, and close the door. Turning off the ceiling fan and directing the air flow away from the patient will be appreciated. After the patient is situated comfortably, wash your hands.
- Collect everything you need including a clean depend, disposable wipes or damp wash cloths, a towel or sheet to place under them, disposable gloves, a trash bag, a bag for soiled clothing, and a change of clothing, if needed.
- Wash your hands, dry them and put on disposable gloves.
- Inform the patient about what you are going to do so they can assist if able. This prepares the patient, so they are not startled by the movement.
- If the bed is adjustable, adjust the bed to just below the waist to make the task easier for the caregiver.
- Put the head of the bed down as far as tolerated by the patient.
- If the patient has adjustable side rails, put the bed rails down.
- Assist the patient in removal of the garments. If they are soiled, place them in the extra bag you brought with you.
- Unfasten the depend and fold it back on itself, containing the excrement inside.
- Take the wipes and begin providing personal cares, wiping from the front to the back to prevent infection. Continue cleaning by folding the wipe and using a clean area each time.
- If the person you are assisting can roll over, remove the soiled depend from underneath their hips, place it into the garbage bag, and help them turn onto their side so you can continue cleaning. Help them turn onto their opposite side, making sure they are clean. Pay attention to the area between the legs, and creases of skin where their legs meet their bottom.
- Remove your gloves and dispose of them, wash your hands, and put on a new pair. Before you replace the depend, inspect the skin for any redness.
- Place a clean depend underneath their hip and help them roll onto their back. Making sure the depend is properly placed.
- Once the skin is dry apply barrier cream or powder to any areas of skin breakdown, as instructed by your nurse.
- Help the patient roll onto their back and fasten the depend in front, making sure that it is not too tight or pinching in the groin area.
- Assist the patient with getting redressed, in new clothing if needed.

- When they are fully dressed, dispose of the trash and wash your hands.

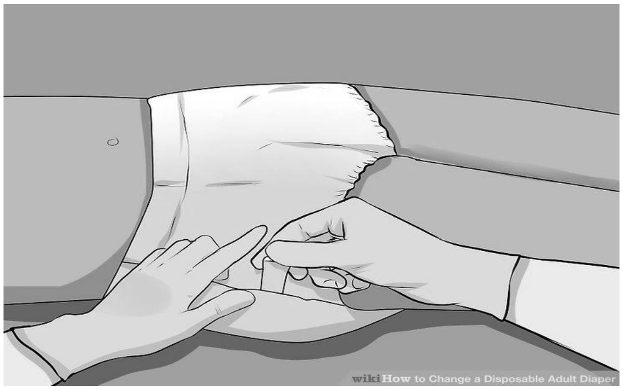
Follow the demonstration below for additional education:

1. Wash your hands.
   Put on disposable gloves.

2. Collect your supplies.
   - Clean depend
   - Disposable wipes or damp wash clothes
   - Chux
   - Disposable gloves
   - Trash bag
   - Bag for soiled clothing
   - Change of clothing

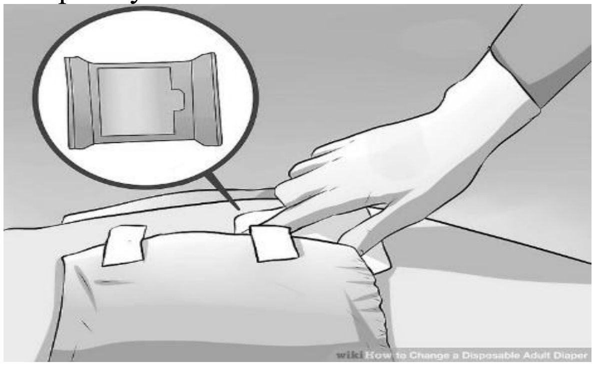


3. Undo the tape sides. Open the sides of the depend. Roll the person gently towards you. Fold the side on the opposite side of the person as far under the person as it will go. Wipe up the front of the person with a wipe moving from front to back.

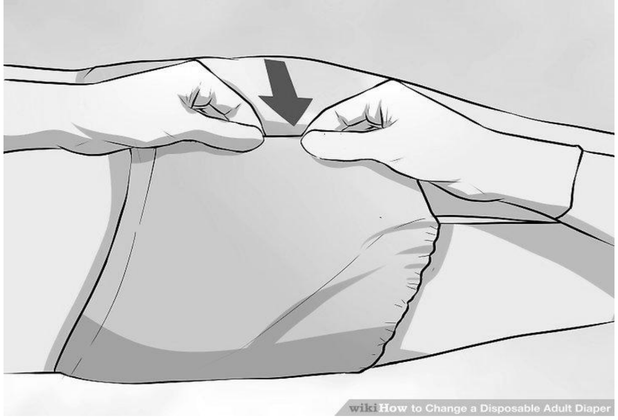


4. Roll the person over. Gently roll the person onto the side. Then, place the towel or chuck under the person's backside to protect the sheets.

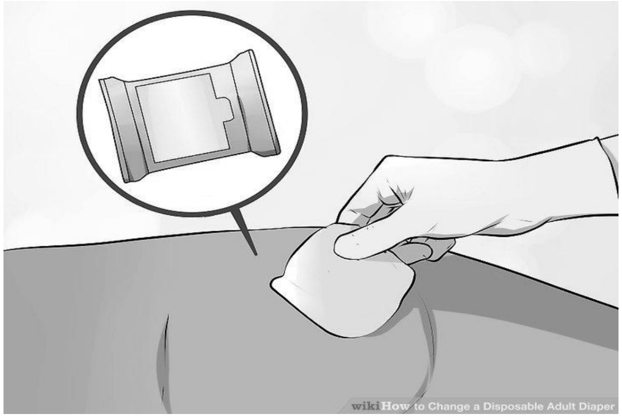
5. Wipe up what you can. Try to get as much as you can out before removing the depend completely.



6. Remove the depend. Dispose of the depend. Pull off your gloves, wash your hands and put on new gloves.


wikiHow to Change a Disposable Adult Diaper

7. Finish cleaning up. Make sure the person is thoroughly clean before moving on.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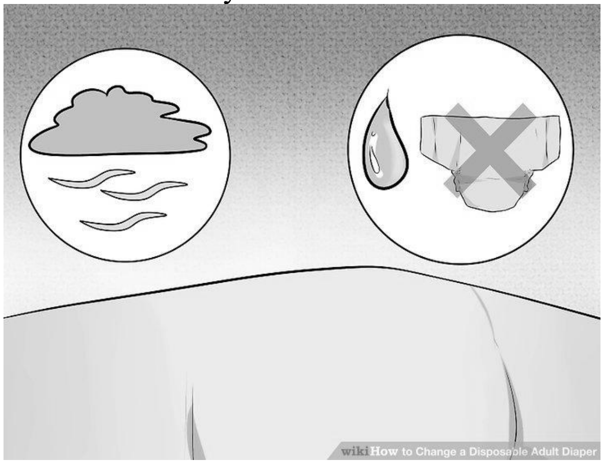
8. Let the person air dry. Once the person is clean, let the area air-dry for a moment.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9. Place the depend underneath the person.


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10. Add cream or powder as needed.

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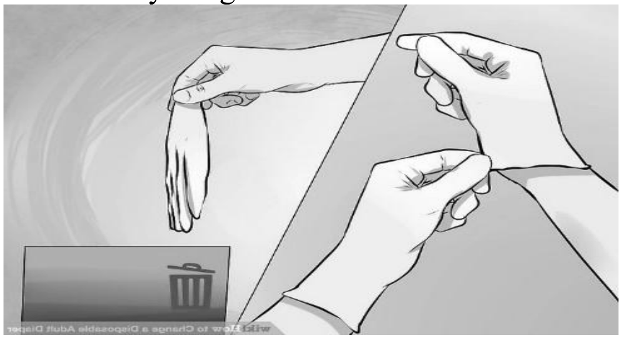
11. Throw away the gloves.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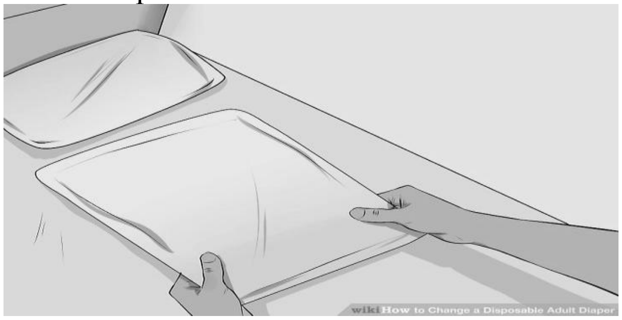
12. Add a disposable bed liner.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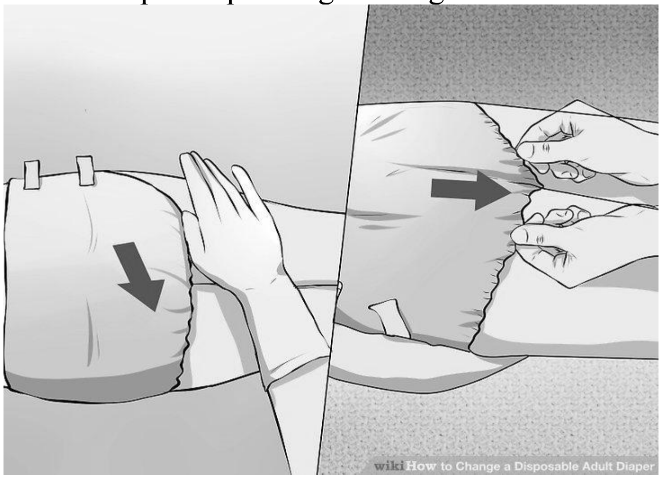
13. Roll the person back. Gently pull the person back towards you, rolling him on the depend. Pull the depend up through the legs.



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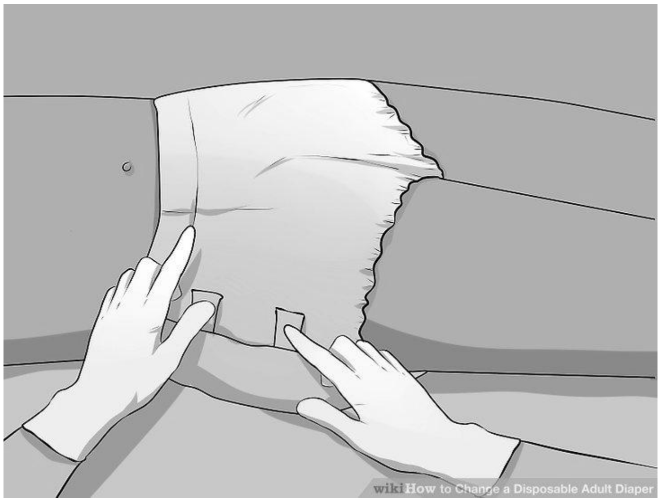
14. Attach the side tabs, which may be Velcro / adhesives.



wikiHow to Change a Disposable Adult Diaper

Bowel/Bladder Management

Bowel and Bladder habits can change with alterations in your nutrition, medication, and activity level. This is normal and expected. Preventing constipation and controlling incontinence is important and something your nurse will work with you on. If you notice changes in your bowel or bladder habits, please let your nurse know.

Getting to the bathroom can become a challenge due to weakness, fatigue, or the urgent need to move your bowels or to urinate. You might find comfort in using equipment such as a wheelchair, walker, or bedside commode.

You may need the help of a caregiver to assist with walking and personal hygiene after using the bathroom. Good skin care is important to prevent infection or soreness. Using disposable wet wipes are helpful, inexpensive and can be purchased in the grocery store or pharmacy.

Incontinence products are available to protect your chair/bedding, such as under pads or "chux". Talk to your nurse about any incontinence issues you have. Rainbow Hospice Care provides under pads and briefs as needed to manage incontinence.

Many factors can increase your risk of bladder infection including changes in fluid intake or hygiene. Pain, urgency, foul smelling urine, or fever may be signs of a bladder infection. Let your nurse know if you are experiencing any of these symptoms. Your nurse can discuss options for equipment or supplies to help manage bladder and bathroom needs.

Catheter Care

A catheter may be called "foley catheter", "urinary catheter", or "cath". Common reasons to have an indwelling catheter are urinary incontinence (leakage), urinary retention (not being able to urinate), or surgery that made this catheter necessary. Catheters can also be used for comfort. Patients who feel weak or fatigued may have difficulty getting to the bathroom or bedside commode. A catheter can be inserted to reduce the burden of getting up and down to empty your bladder. Your hospice nurse can answer questions you have about catheters.

Cleaning the Skin around Your Catheter

Supplies:

- 2 clean washcloths.
- 2 clean hand towels.
- Mild soap.
- Warm water.
- A clean container or sink.

Follow these skin care guidelines once a day or more often if needed:

- Wash your hands well with soap and water. Be sure to clean between your fingers and under your nails.
- Wet one of the washcloths with warm water and apply soap.
- Gently wash all around the area where the catheter goes in with the soapy washcloth. Females should wipe from front to back. Males should wipe from the tip of the penis downward.
- Rinse the washcloth with water until the soap is gone.
- Add more soap to the washcloth. Use it to gently wash your upper legs and buttocks.
- Rinse off the soap and pat dry with a clean towel.
- Avoid using creams, powders, or sprays near this area.

Cleaning the Catheter

Follow these steps twice a day to keep your catheter clean and free from bacteria that can cause infection:

- Wash your hands well with soap and water. Be sure to clean between your fingers and under your nails.
- Change the warm water in your container if you are using a container and not a sink.
- Wet the second washcloth with warm water and soap it up.
- Gently hold the catheter and begin washing the end near your vagina or penis. Move slowly down the catheter (away from your body) to clean it. Avoid cleaning from the bottom of the catheter toward your body.
- Gently dry the tubing with the second clean towel.

You will attach the catheter to your inner thigh with a special fastening device called a stat lock or catheter strap.

You may be given two bags. One bag attaches to your thigh for use during the day. The second one is larger and has a longer connection tube. This bag holds enough so you can use it overnight. You will be shown how to disconnect the bags from the catheter in order to switch them. You will also be taught how to empty the bags through the valve without needing to disconnect the bag from the catheter.

Making Sure Your Catheter Is Working

You will need to check your catheter and bag throughout the day.

- Always keep your bag below your waist.
- Try not to disconnect the catheter more than you need to. Keeping it connected to the bag will make it work better.
- Check for kinks, and move the tubing around if it is not draining.
- Drink fluids as you wish.

When to Call Hospice

A urinary tract infection can be the most common problem for people with a catheter. Call if you have signs of an infection, such as:

- Pain around your sides or lower back.
- Urine smells bad, or it is cloudy or a different color.
- Fever or chills.
- A burning sensation or pain in your bladder or pelvis.
- You do not feel like yourself. Feeling tired, body aches, and have a hard time focusing.
- Your team can discuss how you wish to manage a potential infection.

Also call hospice if:

- You notice a change in your urine.
- Urine is leaking around the catheter.
- You notice blood in your urine.
- Your catheter seems blocked.
- You notice grit or stones in your urine.
- You have pain near the catheter.
- You have any concerns about your catheter.
- Sometimes these issues are normal. Discuss these with your hospice nurse and they can assist you to make a plan, if necessary.

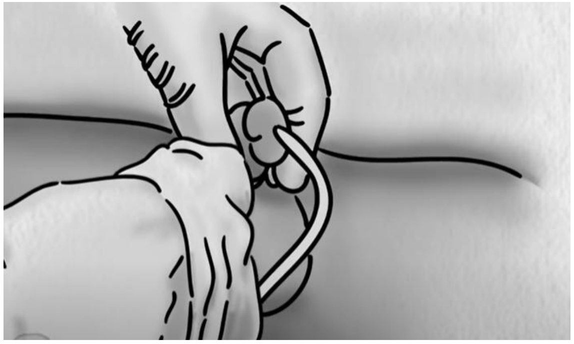
Flushing Your Catheter

Your catheter may become clogged if you have sediment or mucous in your urine. Your nurse may teach you how to flush your catheter to remove clogs or to prevent them.

Cleaning the Skin around Your Catheter

1. Wash your hands well with soap and water. Be sure to clean between your fingers and under your nails.

2. Gently wash all around the area where the catheter goes in with the soapy washcloth. Females should wipe from front to back. Males should wipe from the tip of the penis downward. Gently wash your upper legs and buttocks.



3. Rinse off the soap and pat dry with a clean towel.

Cleaning the Catheter

4. In the morning after you shower, change the night bag to the leg bag. At night before you go to bed, change the leg bag to the night bag. Do this by firmly holding the connection and pulling them apart.

5. Gather your supplies.

6. Place the clean cloth or gauze under the connector to catch any leakage.

7. Pinch off the catheter with your fingers and disconnect the used bag. Wipe the end of the

catheter with an alcohol pad. Wipe the connector on the new bag with the second alcohol pad.

8. Place the leg bag on your calf using the Velcro® straps your nurse gave you. Use a leg strap to secure the tubing to your thigh.

9. Check all connections. Straighten any kinks or twists in the tubing.

10. Empty the urine from the drainage bag into the toilet. Make sure the spout of the drainage bag never touches the side of the toilet or any emptying container.

11. Rinse the bag with cool water. Don't use hot water because it can damage the plastic equipment.

12. To help reduce the smell, fill the bag halfway with a mixture of 1-part white vinegar and 3 parts water. Shake the bag and let it sit for 15 minutes. Rinse the bag with cool water. Hang it up to dry.

Safely Moving Patients

This guide provides step by step instructions on assisting patients to move safely. Access caregiver training videos on Rainbow Hospice Care's website: http://www.rainbowhospicecare.org.

If you have any questions about safely moving a patient, please ask your hospice staff for more information.

Gait Belt – A gait belt is a sturdy cotton belt with a metal buckle. The belt is used to assist in the process of moving a patient from a bed to wheelchair or assist with walking.

How to apply a Gait Belt

1. Place the belt around patient's waist with the tag facing outward and the buckle centered.
2. Thread the metal-tipped end through the buckle hinge over the teeth and tighten.
3. Thread the metal-tipped end through the front buckle opening.
4. Pull tight at each of the webbing to ensure the belt is secure.

Moving from Bed to Wheelchair

- Prepare the patient for moving by explaining what you are about to do.
- Ensure wheels on bed are locked, elevate the head of the bed, and raise the level of the bed to slightly above chair height.
- Ensure the patient has safe footwear with non-slip soles.
- Place the wheelchair next to the bed and lock the wheels. Remove the footrests.
- Move the patient's legs to the edge of the bed and then assist the patient to sit up on the edge of the bed with both feet flat on the floor.
- Move slowly and allow the patient time to adjust to position changes.
- Apply the gait belt around the waist so that two fingers fit snugly under the belt.
- Instruct the patient to assist by pushing up on the bed or using their walker.
- Grasp the gait belt on the side opposite from the wheelchair to steady the patient.
- Instruct the patient to assist in standing on the count of 3.

- Allow the patient to adjust to a standing position.
- After patient is in a standing position tighten gait belt as needed.
- Instruct the patient to move their feet while caregiver also moves their feet to pivot to a position with the patient's back toward the chair.
- Instruct the patient to step backward until they feel the chair on the back of their legs.
- Instruct the patient to reach back for the arms of the wheelchair and assist them to a sitting position.

Prepare the patient for moving by explaining what you are about to do. Ensure wheels on bed are locked, elevate the head of the bed, and raise the level of the bed to slightly above chair height. Ensure the patient has safe footwear with non-slip soles. Place the wheelchair wheel next to the bed and lock the wheels. Remove the footrests.

Move the patient's legs to the edge of the bed and then assist the patient to sit up on the edge of the bed with both feet flat on the floor.

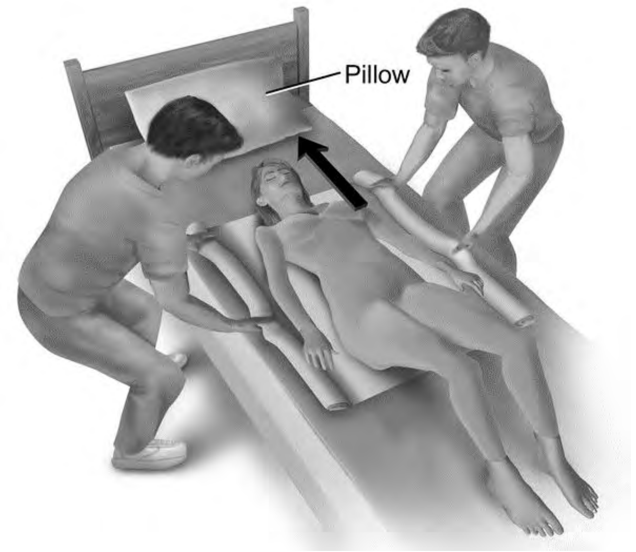
Move slowly and allow the patient time to adjust to position changes. Apply the gait belt snuggly around waist so that two fingers fit snuggly under belt.

Instruct the patient to assist by pushing up on the bed or using their walker. Grasp the gait belt on the side opposite from the wheelchair to steady the patient. Instruct the patient to assist in standing on the count of 3. Allow the patient to adjust to a standing position before letting go of the gait belt.

Instruct the patient to move their feet while caregiver also moves their feet to pivot to a position with the patient’s back toward the chair. Instruct the patient to step backward until they feel the chair on the back of their legs. Instruct the patient to reach back for the arms of the wheelchair and assist them to a sitting position.

Boosting Up in Bed

Patients may slide down in bed especially if the head of the bed is elevated. If the patient is able to help, this process can easily be done with one caregiver. If using a draw sheet this process works best with two caregivers.

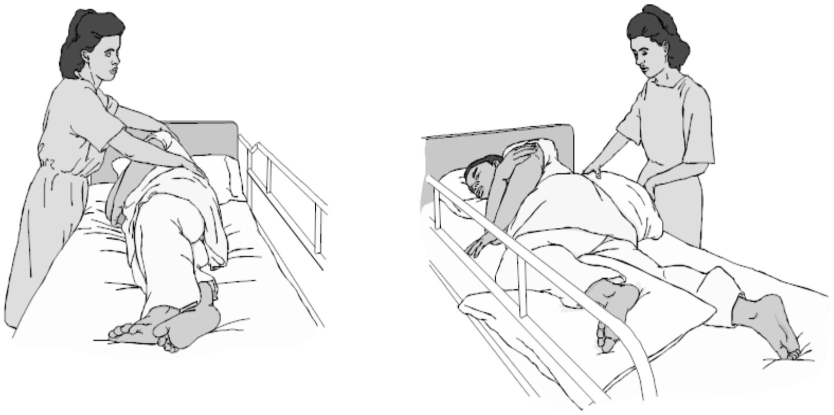


1. Prepare the patient for moving by explaining what you are about to do.
2. Adjust the height of the bed to just below the caregiver’s waist.
3. Move head of bed down flat (elevating the feet may help with positioning).
4. Instruct the patient to cross their arms across their chest.
5. Grasp the drawsheet at shoulder and hip.
6. Instruct the patient to bend their knees and push against the mattress to assist.
7. Carefully boost the patient toward the head of the bed.
8. Raise the head of the bed to a comfortable height, position the patient with pillows for comfort, and lower the bed to a safe position.

Draw Sheet – A folded flat bed sheet used to aid in moving a patient in bed. The sheet is folded in half and placed under the patient in the bed. The sheet is placed across the bed, over the fitted sheet and under the patient from shoulder to knee.

Turning in Bed

- Patients need to adjust position routinely to prevent discomfort and skin problems. If the patient is able to help, this process can easily be done with one caregiver. If using a draw sheet this process works best with two caregivers.
- Prepare the patient for moving by explaining what you are about to do.
- Adjust the height of the bed to just below the caregiver’s waist.
- Move head of bed down flat, as tolerated by the patient.
- Instruct the patient to cross their arms across their chest.
- Grasp the draw sheet at the shoulder and hip and carefully pull the patient to the side of the bed. Lay the drawsheet over the side of the patient.
- Bend the patient’s leg that is closest to the edge of the bed.
- With one hand supporting the patient under the shoulder and the other under the hip, assist the patient to roll toward the center of the bed.
- Place a pillow lengthwise behind the patient’s back and anchor it by tucking the outer edge under the pillow. Then allow the patient to roll back onto the pillow.
- Assist the patient to slightly bend both knees and slide a flat pillow between the knees for comfort.
- Ensure that the patient’s lower arm and shoulder are in a comfortable position. Use a pillow to support the upper arm for comfort.
- Smooth the draw sheet back onto the bed.
- Lower the bed to a safe position.



Roll the patient toward you by placing one hand on their shoulder and one hand on their hip. Place pillows behind the patient to allow them to relax in the side position.

Assisting with Walking

It is important to know the patient’s functional ability before they are moved. Some patients are unable to walk due to weakness, problems with balance, or physical limitations.

- Prepare the patient for safely moving by explaining what you are about to do.
- Ensure wheels on the bed or chair are locked prior to standing.
- Ensure the patient has safe footwear with non-slip soles.

- Apply the gait belt snugly around waist so that two fingers fit snugly under belt.
- If using a walker, place walker in front of patient with wheels locked.
- Instruct the patient to stand by pushing up on the bed or using their walker.
- If they need help to stand, have the walker within reach, assist the patient to stand and then move the walker into position in front of the patient.
- Move slowly and allow the patient time to adjust to position changes.
- The caregiver should walk slightly behind the patient with one hand on the gait belt.
- Check with the patient frequently to know if they are getting tired. Encourage them to sit down when tired.

Having a second person available to push a wheelchair a short distance behind the patient may be helpful.

Preventing Falls

Those with a life-limiting illness are particularly vulnerable to falls. Some reasons might include:

- Weakness or fatigue.
- Medication side effects.
- Problems with balance.
- Impaired vision or sense of position.
- Tingling or numbness in the feet or hands.
- Confusion, which may result in forgetting that help is needed to get out of bed or transfer.
- Incontinence or urgency to use the bathroom.

Safety hazards in the environment can increase the risk for falls, including:

- Throw rugs or slippery floors.
- Poor lighting.
- Clutter.
- Electrical cords or oxygen tubing in walk areas.

To help prevent falls, Rainbow Hospice Care staff will offer suggestions including:

- Before standing, sit upright and count to 30, then stand slowly.
- Equipment such as walker, cane, wheelchair, hospital bed.
- Gait belt − A gait belt is a useful tool for the caregiver to use to provide support and guidance to the patient during walking and transfers.
- If the patient needs assistance to get up- have a call bell or another device that can alert, you.
- Anticipating the patient needs (food/fluid/bathroom) and providing a routine to minimize fall risks.
- Provide 24-hour caregiving or supervision.
- Consider using a Hospice Volunteer for a short period.

For patients who can move around more easily, these things may be helpful:

- Use a cane or a walker.
- Ask for help if you feel unsteady.
- Turn on lights and use nightlights in hallways, bathrooms, and bedrooms. (keep a lamp or a flashlight close to your bed so you don't have to get out of bed to turn on the light)
- Install and use grab bars in tub, shower, and toilet areas.
- Use nonskid adhesive strips or a mat with suction cups in the shower.
- Consider using a shower chair or bench in the shower.
- Consider using a hospice aide (provided by hospice) to help with bathing.
- Avoid using bubble bath or shower oil that might make the bath tub slippery.
- Use your glasses and keep them handy.
- Remove throw rugs or put non slip material under the rugs.
- Wear well-fitted shoes or slippers that have treads on the soles.
- Remove clutter from walkways and stairs.
- Clean up spills quickly.
- Consider using an emergency notification system if you stay alone.

If a patient begins to fall:

1. Don't try to prevent the fall.
2. Guide the patient to the floor, protecting the patients head.
3. Bending your knees, stay close to the patient.
4. If the patient falls, do not panic, they are safe on the floor.
5. Provide a pillow and blanket and call Rainbow Hospice Care for further directive.
6. Reassure the patient that they are safe on the floor and a nurse will be out to assess them.
7. You should contact Rainbow Hospice about any fall. The nurse can provide further direction based on the situation.

You can reach Rainbow Hospice Care anytime by calling 920-674-6255

2

Medications & Symptom Management

Rainbow
Hospice Care

Medication

When someone elects hospice care, the focus changes from curative to comfort. This might include medication management.

Pill Burden Reduction
We will review your medication profile together and reduce your pill burden. Polypharmacy is common with patients who have advanced disease and often times contributes to increased side effects including nausea and lethargy. Your nurse will instruct you on proper medication disposal when needed.

A Handful of Medication:

The Challenge of Pill Burden

This post was originally published in Dr. Clarkson 's End Notes column for the Pratt Tribune.

If you've ever helped as a caregiver to someone in the twilight years of their life, or perhaps you yourself are at this stage, you may have noticed when it was medication time that there were a lot of pills. It is true there are exceptions to this rule, those individuals who only take one or two medications a day. However, this is the exception, and there doesn't seem to be much middle ground. Either you are on pages worth of medication, or hardly any as you begin to enter the last stages of life.

The first question is, how does this happen? A large culprit to this phenomenon stems from the expectations for the doctor/patient encounter. When a patient comes to see a provider with a specific complaint, they expect a remedy. The unspoken words from every patient are "fix me". While most complaints aren't easy to alleviate quickly, culture demands instant relief. Thus, handing out a new medication for a complaint certainly feels like the problem has been addressed. This is not much different to what happens when my 3-year-old skins his knee. He has been enculturated to believe that with any scrape a Band-Aid is the ultimate solution. As a parent, I can tell that most of his injuries medically don't need Band-Aids, and yet when I relent I'm amazed at the immediate soothing effect it has because something has been done to "fix" him. Medications at times are like Band-Aids, they may not be essentially needed, but we expect something from them, and so in turn, they pacify us.

The next issue with medications is the tendency that once started they are never stopped. Someone comes into the hospital for knee surgery and complains of indigestion due to anxiety about the surgery, so an antacid is prescribed. The person is discharged with the new medication, and years later are still taking it, despite not medically needing it. When I put a Band-Aid on my 3-year-old, it takes some convincing after a day that I can remove it, because he is now healed. How funny it would be if we left Band-Aids on indefinitely, never evaluating if the injury healed. Yet this is often the case for pills, started by other specialists, or for specific reasons in the past, we trust their benefit, like the Band-Aid, without pondering if still needed.

When it comes to end of life, the harm of over prescribing and not eliminating medications is something called 'pill burden'. Patients fatigued from their disease and having more difficulty swallowing become burdened by the handful of medications we expect them to take. Many pills can be eliminated because of the above scenarios, but even more can be stopped when we evaluate why someone is taking the pill in the first place.

Many medications prescribed are preventative, meant to stave off unwanted future risks. Some of these drug classes are blood thinners, cholesterol lowering agents, blood pressure medications, dementia medications, and all vitamins. These agents are meant to prevent things years in the future, so it makes no sense continuing them on hospice when time is limited.

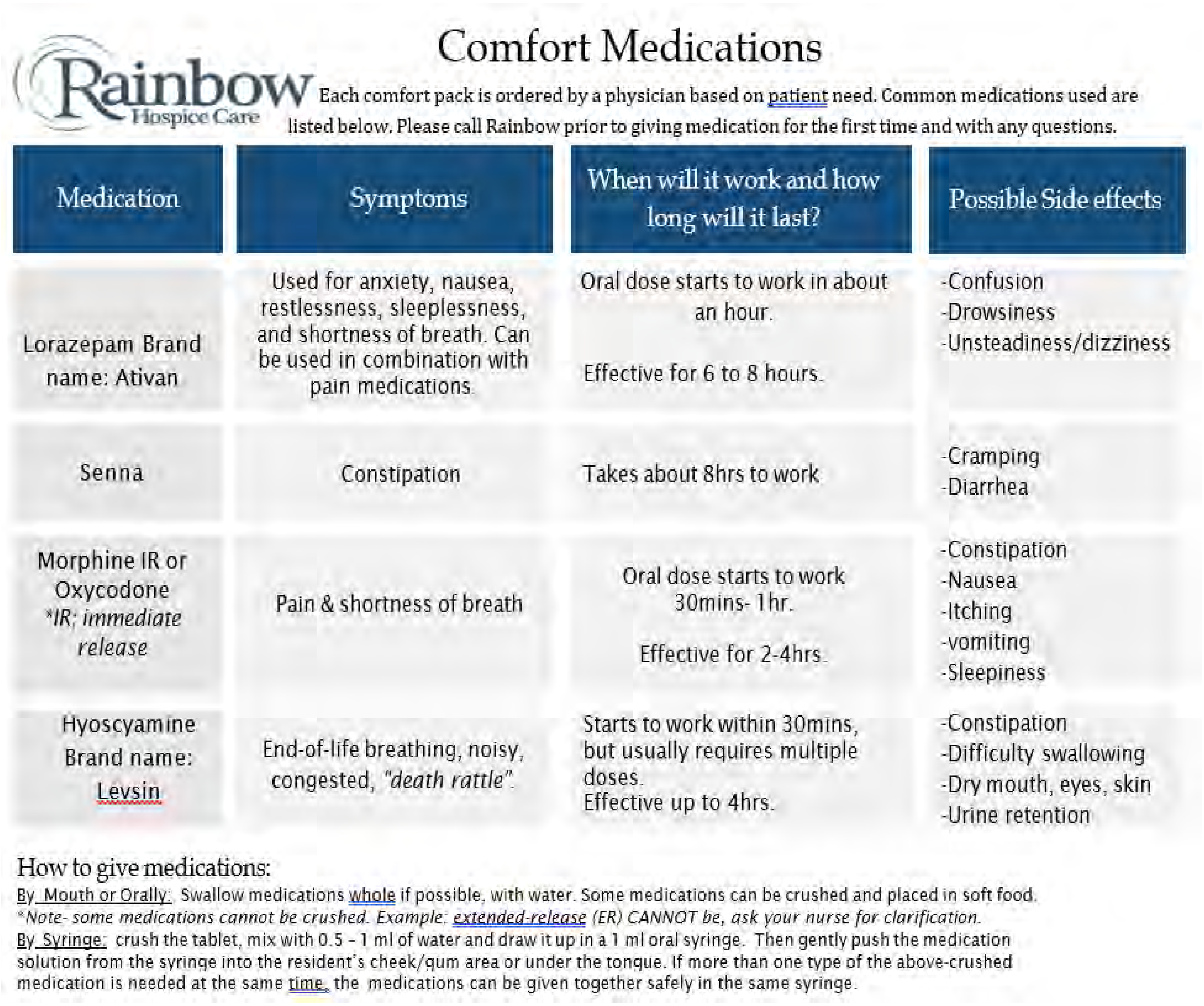
Pill burden doesn't just occur at the end of life. It's okay to be an advocate and sit down with your physician to discuss the necessity of medications prescribed. The key is to ensure the pills you take are working for you, because it can be work to take them in the first place.

http://www.pallimed.org/2014/08/a-handful-of-medication-challenge-of.html

Dr. Clarkson is a hospice physician for Southwind Hospice in Pratt, KS. This post was originally published in Dr. Clarkson's End Notes column for the Pratt Tribune. It is re-published here with the author's permission under a Creative Commons license.

What is a Comfort Pack?

You will be prescribed a “comfort pack” that consists of medications to manage common end of life symptoms and are prescribed uniquely to your needs. These medications will be ready for pick up from your preferred pharmacy after admission to hospice. Your Rainbow Hospice Care nurse will educate you on when to use the medications and how to store them. With each new medication prescribed, you will receive education from your nurse on expected side effects.



Rainbow Hospice Care

Comfort Medications

Each comfort pack is ordered by a physician based on patient need. Common medications used are listed below. Please call Rainbow prior to giving medication for the first time and with any questions.

Medication	Symptoms	When will it work and how long will it last?	Possible Side effects
Lorazepam Brand name: Ativan	Used for anxiety, nausea, restlessness, sleeplessness, and shortness of breath. Can be used in combination with pain medications.	Oral dose starts to work in about an hour. Effective for 6 to 8 hours.	-Confusion -Drowsiness -Unsteadiness/dizziness
Senna	Constipation	Takes about 8hrs to work	-Cramping -Diarrhea
Morphine IR or Oxycodone **IR; immediate release*	Pain & shortness of breath	Oral dose starts to work 30mins- 1hr. Effective for 2-4hrs.	-Constipation -Nausea -Itching -vomiting -Sleepiness
Hyoscyamine Brand name: Levsin	End-of-life breathing, noisy, congested, *“death rattle”*.	Starts to work within 30mins, but usually requires multiple doses. Effective up to 4hrs.	-Constipation -Difficulty swallowing -Dry mouth, eyes, skin -Urine retention

How to give medications:

By Mouth or Orally: Swallow medications whole if possible, with water. Some medications can be crushed and placed in soft food.
**Note- some medications cannot be crushed. Example: extended-release (ER) CANNOT be, ask your nurse for clarification.*
By Syringe: crush the tablet, mix with 0.5 – 1 ml of water and draw it up in a 1 ml oral syringe. Then gently push the medication solution from the syringe into the resident’s cheek/gum area or under the tongue. If more than one type of the above-crushed medication is needed at the same time, the medications can be given together safely in the same syringe.

Frequently Asked Questions

How will you know when to use these medications?

The hospice nurse will provide instructions on use. The comfort pack medications are commonly used when new or sudden symptoms occur. Having these medicines readily available greatly improves the ability to provide prompt relief when these symptoms are identified by families, facility staff, and/or the hospice team. The nurse may instruct you, in person or over the phone, to use these when there is an urgent need. Consideration may be taken to change the prescription and/or add a scheduled dose with each administration.

Why are tablets prescribed versus liquid?

Providers routinely order tablets versus liquid for several reasons. These medications are typically prescribed with very small quantities (usually 5 tablets) of each to have in case symptoms arise that need treatment quickly. If liquid was prescribed, pharmacies are required to give the full bottle of medication, which causes waste. Tablets can be used throughout end of life by giving it via syringe. Also, medication in liquid form typically needs to be stored in a refrigerator, which is often difficult when storing multiple patient medications.

What does "give sublingually" or "buccally" mean?

This identifies where the medication should be administered, sublingually; under the tongue or buccally; the side of the cheek, typically when a patient's swallowing ability is compromised. Medications should be crushed, reconstituted, and given with a 1ml syringe. Notify Rainbow if education is needed on this. *Be sure good oral care is performed BEFORE administering, if not it can affect absorption. Avoid eating/drinking for at least 5 minutes.*

Will giving morphine hasten death?

While morphine is an effective pain reliever, misconceptions can cause patients and families to worry that morphine will speed up the dying process. Morphine, when used properly and in the appropriate doses, does not hasten death.

Rainbow Hospice Care is here for you 24/7. Please call day or night to speak with a nurse about symptom management or with any questions: (920) 674-6255.

Does Morphine Make Death Come Sooner?

Many people worry about the use of morphine in palliative care. Morphine and other medications in the morphine family, such as hydromorphone, codeine and fentanyl, are called opioids. These medications may be used to control pain or shortness of breath throughout an illness or at the end of life. Patients and families sometimes worry that opioids will speed up the dying process.

Morphine is sometimes used when a person is in the advanced stages of illness, and his or her overall condition is declining. If the person is experiencing moderate to severe pain or shortness of breath, his or her doctor will often prescribe morphine. This opioid helps maintain the person's comfort throughout the illness and up to the time of death. A person declines because of the illness with or without the morphine.

When a patient is receiving regular pain medication such as morphine in the final hours or days of life, there is always a "last dose". To family at the bedside, it may seem like the drug caused or contributed to the death, especially if death occurs within a few minutes. However, this dose does not actually cause the person's dying. It is simply the last medication given in the minutes or hours before the death naturally occurs.

We know that morphine and other opioids are not a factor in the death of a person with advanced illness. The following information explains why:

- There is no evidence that opioids such as morphine hasten the dying process when a person receives the right dose to control the symptoms he or she is experiencing. In fact, research suggests that using opioids to treat pain or shortness of breath near the end of life may help a person live a bit longer. Pain and shortness of breath are exhausting, and people nearing the end of life have limited strength and energy. So, it makes sense that treating these symptoms might slow down the rate of decline, if only for a few hours.

- If a person has never received morphine, the initial doses given are low. They are gradually increased to relieve the person's level of pain or shortness of breath. After a few days of regular doses, the body adjusts to morphine. The patient becomes less likely to be affected by morphine's most serious side effect-the slowing of breathing. It would take a large dose increase over a short time to harm someone. Morphine doses are increased gradually and only as needed to maintain comfort.

- The last dose is the same as the doses the patient has previously received and tolerated. The way the medication is given might change when someone can't swallow any longer. If the medication needs to be given by a different route, the dose is calculated to equal the amount previously given by mouth.

In the last few hours of the natural dying process, a person's breathing becomes shallower and faster than normal. The breathing muscles become weak like all the other body muscles. When the breathing muscles are weak, extra muscles help out. It may look like the person is working hard to breathe, but does not always mean that they feel short of breath. The person's breathing pattern often becomes irregular with pauses. These pauses are often followed by a few fast and deep breaths. The person dies when he or she does not draw a breath again after a pause.

These changes in breathing are a sign that the control center for breathing is failing. The person may seem to be working hard to breathe, but this is a natural and normal response of the body shutting down and losing function.

If there are concerns about increased rate and work of breathing, gasping for air, and that the person is distressed, this suggests an ongoing need for giving the person additional regular doses of morphine to relieve the distress.

Morphine and other medications in the morphine family often play an important role in maintaining the person's comfort throughout an illness and the dying process.

You can find more information at these websites:

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/Asked+and+Answered/Medications/Does+morphine+make+death+come+sooner_.aspx

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/The+Gallery/For+Professionals/David+Roy_+Pain+medication+myths.aspx

When to Give Pain Medication

Treating pain is important, and there are many medicines and treatments that can be used. Pain medication is not always necessary to relieve pain. Your nurse may recommend medication alternatives such as relaxation, exercises, distraction, ice, or repositioning. If one medicine or treatment does not work, there are others that can be tried. To help your pain medicine work best, make sure you have the right medication, the right dose, and that you are taking it at the right time. Always take your medication as directed by your nurse or physician.

Occasional Pain: If you have occasional pain, you may be directed to take pain medication as needed. If some activities are painful, such as riding in a car, you may be directed to take pain medication prior to those activities to prevent or reduce pain.

Consistent or Continuous Pain: If you have more consistent pain, you may be directed to take pain medication on a scheduled basis, like daily or twice a day. Take your medicine as directed. Taking medicine regularly and as directed helps to keep pain under control. Do not skip a dose of medicine or wait for the pain to get worse or come back before taking your medicine. The best way to control pain is to prevent it. Check with your nurse before starting a new medication. Some medications work well with others, and some do not. Your nurse can provide you with information about new medications.

If the way you are taking pain medicine is not working for you, changes can be made. Talk openly to your hospice team so you can work together to find the pain medicine and treatments that can help you the most.

Side Effects of Pain Medication

All medicines <u>can</u> have some side effects. Not all people <u>will</u> experience side effects *from their medications, and some people have different side effects than others. Most side effects can be managed. Many side effects happen in the first few hours of treatment and gradually go away. Do not stop taking your pain medicines. Call your hospice nurse if you experience side effects because many things can be done to help prevent or treat them. Some of the most common side effects of pain medicines are:*

- Constipation: Pain medications can slow down the bowel allowing too much water to be absorbed from the waste matter. This leads to hard and/or infrequent stools. When taking pain medication, your nurse will recommend a "bowel regimen" that includes certain foods, stool softener, and/or a laxative.
- Nausea and vomiting: If this happens, it usually only lasts for the first day or two while the body adjusts to the medication. A medicine to control nausea and vomiting can be prescribed to help.
- Sleepiness: Some people who take pain medicines feel drowsy or sleepy when they first take the medicine. This usually only lasts two to three days while the body adjusts to the new medication.

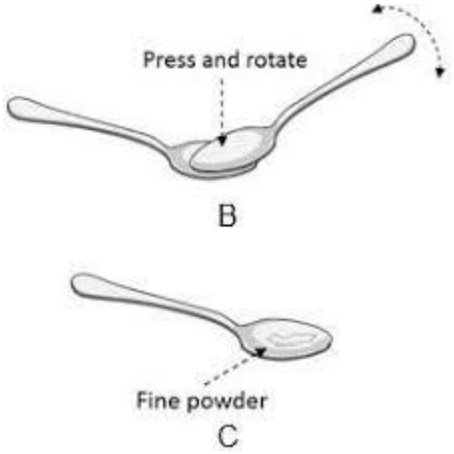
It is important to:

- Take stool softeners and laxatives routinely as directed to prevent and treat constipation.
- Drink as much water, juice, and other liquids as is comfortable.
- Eat fruits and vegetables, if able.
- Call your hospice nurse if you have not had a bowel movement in 3 days.

More serious side effects of pain medicines are rare. To help prevent serious side effects, the amount of medicine that will be prescribed will depend upon your age, height, and weight as well as how much pain you are having and what other medicines you are taking. If you have any side effect from any medication you are taking that concerns you or does not go away, please tell your care team right away.

Medication Administration with a Syringe

When swallowing becomes difficult, medications can be given with a syringe. There are medications that cannot be crushed. Your Rainbow Hospice Care nurse will instruct you on these medications.



This process has a few simple steps:

1. Gather the syringe, medication bottle and 2 spoons or a pill crusher. (Smaller metal spoons are easier to work with)
2. Place a paper towel onto the counter space (this prevents pieces of the pill to be left on the kitchen counter for safety purposes)
3. Take the desired medication from the prescription bottle and place the pill(s) on one of the spoons.
4. Take the other spoon and use it to crush the pill in between both spoons. (This takes a little practice initially)
5. Continue crushing the pill between both spoons until you have a fine powder (there should be no pill chunks)
6. Now you need to add water to this spoon.
7. Each pill generally needs 2-3 DROPS of water. Your kitchen faucet works well for this. Turn on your kitchen faucet and continue to slow the water down until the water is "dripping" from the faucet.
8. Now, place that spoon under the dripping faucet (remember, 2 or 3 drops is usually all you need)

9. Take the syringe and mix it up on the spoon to dissolve it. If it's "thick" you will want to add one more DROP of water. Continue to do this until you have the right amount of water. You want it to a nice thin consistency that is easy to draw up into the syringe.
10. Now, go ahead and take the syringe and "suck" the medication from the spoon into the syringe. If there is a syringe cap handy, place it on the syringe. If you don't have a cap, place the syringe "plunger down" in a cup (so the liquid doesn't drip out of the syringe)
11. You should have anywhere from ½ a syringe to a full syringe of fluid drawn up. (1ml syringe)

Now that you have crushed the medication and drawn it up into the syringe, you will learn how to administer this medication.

1. If there is a cap on the syringe, remove the cap.
2. Place the tip of the syringe into the patient's mouth, either against the inside of the cheek, under the tongue or along the bottom gum line (just inside of the lip, before the teeth)
3. Start to slowly push the plunger to give the medication.

How to Help with Trouble Breathing

Trouble breathing (shortness of breath) is an uncomfortable feeling like you cannot catch your breath.

Signs of Trouble Breathing

- Restlessness or anxious feeling
- Fast Breathing
- Feeling of not getting enough air
- Being winded when talking
- Fatigue

What Causes Trouble Breathing?

- Anxiety
- Movement
- Exercise
- Talking
- Posture
- Coughing
- Secretions
- Hot and humid weather
- Infection
- Illness related changes in lungs

How Can We Help with Trouble Breathing?

- Be calm and reassuring.
- Minimize activities that increase trouble breathing.
- Keep frequently used items within reach to reduce energy needed to reach items.
- Use a small fan to circulate air.
- Keep the room cool.
- Use a cool mist humidifier to increase moisture in room air.
- If using oxygen, make sure oxygen is flowing.
- Elevate the head with pillows.
- Raise the head of the bed.
- Request a hospital bed.
- Sit upright and lean slightly forward, if able.
- Instruct the patient to breathe in through the nose as deep as possible and breathe out through puckered lips.
- Encourage rest.
- Plan activities with frequent rest periods.
- Try relaxation techniques like meditation or music.
- Give medicines as prescribed for trouble breathing.
- Give oxygen as prescribed for trouble breathing.
- Not everyone will benefit from oxygen, ask your team if it would be helpful.

What If These Things Do Not Help?

Call your hospice team. Your hospice team will help by evaluating your loved one and making recommendations to help you breathe as comfortably as possible.

Trouble with Constipation

Constipation is something your hospice team takes seriously and watches closely. You can expect your hospice team to ask you questions regarding your bowels with every visit. Constipation can be common but can be easily controlled.

Please let your team know if your bowel habits have changed.

Causes of Constipation

- Decreased activity
- Medications
- Changes in your diet
- Decreased fluid intake

Symptoms of Constipation

- Straining to have a bowel movement
- Stool is hard and difficult to pass
- You haven't had a bowel movement in 3 days or longer
- You have blood in your stool

What You Can Do

- Have honest conversations with your nurse about changes in your bowels
- Drink water or other fluids if you are able to tolerate it
- Take medications as prescribed for your bowels.
- Keep track of your bowel movements and share that information with your nurse

Feelings of Anxiety or Sadness

Anxiety is a feeling of fear, worry, or unease. It can be a reaction to stress, or it can occur in people who are unable to identify significant stressors in their life. Stress and anxiety are not always bad. In the short term, they can help you overcome a challenge. Examples of normal stress and anxiety include worrying about a personal or family member's illness, feeling nervous before a new job, or being embarrassed in certain social situations. If we did not experience some anxiety, we might not have the energy or drive to do things that we need to do.

What Causes Stress and Anxiety?

For most people, stress and anxiety come and go. They usually occur after particular life events, but then go away. Common stressors include:

- Death or anticipated death of a family member or friend.
- Family or friend's illness.
- Personal illness or injury.
- Caregiving.
- Moving.
- Starting a new school or job.
- Getting married.
- Having a baby.

Stress and anxiety can produce both physical and psychological symptoms. People experience stress and anxiety differently. Common physical symptoms include:

- Stomachache.
- Muscle tension.
- Headache.
- Rapid breathing.
- Fast heartbeat.
- Sweating.
- Shaking.
- Dizziness.
- Change in appetite.
- Trouble sleeping.
- Diarrhea.
- Fatigue.

In addition to physical symptoms, stress and anxiety can cause mental or emotional ones. These can include:

- Feelings of impending doom.
- Panic or nervousness, especially in social settings.
- Difficulty concentrating.
- Irrational anger.
- Restlessness.

What you can do:

- Writing out thoughts or keeping a journal.
- Mental Distractions.

- Meditation and relaxation exercises.
- Scheduling time for hobbies.
- Practicing deep breathing.
- Spending time with family and friends.
- Laughing – humor can be a powerful tool.
- Getting enough sleep.
- Limiting caffeine and alcohol consumption.
- Eat for pleasure. Some foods and beverages may be soothing.
- Talk to your hospice team.

What can hospice do?

- Help to determine the cause of anxiety.
- Provide education on interventions for anxiety and stress.
- Discuss your goals relating to managing anxiety and stress to best help you determine the anxiety control methods that will be most comfortable and effective for you.
- Assist you in getting a prescription for medication to manage anxiety.
- Assist you in getting needed support from friends, family, volunteers, or hospice counselors.
- Listen.

Sadness

Sadness is a *normal emotion* for people struggling with illness and is a *normal reaction* to difficult situations. Allow yourself some grace and give yourself permission to feel sad and have "bad days". The bad days don't last forever. This is an emotion that comes and goes. Give yourself permission to feel sad.

Symptoms of Sadness:

- Losing interest in activities you typically enjoy
- Isolation and wanting more "alone time"
- Trouble concentrating
- Sleeping more
- Agitation or irritability
- Crying

Symptoms that need immediate attention:

If you have any of the following symptoms, please contact Rainbow Hospice

- Feelings of worthlessness and hopelessness
- Recurrent thoughts of death, suicide plans or attempts

Depression

Depression is a feeling of sadness and hopelessness that feels like it will never go away, and it gets in the way of your daily activities. Those suffering from depression take little to no pleasure in things that once brought them joy. Symptoms of depression can last for weeks, months or longer.

- Depression is different from "normal" sadness.
- With "normal" sadness, you can still function normally, but you have less interest in activities and more fatigue, but you understand this will get better.
- People with depression have a difficult time seeing any brightness in the future. It feels like it will never get better. It doesn't stop after just a day or two. It will continue on for weeks on end, interfering with the person's work or school, their relationships with others, and their ability to enjoy life and just have fun.
- *Depression is treatable with medications, counseling, or both.*

What to do for Restlessness & Agitation

Restlessness and Agitation are common symptoms at the end of life and can be severe at times. It can be difficult or stressful for a caregiver or family member when a patient's mood or personality seems to change. It can bring on feelings of bewilderment, helplessness, or not knowing what to do.

What is Restlessness & Agitation?

Restlessness and Agitation may cause the person to pace, handwringing, inability to be still and sometimes irritability.

What Causes Restlessness & Agitation?

- Pain or other uncomfortable symptoms
- Illness related changes in condition
- Psychological, spiritual, or emotional distress
- Being uncomfortable – tired, cold, or warm, needing to have a bowel movement or urinate
- Being overstimulated - bright lights, TV, other noise.

What Can We Help with Restlessness & Agitation?

- Use a gentle voice & reassuring touch.
- Create a calm, quiet environment: quiet music, limit visitors, and turn down the TV.

- Check basic needs (check comfort such as pain, temperature, hunger, thirst, or dry mouth)
- Be sensitive to any cues that might signal there is an issue the person wants to resolve.
- Let them do as much on their own as possible.
- Provide close supervision during periods of agitation to ensure the patient's safety as much as possible.
- Remind them who you are and explain anything you will be doing ahead of time.
- Try music. Consider having them listen to their favorite type of music.
- Offer support and verbal reassurance (may need to repeat verbal reassurances).
- Aromatherapy
- Try exercise or dancing.
- Try saying familiar prayers or familiar songs.
- Try familiar tasks such as folding washcloths, sorting cards, or organizing papers.
- Medication to help with agitation if ordered.

What if These Things Do Not Help?

- Give them space if it is not a safety issue and try again later.
- Call your hospice team. Your hospice team will help by evaluating your loved one and making recommendations to best alleviate agitation and restlessness.

Weakness and Fatigue

Weakness and Fatigue are terms used to describe when a person has less energy or ability to do the things he or she used to normally do and might include a lack of desire.

Weakness and fatigue are *expected*, and energy levels can vary from day to day and from morning to night. If the body is tired, it needs to rest.

How to Help

- Take it easy and plan rest periods to conserve energy for the important things.
- Listen to the body and rest when needed.
- Patients may sleep the majority of the day and have short periods of wakefulness. Reassurance that this is normal and expected is important.
- If you need training with personal care assistance, the hospice team can help.
- Watch for cues that certain activities might be too much for the patient.
- Modify or eliminate some daily activities.
    - Reduce frequency of showers/baths and assist with sponge baths as needed.
    - Provide assistance with meal preparation and/or use meals on wheels programs.
    - Assist with housekeeping tasks.
    - Utilize medical equipment such as walker, wheelchair, shower bench, hospital bed.

- Understand that as the disease progresses, patients become weaker. Always be ready to modify routines frequently.
- Nurses and hospice aides can provide education on safely moving. They can offer equipment options available to you to maintain the safety of the patient and conserve energy.

Nausea and Vomiting

Nausea is the feeling of sickness in the stomach that *may* come with an urge to vomit. Vomiting is the emptying of stomach contents, through the mouth.

The signs, symptoms and treatments can vary from one person to the next. Let's review some of the most common signs, symptoms and causes:

Anxiety- Anxiety leaves an uneasy feeling in the stomach and can cause nausea. Controlling anxiety can help. Refer to the teaching sheet on anxiety for relief options.

Constipation- If you are constipated, this can prevent you from eating, will cause stomach pain and will leave you feeling nauseated. This could lead to vomiting. Constipation relief is outlined in a separate teaching sheet.

Strong odors- Refrain from strong scented lotions, aftershave, candles and body wash. Meal preparation is not avoidable but preparing foods that are not heavy with grease can help. Positioning a fan to blow odors away from the patient will help. Any odor identified to induce these symptoms should be avoided.

Pain- proper pain management is necessary to reduce many symptoms, including nausea and vomiting. Proper pain control might include medications that cause constipation and are hard on the stomach. Most pain medications should be taken with food and might require a stool softener with frequent use. Please refer to the pain teaching sheet for further guidance.

Medications- medication taken on an empty stomach might cause nausea and vomiting. Even if they aren't medications that cause constipation. Speak with your Rainbow Hospice team to review side effects of the medications you are taking.

Recommendations that might help:

- Eat small and frequent meals (bland foods are best: Dry toast, crackers, pretzels)
- Avoid high fat foods
- Avoid caffeine, dairy, spicy and anything with a strong odor
- Reduce stimulation (turn lights down, minimize noises)

- Take a prescribed medication if needed. Reach out to Rainbow if you need a medication.

When to call Rainbow

- Nausea or vomiting that prevents you from resting.
- Vomiting that is brown/black or red in color.

Nutrition and Hydration

For many people, food is love. When we don’t know what to say, we cook. When we don’t know how to help, we cook. We make a dish to pass for any event. Comfort foods provide comfort. This is all we know, and this is what we are comfortable with. *This is also something that we need to be comfortable changing, when someone is at end of life.*

It is important to remember:

- Loss of appetite is *normal and expected and does not cause distress.*
- They will feel dry, but typically not hungry or thirsty as their disease progresses.
- Their body will not use any food or fluid, the way a healthy body will.
- Allow the patient to listen to their body.
- Eat when you are hungry, stop when you are full.

Do not feel guilty about eating around your loved one but do be aware that certain smells can cause nausea.

What might **happen if we don’t listen to the body?**

- Fluid may build up causing additional distress. (See above, *the body will not use food and fluid the same way as a healthy body)*
- Stomach cramps and pains
- Nausea and vomiting

The fluid will go somewhere, but it will not go where it needs to go for proper hydration. (IV hydration is no different)

How to help:

- Mouth swabs for moisture. (The patient can control how much fluid they receive with mouth swabs if swallowing is becoming impaired)
- Listen to the body. Eat when you are hungry, stop when you are full.

- If there is a desire to eat, offer bland foods.
- Offer “sips and bites” or small meals (*Offering a full plate of food might leave the patient feeling overwhelmed and guilty if they turn it away or don’t eat all of it)*
- Explore other options that can offer comfort. (Reading, holding a hand, apply a cool compress to the forehead)

Wong-Baker FACES® Pain Rating Scale

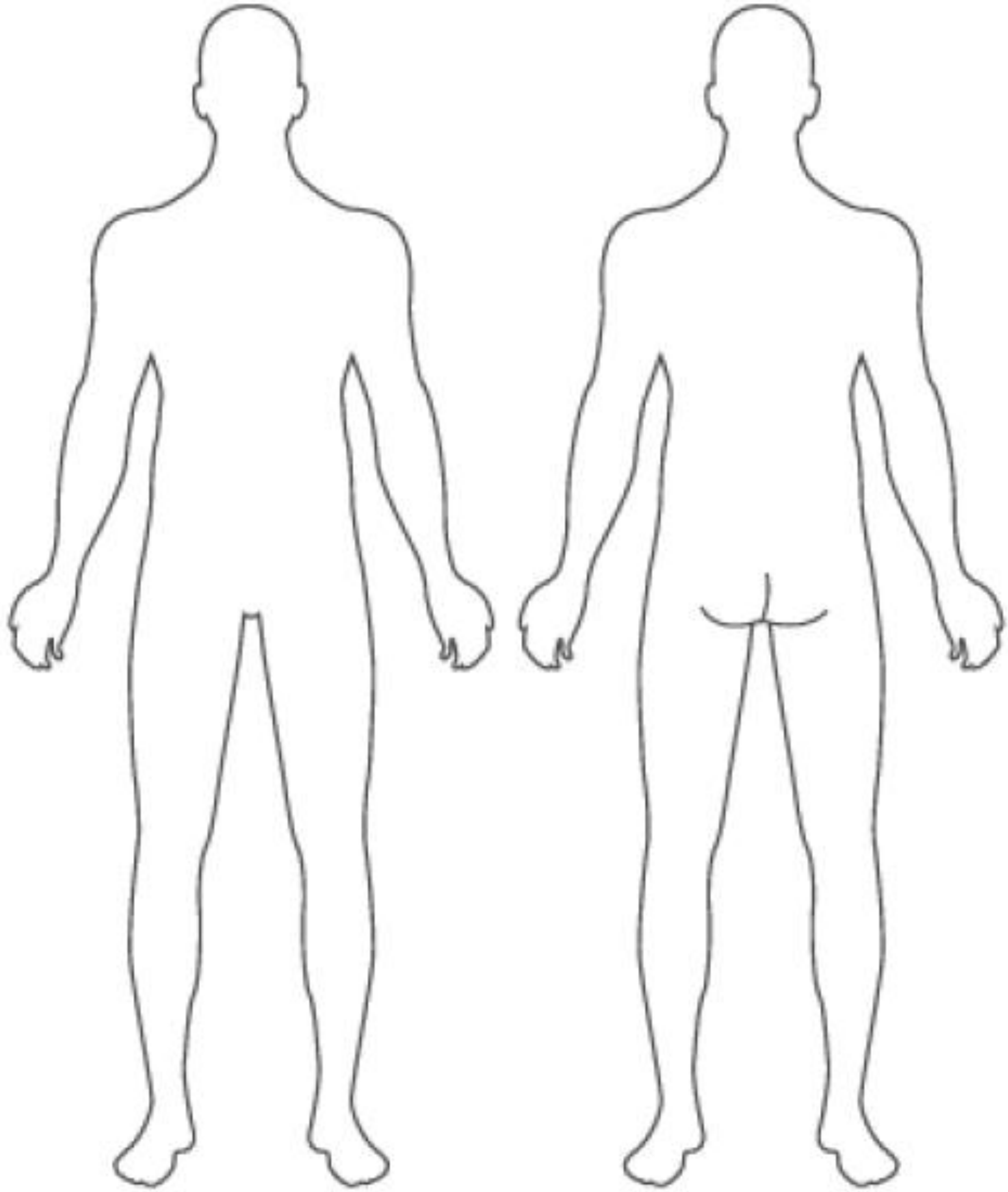
Instructions for Usage

Explain to the person that each face represents a person who has no pain (hurt), or some, or a lot of pain.

Face 0 doesn't hurt at all. Face 2 hurts just a little bit. Face 4 hurts a little bit more. Face 6 hurts even more. Face 8 hurt a whole lot. Face 10 hurts as much as you can imagine, although you don't have to be crying to have this worst pain.

Ask the person to choose the face that best depicts the pain they are experiencing.

Pain Location Chart



3

Infection Prevention

Infection Prevention

Rainbow
Hospice Care

Infection Prevention: Protecting Yourself & Others

Infections can be caused by bacteria, viruses, or other germs. They can be spread easily from person to person, but there are steps you can take to protect yourself and others. Discuss any questions with your Rainbow Care team.

Notify Rainbow: Let your team know if you or anyone in your home has symptoms of illness such as fever, cough, sneezing, nausea, vomiting, or diarrhea. This helps your team to provide support. It also helps staff know what precautions to take when visiting to protect themselves and their other patients. Please let us know as soon as feasible, if you or someone in your household has been diagnosed with a communicable (infectious) disease. Common communicable diseases are influenza, c-diff, COVID-19, gastroenteritis ("stomach flu"), Norovirus, shingles, or Respiratory syncytial virus (RSV).

Wash Your Hands: Washing your hands regularly with soap and water is one of the most effective ways to prevent the spread of infection. Wash your hands:

- Before preparing or eating food
- After using the bathroom
- After blowing your nose, coughing, or sneezing
- After touching an animal, animal feed, or animal waste
- After being in a public place or touching items in public

Cover Your Coughs and Sneezes: Covering your mouth and nose when you cough or sneeze can help prevent the spread of infection. Use a tissue or your elbow to cover your mouth and nose.

Stay Home When You're Sick: If you're feeling sick, stay home to prevent the spread of infection to others. Avoid close contact with others, including shaking hands or hugging.

Do Not Share: Do not share towels, dishes, or personal items with someone who has an infection.

Get Vaccinated: Vaccines are a safe and effective way to prevent infections, such as the flu and pneumonia. Talk to your healthcare provider about which vaccines you should get.

Take Precautions in Public: When in public, avoid touching your face, especially your eyes, nose, and mouth. Wear a mask if recommended by public health officials.

Dispose of Waste Properly: Dispose of waste properly by using sharps containers for items that could poke, stick, or cut your skin. Flush body fluids and human waste. Consider double bagging items that have blood or body fluids on them before disposal in trash. If you or your loved one lives in a facility setting, be sure to follow facility specific guidelines for waste disposal.

Follow Isolation Precautions: Some infections require special care to prevent the spread of germs. Your team may need to use a gown, gloves, or a mask to protect themselves and their other patients. If you have been asked to follow "isolation precautions", please follow the instructions you receive.

Limit Visitors: You may want to limit visitors if you or someone in your home has an infection. Ask friends and family to avoid visiting if they are ill. Remind your visitors to wash their hands at the beginning of the visit and before they leave.

When to Seek Medical Attention: If you develop symptoms of an infection, such as a fever, cough, or sore throat, seek medical attention. If you have been in close contact with someone who has a confirmed infection, you may need to be tested for the infection.

In summary, taking steps to prevent the spread of infection is important for protecting yourself and others. Wash your hands regularly, cover your coughs and sneezes, stay home when you're sick, clean and disinfect surfaces, get vaccinated, take precautions in public, and seek medical attention when necessary.

General Cleaning Tips to Prevent Infection

Routine cleaning can greatly reduce the risk of picking up germs from surfaces around the house.

- Ventilate with fresh air when possible.
- Dust and vacuum regularly – weekly if possible.
- Clean and disinfect frequently touched surfaces in your home and workplace, including doorknobs, countertops, and phones. Use a household disinfectant that is effective against germs.
- Use a clean, dry cloth or paper towel to clean and dry all surfaces.
- Mop kitchen and bathroom floors weekly and after spills.
- Clean the inside of the refrigerator routinely with soap and water.
- Wear gloves and wash hands when cleaning birdcages, litter boxes, aquariums, etc.
- Clean soiled household items and medical equipment thoroughly.

- Clean the kitchen and bathroom counters and other surfaces with household disinfectant cleaners.
- Do not use the same cleaning cloth to clean the bathroom and kitchen.
- Do not pour mop water down the kitchen sink. Consider using disposable mop heads.
- Do not clean rags or mops in the kitchen sink.
- Do not clean bedpans, urinals, etc. in the kitchen sink.

Keep Your Skin Healthy: Your skin is your body's first line of defense against germs. Caring for your skin can prevent infections.

- Apply moisturizer to your skin to prevent dryness.
- Bathe regularly.
- Wash your hair at least once a week.
- Brush your teeth after meals and before going to bed.
- Change the water in your denture cup every day. Wash your denture cup with soap and water at least once a week.
- Trim nails weekly or as necessary. Do not trim nails of someone with diabetes, loss of sensation, or poor circulation in feet or hands. Consult your team.
- Wear clean laundered clothes.
- Change soiled clothing and bed linens promptly.
- Do not share towels, washcloths, toothbrushes, or razors.

Infection Prevention Tips for Caregivers: As a caregiver, you play an important role in preventing the spread of infection to your loved one. Here are some steps you can take to protect yourself and your loved ones:

- Wash your hands before and after handling any body fluids or waste in the home is always a good idea. This simple act is the most effective method known today for preventing the spread of germs.
- Wear gloves to handle body fluid or waste. Wash your hands after removing gloves.
- You can use disposable gloves to prevent contact with body fluids or waste when you provide care.
- In addition to wearing gloves, if large amounts of body fluids are present, you may want to wear an apron or smock to prevent your clothing from being soiled.
- Wear Personal Protective Equipment (PPE): Wear PPE when providing care, if directed by your team. Examples of PPE include gloves, disposable gowns, masks, and eye protection.
- Remove body fluids or waste from surfaces and containers with soap and water or a household disinfectant solution.

- You can wash clothes and linens as you ordinarily would. Using an automatic washing machine, use soap or detergent and either hot or cold washing cycles. Follow the instructions on the soap or detergent package.
- If stains due to blood, drainage, or feces are present, soaking the clothes in cold water and bleach will remove the stains.
- Flush all liquid waste down the toilet. Be careful to avoid splashing when you are pouring liquids into the bathroom. Tissues, or other flushable items with body fluids or waste on them, may also be flushed.
- Paper towels, sanitary pads, wound dressings, and other items soiled with body fluid or waste that is not flushable should be placed in a plastic bag. Close the bag securely before placing it in a trash container.

Taking steps to prevent the spread of infection is important for protecting yourself and your loved ones.

How to Clean Your Hands Properly

Why is Handwashing Important? Washing your hands regularly with soap and water is one of the best ways to prevent the spread of germs and stay healthy. Germs can easily be spread from your hands to your face, food, or other surfaces you touch, so it's important to wash your hands often to prevent getting sick.

When Should You Wash Your Hands?

- Before preparing or eating food
- Before and after caring for someone who is sick or treating a wound
- After touching frequently touched objects or surfaces
- After using the bathroom, changing diapers, or cleaning up after a child
- After blowing your nose, coughing, or sneezing
- After touching an animal, animal feed, or animal waste
- After handling garbage
- After blowing your nose, coughing, or sneezing
- After being in a public place or touching items in public
- Before and after caring for someone who is sick

How to Wash Your Hands:

1. Wet your hands with clean, running water (warm or cold) and apply soap.
2. Rub your hands together with the soap for at least 30 seconds, making sure to lather the backs of your hands, between your fingers, and under your nails.
3. Scrub your hands for the entire 30 seconds. You can count to 30 or sing "Happy Birthday" twice in your head to time yourself.
4. Rinse your hands thoroughly under running water.
5. Dry your hands with a clean towel or air dry them.

Tips for Handwashing:

- Use liquid soap instead of bar soap, which can harbor germs.
- Don't use antibacterial soap unless directed by a healthcare professional. Regular soap is effective at removing germs.
- Avoid touching your face, especially your eyes, nose, and mouth, as much as possible.

Tips for Hand Sanitizer:

- Put a small amount of hand sanitizer in the palm of one hand.
- Rub your hands together, making sure to cover all surfaces of your hands and fingers, including the backs of your hands and between your fingers. Rub your hands for at least 30 seconds or until the hand sanitizer has dried.
- Do not rinse or wipe off the hand sanitizer.

Home Sharps Container Disposal

Definitions:

Sharps: Devices capable of puncturing, cutting, or penetrating the skin (these include needles, lancets, intact or broken glass contaminated with blood or body fluids, and intact or broken hard plastic contaminated with blood or body fluids)
Sharps Container: Small rigid red plastic container for disposal of all sharps.

Importance of Proper Sharps Disposal:

Improper disposal of sharps can lead to:

- Injuries and potential infections or diseases.
- Harm to children, pets, and anyone who comes into contact with these items.

For the safety of the patient, caregivers, visitors, and hospice staff place all sharps in the sharps container.

If you have any treatments or tests that require sharps devices, your nurse can provide you with a sharps container.

Keep sharps containers out of the reach of children.

Place Sharps in an Approved Container: Do not throw sharps into the trash. Needles should never be recapped or broken and should be placed in the sharps container immediately after use. If one is not available, a heavy-duty plastic container, like a laundry detergent or bleach bottle, can be used. It should be leak-resistant, remain upright during use, and have a tight-fitting, puncture-resistant lid.

Never put sharps containers out with the trash or recyclables.

When the container is ¾ full, store it out of reach of children and dispose of it properly by taking it to a sharps collection site. Most pharmacies and physician offices accept sharps containers.

For safety purposes, Rainbow Hospice staff is not permitted to take sharps containers out of a patient's home.

4

Supplies & Equipment

Rainbow Hospice Care

Supplies

Rainbow Hospice Care manages your medical supply needs to maintain your comfort based on your plan of care. Your nurse will routinely assess your need for medical supplies and provide information to you about supply options to help manage your care safely and comfortably. Supplies will be provided based on your individual plan of care. Rainbow Hospice provides medical supplies and incontinence products when related to your primary illness or a related condition.

Your hospice team will work to anticipate your medical supply needs to ensure you have what you need.

The hospice team will deliver any supplies you need to your home. If there are supplies you need on a regular basis, your nurse will order your supplies to be delivered directly to your home. Typically, these deliveries are made by FedEx. If you have any questions or concerns about your deliveries, please let your hospice team know.

Your hospice staff will provide instruction on use of supplies.

Common Supply Needs

- Gloves.
- Mouth Swabs.
- Protective Under pads or Chux.
- Sharps Containers.
- Wash Basin.
- Urinal.
- Catheter Supplies.
- Tube Feeding Supplies and Nutrition.
- Wound Care Supplies.
- Incontinence Products.
- Other Home Treatment Supplies.

Commonly used daily personal care supplies such as shampoo, soap, wet wipes, deodorant, denture cream, and toothpaste are not covered and not provided by hospice. If you have any questions about products that are covered or provided by hospice, please talk with your nurse.

For patients living in a facility, such as Assisted Living, RCAC, CBRF or nursing home, RHC works closely with the facility to ensure you have these supplies, particularly in nursing homes. The facility provides for these basic supplies through contract with RHC.

Medical Equipment

You may need equipment such as a hospital bed, wheelchair, beside commode, etc. to assist you. Your hospice nurse will recommend equipment to enhance your safety or comfort. The equipment supplier will demonstrate the proper use and care of the equipment to you upon delivery. Your nurse is knowledgeable and available to assist with any concerns or questions about the use and care of the equipment. This section provides information about the most commonly used equipment. You may also hear equipment referred to as DME (Durable Medical Equipment). Equipment needs vary from patient to patient.

Trouble Shooting Equipment Problems:

If electric equipment is not working, please check to see that it is plugged in.

Call Rainbow Hospice if you have any equipment problems. We will work with our equipment company to trouble shoot or get the item repaired or replaced.

Some equipment and other items are supplied by Rainbow Hospice Care through the facilities, let us know if you have any concerns.

Electric Bed and Mattress

Patients typically choose to have a hospital bed when it becomes difficult to get into and out of a regular bed, if they need the head of the bed elevated for breathing comfort, or if they need assistance with personal care such as bathing, transfers, or repositioning.

The bed is electric and must be kept plugged in to allow handheld control pad to function. The control pad moves the head and foot of the bed up and down for your comfort. Controls also allow you to move the entire bed up and down to a good working height if you need assist with bathing or repositioning. You should keep the control pad within easy reach.

Side rails are available, if you prefer to use the rails for ease of movement in bed. Your nurse can provide information about whether side rails would be beneficial.

Elevating the foot of the bed slightly can help prevent the patient from sliding down in bed. It can also be effective in reducing swelling in the legs and feet.

The mattress on the electric bed is specialized to reduce pressure and helps to prevent sores that can develop when patients have reduced strength and energy to adjust their own position. If a patient has weakness or loss of energy and strength, it is important to ensure that they have assistance to reposition frequently. Adjusting position every couple of hours is recommended. Even small adjustments in position can help prevent skin complications.

Some mattresses have air pumps that circulate air through the mattress to alternate the pressure throughout the mattress. These mattresses are effective in reducing pressure for even the most severe wounds. Even with this specialized mattress, patients should continue to readjust position.

You will need to supply sheets for the bed. Long twin fitted sheets fit best. Most twin sheets will work, especially those made of stretchy fabric. If necessary, a full or queen flat sheet can be used by tucking it in around the edges of the mattress.

Cleaning Instructions:

Keep sheets on the mattress to help keep the mattress clean. Change the sheets weekly or as needed to help prevent infection. The mattress can be cleaned with soap and water and allowed to air dry as needed. It is recommended to use absorbent pads under a patient if there is a chance they might be incontinent of bowel or bladder. Hospice will provide you with disposable under pads called "chux". You can purchase cloth under pads at some pharmacies or online. If you would like some recommendations, talk with your nurse.

Over the Bed Table

An over-the-bed table may be provided along with your hospital bed. These tables are useful to place meals or other objects the patient would like to keep close. Phone, drinks, books, Kleenex, lip balm, etc.

To raise the table, pull up on the adjustment lever (located underneath the tabletop) with one hand and raise the table to the desired position, then release the adjustment lever.

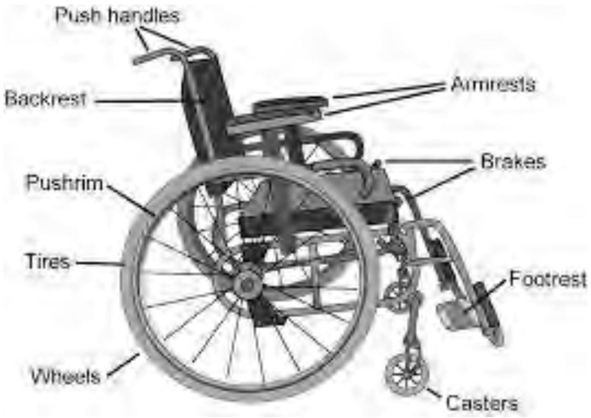
To lower the table, pull up on the adjustment lever with one hand and with the other hand apply pressure straight down on the table over the vertical adjustment bar and release the lever.

Cleaning Instructions:

The table should be wiped down weekly with a household sanitizing spray and paper towel or as needed when dirty to help prevent infection.

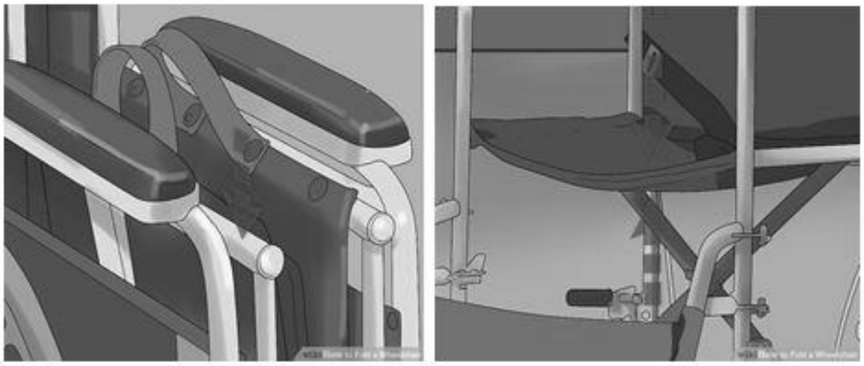
Wheelchair

Patients typically use a wheelchair if physical activity is an increasing burden or if walking is no longer safe due to weakness. Wheelchairs are also useful for patients who get tired quickly or have difficulty breathing with activity. Using the wheelchair can conserve energy for other important tasks such as visiting with family or friends. Getting outside or going on an outing may seem like too much work, but a wheelchair can make these activities easier.

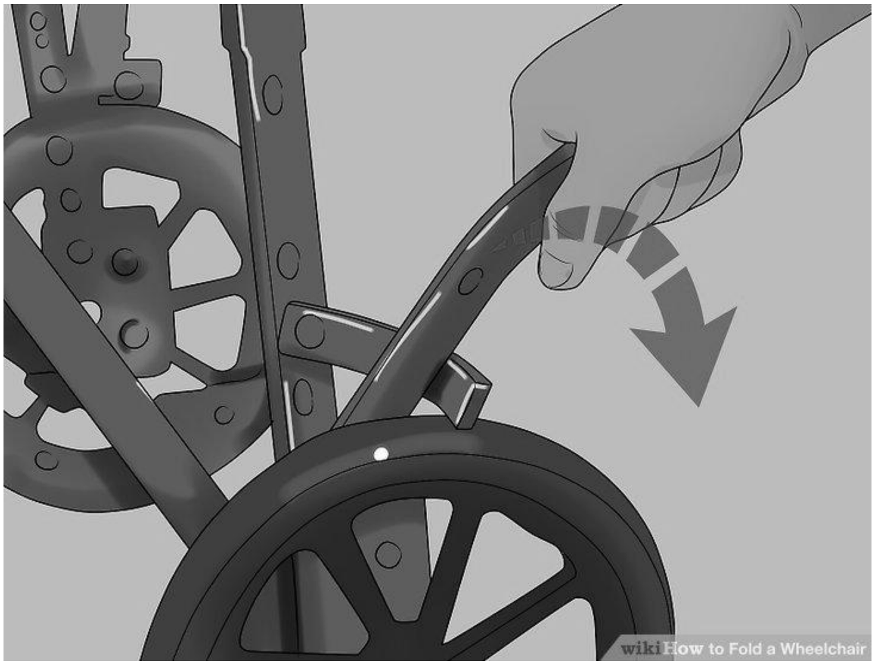


Always lock both wheels before transferring into or out of the wheelchair. Remove foot pedals during transfer for safety. Your nurse can demonstrate the proper method for transferring. You can also reference the personal care section for step-by-step instructions.

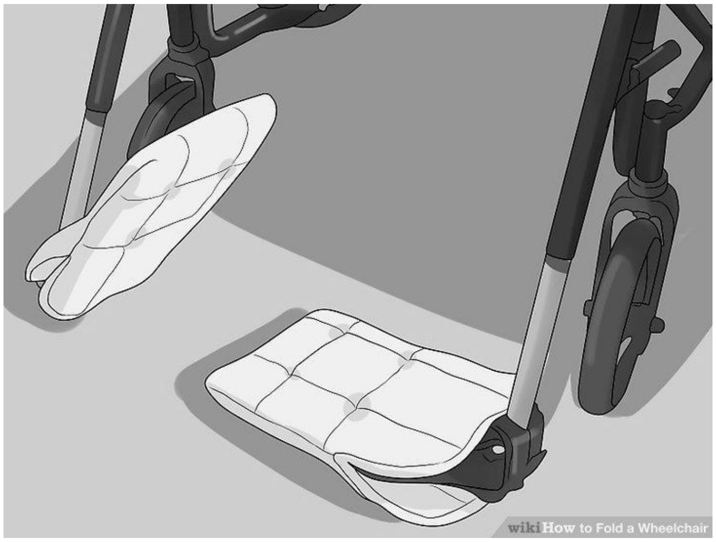
- Folding and unfolding the wheelchair
  To fold, simply grasp the center edge of the seat upholstery and lift up. To unfold, tilt the chair slightly to one side to raise the wheels on the opposite side off the floor. Then press down on one or both seat rails.



- Applying the wheel locks
  Push forward on the lock tips, (or pull back on the pull to lock type), until the locks snap into the locked position. Do not attempt to enter or exit the wheelchair without having the locks securely engaged.



- Folding the footrests up into a vertical position
  If the footrests are equipped with heel loops, these must first be pulled forward over the rear of the footrests. The footrests themselves can then be folded up into the vertical position by lifting on the inside edges of the footrests.



- Releasing and swinging away the footrests

  Whether the wheelchair is equipped with standard footrest or elevating leg rests, this procedure permits the user to make much closer approaches for easier, safer transfers to beds, toilets, automobiles, etc. Simply activate the release mechanism and swing the footrest around to the side of the wheelchair. While in this swing away position, the footrest can also be removed from the chair entirely, by simply lifting it off. This removal will make lifting the chair or loading it into a car much easier for the caregiver.

  From the swing-away position the footrest can be returned to the standard position by simply swinging it back to the front of the wheelchair. It will lock automatically in the forward position. If the footrest has been removed from the chair, simply replace it in the swing-away position, and then swing it back to the standard front position when required.


- Elevating leg rest adjustment

  If the wheelchair is equipped with elevating leg rests, the legs of the user can be elevated by simply lifting the leg rests up to the desired position. To lower them, support the leg rest with one hand while activating the elevation release mechanism with the other hand and lower the leg rest to the desired position.

- Footrest length adjustment
  The position of the footrest on either standard footrests or elevating leg rests is adjustable to fit the user's leg length. The footrest should be adjusted to support the weight of the user's foot and lower leg in such a position that permits weight bearing by the thighs.

Cleaning Instructions:

The chair frame and seat can be wiped down monthly with a household sanitizing spray and paper towel or as needed when dirty to help prevent infection.

Walker

Walkers are useful to increase stability and safety while walking. Your walker should be adjusted according to your height and weight. Contact your nurse if you have any questions.

Use caution if your walker has a spring-loaded locking device. Avoid pressing or bumping these, as it will collapse the walker.

Put on the shoes you will be wearing when you use the walker. Shoes with nonskid soles are best. Stand up straight with your feet close together, relax your shoulders, and put the walker in front and partially around you. Grasp the side of the walker and look at the position of your elbows. Your elbows should be nearly straight.

The tops of the handgrips should be at the crease of your wrist; if not, adjust the walker's height by pushing in the button on each of the walker's legs and sliding the tubing up or down as appropriate. Make certain the button locks back into place and that the legs are adjusted to the same height. Take a few practice steps with the walker to ensure that you can move the walker without bending over.

- Safely moving with a walker
    - ☐ Wear shoes that fit well; tennis shoes or tied oxford style shoes with rubber soles are good choices. Avoid shoes that slide off your feet, such as slippers. Gripper socks are also a good option. Also avoid shoes with high heels or slippery soles.
    - ☐ To safely carry small items, attach a lightweight basket or bag to the walker's metal frame with snaps, Velcro straps, or hooks.
    - ☐ Make sure that the surface you are walking on is clear, flat, dry and well lit.
    - ☐ Remember to look ahead when you are walking instead of looking at your feet.
    - ☐ Do not use the walker if you have severe dizziness.
    - ☐ We strongly encourage you to remove <u>all</u> throw rugs as it is easy to trip over them.
    - ☐ Some four wheeled walkers have brakes; it is important to lock the brakes before standing or sitting. Brakes should be locked when stopping for rest as well.

Cleaning Instructions:

The walker frame can be wiped down weekly with a household sanitizing spray and paper towel or as needed when dirty to help prevent infection. Ensuring good handwashing and wiping down hand grips daily with a sanitizing spray can help prevent spread of germs.

Bedside Commode

Bedside commodes are useful when patients are tired or have poor activity tolerance. They can be placed next to the bed or chair. This allows the patient to transfer from bed or chair directly to the commode thus making the task much easier. If a patient is going to the bathroom frequently, multiple trips to and from the bathroom can consume a lot of energy. A bedside commode can be helpful.

Sometimes the bedside commode is kept at the bedside and others prefer to bring the commode to the patient when needed and store it out of the way when not in use. The removable bucket allows the caregiver to easily empty and clean the bucket with each use.

The height can be adjusted by pressing the spring-tension buttons on each leg and telescoping the leg in or out to the desired length. Care should be taken to see that the spring-tension buttons pop back out and lock securely into selected hole.

Keeping wet wipes or toilet paper with the commode is recommended. The bucket should be rinsed with soap and water after each use.

Cleaning Instructions:

The commode frame and seat can be wiped down weekly with a household sanitizing spray and paper towel or as needed when dirty to help prevent infection.

Shower or Bath Bench

Installation of the standard bath bench consists simply of placing it in the tub in the appropriate position, usually near the end opposite the faucets. Most bath seats have rubber or plastic feet that are slip resistant, but certainly not slip proof. Wiping these feet with alcohol removes any oil or grease and enhances the slip resistant characteristics. The feet should be cleaned initially on a new product and repeated periodically during regular use. It is also important to keep the bathtub clean and free of soap film to help prevent slipping.

Cleaning Instructions:

The bench frame and seat can be wiped down weekly with a household sanitizing spray and paper towel or as needed when dirty to help prevent infection.

Transfer Bench

The transfer bench permits a sliding transfer from a wheelchair to a bathtub. This sliding type of transfer can be performed because the transfer bench extends out beyond the edge of the tub.

The transfer bench is also helpful to users who have difficulty stepping over the side of the tub safely. Once seated on the bench, with legs outside the tub, all that is required is to lift one leg at a time into the tub and slide over.

Installation of the transfer tub bench consists of simply placing it in the tub in the appropriate position. Cleaning the rubber feet or suction cups with alcohol removes any oil, grease or talc and enhances the slip resistant characteristics. The feet should be cleaned initially on a new product and repeated periodically during regular use. It is also important to keep the bathtub clean and free of soap film to help prevent slipping.

The bench is placed in the tub facing the faucet end, with the two outer legs resting on the floor outside the tub. The two inner legs should be adjusted to a height approximately even with the side of the tub. The outside legs should then be adjusted so that the seat slopes slightly toward the inside of the tub. With this setting, any water falling on the seat surface drains into the tub.

A hand-held shower is usually a necessity with the use of a transfer tub bench. Other bathing aids such as non-slip safety mats or tread may also be very helpful.

Cleaning Instructions:

The bench frame and seat can be wiped down weekly with a household sanitizing spray and paper towel or as needed when dirty to help prevent infection.

Patient Lift

Some patients lose strength or coordination in their limbs due to disease progression, but still have energy and strength to sit up in a chair. These patients might benefit from a mechanical lift to transfer from bed to chair and back again. Lifts are not appropriate for patients who do not tolerate activity or sitting up in a chair. If a patient has poor activity tolerance, or loses the ability to transfer on their own, your nurse will discuss goals and comfort options. Patients often have more energy and report being more comfortable remaining in bed.

A sit to stand lift is recommended when a patient tolerates sitting up in a chair, is still able to support their own weight in a standing position but no longer has the strength to push themselves to a standing position with light support from one caregiver.

A full mechanical lift (Hoyer Lift) is recommended when the patient tolerates sitting up in a chair but is unable to participate in the transfer with light support from one caregiver and is unable to support their full weight when in standing position.

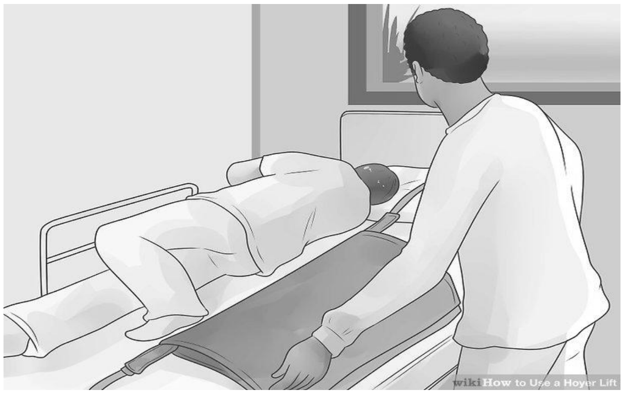
Safety Precautions:

- Never exceed the maximum capacity of the lift.
- Unplug the lift prior to use.
- Never push or pull on the lift boom to avoid tipping it over.
- Do not lock the brakes or block the wheels when lifting a patient. The wheels must be free to roll to allow the lift arm to center over the base.
- The weight must be centered over the base.
- When lifting always keep patient centered over the base and facing the attendant who is operating the lift.
- Patients (especially when wearing slippery garments) may slide out of the sling if it is not adjusted properly.
- To reduce the hazard of tipping over, spread the adjustable base to its widest position before lifting anyone.
- Do not move the lift and the patient over shag or deep pile carpeting, thresholds, unpaved surfaces, outdoors, or anywhere that an obstruction can cause wheel stoppage and tip over.

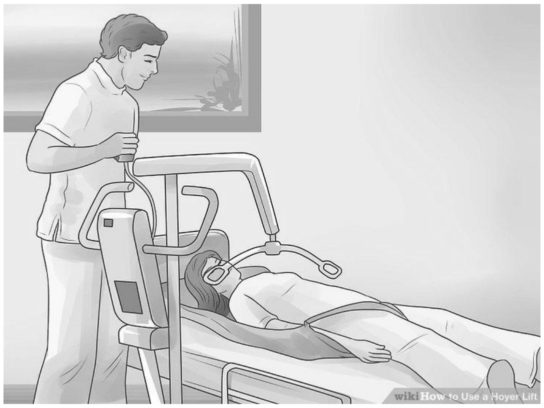
Transfer from Bed to Chair using a Full Mechanical Lift:

1. If the patient is in a hospital bed, raise the level of the bed to the highest position before moving the patient onto the sling. Note: This will reduce strain on the caregiver's lower back.

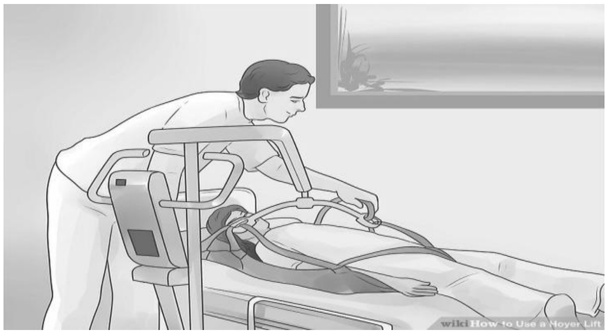
2. Place the sling under the patient.



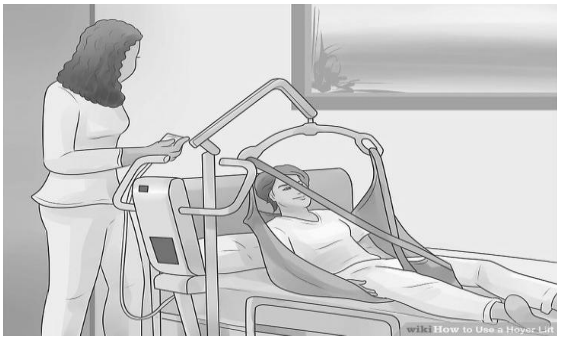
3. Move the lift into position so that the open end of the base is as far under the bed as possible.



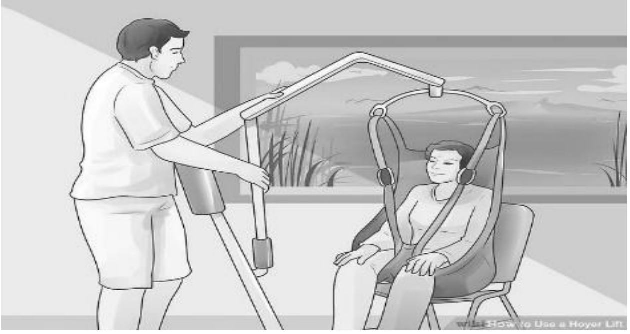
4. Hook the sling to the lift as instructed.



5. When the patient is ready to be lifted, lower the level of the bed to decrease the distance you have to elevate the patient.
6. Raise the lift until the patient's buttocks are above the surface of the bed.



7. Move the lift into position so that the open end of the lift base straddles the chair.
8. After the patient has been centered on the chair, rotate them so that their back is toward the chair back.
9. Use the hand bar to adjust the patient's position to a sitting position.

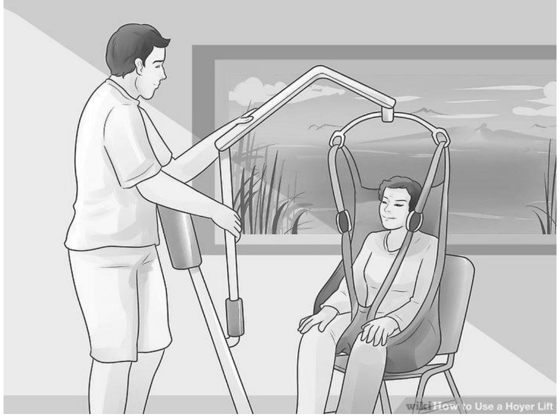


10. Carefully lower the patient onto the chair.
11. Remove the sling.

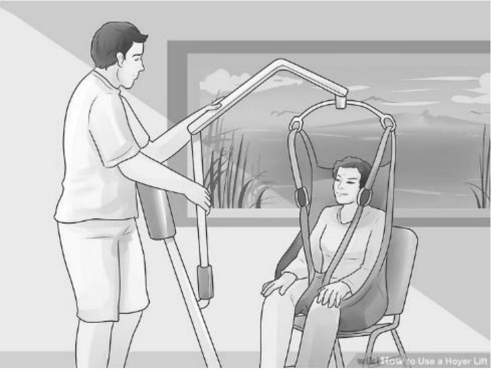
Transfer from Chair to Bed using a Full Mechanical Lift:

1. Place the sling under the patient.

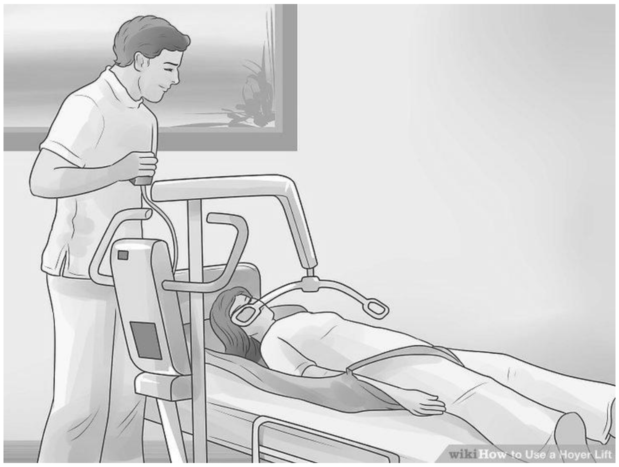
2. Move the lift into position so that the open end of the lift base straddles the chair.



3. Hook the sling to the lift as instructed.
4. Raise the lift until the patient's buttocks are off the chair and continue to raise the patient until their buttocks are above the height of the bed. You may need to lower the bed to the lift's height. If the patient cannot be lifted above the bed, do not pull the patient on to the bed. This can result in a tip over and could cause serious injury to the patient and attendant.



5. Move the lift into position so that the open end of the base is as far under the bed as possible.
6. After the patient has been centered on the bed, rotate the patient so that they face the foot of the bed.



7. Carefully lower the patient onto the bed.

8. Remove the sling and position the patient comfortably in bed.

Oxygen Equipment

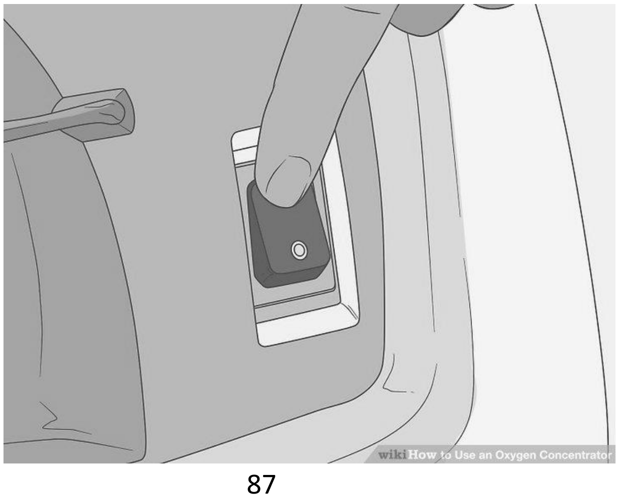
Oxygen Concentrator

An oxygen concentrator is a machine that separates room air into oxygen and nitrogen. The nitrogen is discarded, while the oxygen is stored, concentrated and delivered at 90% to 95% purity. Please Note: *The use of this device does not reduce the oxygen in the room air because of the small amount of oxygen required.*

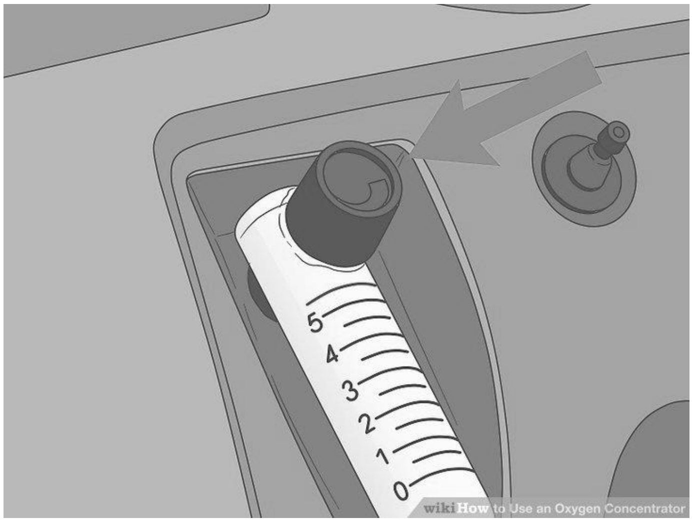
Turning the Concentrator On:

1. Plug the concentrator into a properly grounded electrical wall outlet. Do not use an extension cord. Do not plug into an outlet controlled by a wall switch or dimmer.

2. Attach the tubing from your cannula to the oxygen outlet.
3. Set switch to the "ON" position.



4. Turn the flow adjustment knob until the flow meter registers the flow rate prescribed by your doctor. Your doctor prescribed the flow of ______ liters per minute.



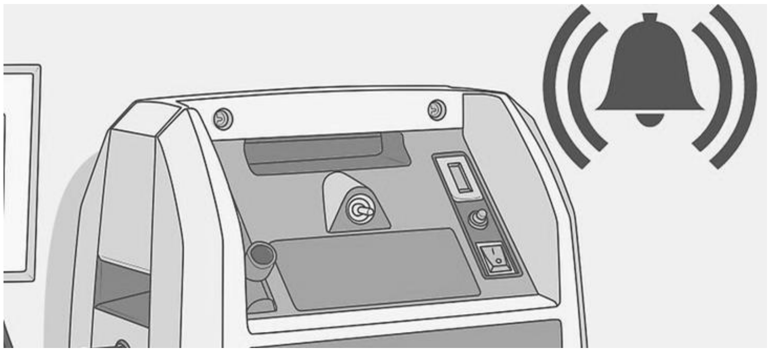
5. Put on the cannula and adjust for comfort. See **"Facts about Your Nasal Cannula"** in the general information section on oxygen therapy that was provided with these instructions.

Turning the Concentrator Off:

1. Remove the nasal cannula.
2. Set the Concentrator power switch to the **"OFF"** position.
3. It is not necessary to turn the flow control off after it has been set properly. It should be checked, however, each time the concentrator is turned on and periodically during use. The flow control may require minor adjustments from time to time.

Alarm:

Oxygen concentrators are equipped with an alarm to alert you in case of power failure or an equipment malfunction. If the alarm goes off, first check to see that the power cord is still connected to the electrical wall outlet. Then check other electrical appliances in the home to determine if there is a power failure or if a fuse or circuit breaker has blown.



If there is a power failure, turn the concentrator off to stop the alarm. Then, turn on your backup cylinder system and connect your oxygen tubing to it. If your electrical service does not return within a reasonable length of time notify our office so you can be provided additional oxygen for your backup system.

If you determine that there is no power failure and that the alarm indicates an equipment malfunction, turn the concentrator off. Then, turn on your backup cylinder system and connect your oxygen turning to it. *Notify Rainbow Hospice Care of the malfunction immediately.*

If you find it necessary to use your backup cylinder system during several intermittent short-term power failures, it is important to check the pressure gauge to ensure that you have an adequate supply of backup oxygen. Please follow the instructions provided for your backup system to determine the amount of oxygen you have left.

Oxygen Concentrator Cleaning and Maintenance

Twice each week you will need to clean the inlet air filter. This sponge-like filter should be removed and washed under running tap water. Be sure to shake out the excess water, then press or squeeze dry with a clean towel before replacing the filter. *The concentrator should NOT be used without this filter in place.*

You should also wipe down the outside of the concentrator with a damp cloth periodically. Make sure that the concentrator if off and unplugged prior to cleaning the cabinet.

Oxygen Concentrator Safety Precautions

Never place your concentrator directly against a wall, drapes or other objects. There must be 12 – 18 inches around concentrator to allow free circulation of air around all sides of the unit. You may notice some heat from the unit, but this is normal.

"No Smoking" signs should be prominently displayed in all areas where oxygen is being used or stored. Follow all of the other safety precautions outlined in the general instructions.

Oxygen Humidifier

A humidifier is often included as part of your oxygen equipment. A humidifier is a bottle that is filled with distilled water and attached to the oxygen system to moisten the oxygen before you inhale it. Medical oxygen is dry and breathing in dry air can increase dryness in the nose mouth and throat. If you use a humidifier, it MUST be kept clean at all times. Bacteria can grow in the water and on the wet surfaces in the moist environment of the humidifier. This bacteria growth can lead to infection. Distilled water is recommended primarily to ensure the water is bacteria free and has no minerals or metals. Distilled water is inexpensive (approximately $1/gallon) and can be purchased at the local grocery store or pharmacy.

Humidifier Care:

Empty, rinse and refill your humidifier every day. Do not overfill. Wash hands before refilling humidifier. Be sure that the cap is screwed on to the bottle tightly enough to prevent leaks and that the humidifier fitting is properly attached to the oxygen equipment.

1. Your humidifier should be thoroughly cleaned and sanitized at least once a week, more often if directed by your physician or nurse.
2. Disconnect the tubing to the cannula or mask and unscrew the humidifier fitting.
3. Disassemble the humidifier; there are two parts, the bottle and the cap with the stem attached.
4. Avoid touching any of the internal parts of your humidifier with your hands or allowing them to touch the surfaces of countertops, sinks, etc., when you are adding water or when you are sanitizing.

Humidifier Cleaning Instructions:

To clean your humidifier you will need:

- Dishwashing detergent
- White vinegar
- A small brush (a bottle brush or tooth brush)

- Two basins or buckets

  Basin #1 contains warm water and detergent. This detergent solution should be discarded after each cleaning.

  Basin #2 contains one cup of white vinegar to three cups of water (double the amount if necessary to have enough solution to cover the disassembled humidifier completely when soaking).

1. Wash the disassembled humidified in warm sudsy water (basin#1). Use a brush to remove any residue.
2. Rinse all parts thoroughly under clear, warm running water.
3. Soak all parts in vinegar solution for 20 minutes (basin #2). Make sure all parts are completely submerged in the solution.
4. Wash hands before removing humidifier components from the solution. Avoid touching internal surfaces with your hands.
5. After soaking, rinse all parts in warm running tap water.
6. Shake off excess solution. Place on clean paper towels and cover with paper towels. Allow to thoroughly air dry.
7. Once completely dry, store cleaned humidifier in clean Ziploc or twist tied plastic bags.
8. It is best to have two humidifiers, one to use while the other is being cleaned and sanitized. Remember: Never touch the inside of the humidifier or the stem. You should discard the humidifier if you notice discoloration of the bottom of the stem inside the humidifier.

Nasal Cannula and Tubing

A nasal cannula is the flexible plastic device with the two short tips or prongs that fit into your nostrils. It is used to administer low to moderate oxygen concentrations through your nose.

With the humidifier, tubing and cannula connected, set the oxygen flow at the prescribed flow rate. Insert the tips of the cannula in the nostrils. Slip the two smaller plastic tubes over the ears and down under the chin. Adjust the plastic slide until the cannula fits snugly, but comfortably.

1. A nasal cannula should always be worn with the prongs curved toward you.

2. You do not always have to breathe through your nose when using a nasal cannula. The continuous flow of oxygen will collect in the space in your nose and throat. Each time you inhale, you breathe this collected oxygen into your lungs.
3. The flow rate prescribed by your doctor is set on the flow meter of your oxygen system. DO NOT increase the flow rate to compensate for longer tubing.
4. If your nose becomes irritated from wearing the nasal cannula for long periods of time, you may want to use a *water-based lubricant* inside your nostrils. It may be helpful to consult your doctor or pharmacist, who can suggest a good water-based preparation. DO NOT use an oil-based lubricant such as Vaseline.
5. It is recommended that you change cannulas at least every two weeks to avoid possible contamination. You may change more frequently if cannulas are crusted from nasal drainage or damaged.
6. Tubing to the cannula should be replaced monthly. If no humidifier is used, the tubing should be changed every three months.

Oxygen Safety Precautions

Oxygen does not explode and it does not burn, but an atmosphere enriched with oxygen will make a fire burn faster and hotter. To avoid the chance of fire and other possible hazards associated with oxygen follow these rules:

1. Do not permit open flames or smoking in the room where the oxygen is being used and/or stored.
2. Do not permit the use of friction toys or other devices that may create a spark where oxygen is being used and/or stored.
3. Do not use electrical equipment in an oxygen-enriched atmosphere. (Examples: electrical shavers, electric blankets, electric heating pads, etc.) *Keep these appliances at least five feet from any oxygen source*.
4. Do not use any petroleum products such as oil based lotions, creams or Vaseline while receiving oxygen. Do not handle or allow anyone to handle oxygen equipment with these substances on their hands.
5. Do not use aerosol sprays in the vicinity of oxygen.
6. Do not use alcohol or alcohol-based products, or products containing ether or flammable products.
7. Do not use oil or grease on oxygen equipment.
8. Do not allow oxygen tubing to be covered by bedding or any other objects.
9. Do not route longer oxygen supply tubing under carpet or furniture.

10. Do not leave oxygen turned on when not in use.
11. Do not abuse or handle oxygen containers roughly.
12. Do not store oxygen in a confined area.
13. Do not allow untrained persons to use or adjust the equipment.
14. Do not attempt to repair oxygen equipment.
15. Do not place containers near radiators, heat ducts, stoves or any other sources of heat.
16. Do not open cylinder valves quickly.
17. Do not transport oxygen in an enclosed area such as the trunk of a car.
18. *Do* use a stand for all oxygen cylinders in use. Extra Cylinders may be secured upright in a rack. Smaller portable cylinders may be stored lying on the floor.
19. *Do* use all cotton clothing and all cotton bedding to avoid sparks from static electricity. Avoid use of nylon and other synthetic fibers as well as wool.
20. *Do* keep oxygen equipment out of reach of children.
21. *Do* keep oxygen equipment free of dust by wiping it off periodically with warm soapy water. A mild household detergent may be used if necessary.

Portable Oxygen Cylinders

1. Prior to each use, inspect product for visible damage. Do not use if damage is found.
2. Check cylinder valve to be sure it is not bent or damaged. A damaged valve could leak or fail, or it may not make a tight connection when cylinder is placed into use.
3. Make sure product and cylinder valve are free of oil, grease, or other contaminants.
    - Do not use products if oil, grease or dirt is found. Particles propelled in a high-velocity oxygen stream could create a spark, causing a fire. Oil and grease can react with oxygen and other oxidizers, causing an explosion.
4. Before installing regulator, "crack" the cylinder valve by opening the valve slightly and closing to remove any foreign particles.
5. Be sure the regulator is in the "OFF" position.
6. Ensure the high pressure inlet port has a washer to make a proper seal.
7. Align the regulator pins to the cylinder holes.
8. Hand tighten the T-Handle.
9. Using a cylinder key or wrench, SLOWLY open the cylinder valve counterclockwise until open.
10. Set the dial to your prescribed liter flow.

11. To remove the regulator from the cylinder:
    - Completely close oxygen cylinder valve with cylinder key or wrench.
    - Set regulator in the "OFF" position.
    - SLOWLY loosen T-Handle and remove regulator from cylinder.

Oxygen Travel Tips

- Transport oxygen in the back seat of your car, never in the trunk. Secure the oxygen concentrator in a stable, upright position.
- Open your window one inch or more when transporting oxygen, to prevent any accumulation of oxygen in your car.
- Always keep portable pack in an upright position when handling as well as when transporting. Try using a seat belt and/or hanging the portable unit from a headrest.
- Contact Rainbow Hospice Care in advance if you plan to travel outside your usual area.

Portable Oxygen Use Duration Chart

LPM	E CYLINDER	B (M-6) CYLINDER
	Hours & Minutes	*Hours & Minutes*
1	7 hrs 56 minutes	1 hr 55 minutes
2	3 hrs 58 minutes	57 minutes
3	2 hrs 38 minutes	38 minutes
4	1 hr 59 minutes	28 minutes
5	1 hr 35 minutes	23 minutes
6	1 hr 19 minutes	19 minutes
8	59 minutes	14 minutes
10	47 minutes	11 minutes
15	31 minutes	7 minutes

5

Inpatient Center

Rainbow Hospice Care

Rainbow Hospice Care Inpatient Center

Most people say they hope to receive end of life care in the comfort of their own home, surrounded by the people and things most important to them. Thankfully, for the majority of Rainbow Hospice Care patients, home care is not only possible, it's all they will ever need.
Sometimes, the hospice team determines that a higher level of medical and nursing attention is necessary. If this happens, the specialized care available at the Rainbow Hospice Care Inpatient Center may be the best option.

What makes Rainbow Hospice Care Inpatient Center Special?

The Rainbow Hospice Care Inpatient Center is a true community asset—with the land and all construction costs funded by donations. The 12,000 square foot freestanding facility is built to hospital code but offers a peaceful, homelike setting. It is uniquely designed, equipped, and staffed to provide the best physical, emotional, social and spiritual care for those facing the end of life.

The center is staffed by highly skilled Registered Nurses (RNs) and Certified Nursing Assistants (CNAs) with access to physicians, social workers, bereavement counselors, chaplains, dietitians, trained volunteers, and other experts in providing end-of-life care.

Admission Process

Admission to our center is arranged by your hospice care team through the patient's primary physician or other health care provider. A nursing assessment is required for all referrals to verify the most appropriate level of care. If the patient is already receiving hospice care at home, admission is coordinated through his or her Rainbow Hospice Care clinical team.

Who Pays for Inpatient Care?

Like hospice home care, short-term acute care and respite stays at the inpatient level are typically covered by Medicare and Medicaid, if eligibility criteria are met. Private insurance benefits and coverage varies by plan. Our staff will work with you to determine which coverage and/or payment options are available, depending on your specific needs and circumstances.

Types of Care

- *General Inpatient (GIP)* – *Short-term acute care* is available to those needing more intensive medical and nursing care than can be realistically managed at home. Examples include uncontrollable pain, nausea and vomiting, severe shortness of breath, agitation, seizures, and other difficult symptoms. Most patients are able to return home again when their symptoms stabilize. For those who can't return home, we help to arrange alternative accommodations. As a result, inpatient stays are fairly short-term.
- *Respite care* is also available to hospice patients for up to five days at a time when their families need a break from continuous caregiving activities.
- For longer term inpatient care options, please consult with your social worker.

The Rainbow Hospice Care team:
Specially trained registered nurses (RNs) and certified nursing assistants (CNAs) are available around the clock, with shift changes every 12 hours (the day shift runs from 7:00 a.m. – 7:00 p.m., and the night shift from 7:00 p.m. – 7:00 a.m.). Other clinical team members make frequent regular visits. Following is an explanation of roles and responsibilities of many key staff available to you.

Physician Medical Director, Hospice Physicians and Nurse Practitioners are medical professionals that assess patient needs, order medications and treatments, honestly discuss benefits and side effects so that you can make informed decisions and collaborate with the patient's primary physician.

Registered Nurses (RNs) Assess and manage symptoms such as pain, nausea and vomiting, trouble breathing, anxiety, seizures, administer medications, treatments, and procedures, educate and support patients and families, and keep the physicians informed of the patient's condition and needs.

Certified Nursing Assistants (CNAs) respond to call lights and provide personal care assistance such as bathing, dressing, toileting, repositioning and transfers, eating and drinking, monitor patients and report significant changes to RNs.

Other professional caregivers including social workers, chaplains, grief counselors, nutritionists, and complementary therapy providers can offer emotional, social, and spiritual support to both patients and families.

Trained volunteers provide valuable support to staff, families and patients' friends through a broad range of activities. Those activities include:

- Greeting visitors and giving tours of the building
- Providing companionship to patients and families
- Preparing and presenting meals for our patients and guests
- Assisting with direct-care of patients
- Helping with administrative, housekeeping, gardening, and landscaping tasks
- And more.

Dining options: A wide variety of off-site food establishments from fast-food drive-ins to high-end restaurants are located within easy access to our facility. Detailed information, including maps, menus, and phone numbers are available at the nurse's station and reception desk.

Children are always welcome at the Rainbow Hospice Care Inpatient Center. Younger children may enjoy the play area located in the family room. To ensure their safety and security, we ask that all children under the age of 12 be supervised by an adult at all times.

Well-behaved pets are also welcome; however, there are some restrictions to ensure the safety and comfort of all. If you'd like to bring a dog, cat, or other animal for a visit, please be sure to check in with our staff first.

Our 12,000 square foot building is situated on four acres, surrounded by beautiful views, gardens, woodlands, and paved pathways. A pond and fountain is located across the road. For your safety, please stay on paved walkways and away from steep hillside embankments. No swimming or wading is allowed in the pond.

A NO SMOKING policy is in effect for all areas of the buildings. There is no smoking on patient patios. Please use designated receptacles, located at the front entrance to discard cigarettes before entering the building.

Public restrooms are located on both the upper and lower level of the building. Two main restrooms can be found in the great room between the main entrance and the nurse's station (next to the chapel).

Overnight stays can be arranged easily. Limited sleeping accommodations for families and friends are available in each patient suite. Several hotels and motels are located nearby. For details, please check with staff.
Mail, Messages and Deliveries: Staff will bring all phone messages, mail, flowers, or other deliveries to the patient suite directly upon receipt. Stamped outgoing mail can be given to staff at the nurse's station.

Visiting Hours: The center is open around the clock, 365 days a year and visitors are welcome any time, day or night.

Entrance: Visitors are encouraged to use the main entrance and upper parking lot. When the front doors are locked, simply press the doorbell located to the right of the door and our staff will buzz you in.

Location: The Rainbow Hospice Care Inpatient Center is ideally situated in Johnson Creek, just north of the intersection of I-94 and Highway 26. Easily accessible from all directions, the location allows patients to remain close to home—providing greater convenience and connection to family and friends who don't have to navigate time-consuming, long-distance commutes in order to visit loved ones. Our Inpatient Center is at 1225 Remmel Dr. Johnson Creek, WI 53094.

Building tours:
Please let us know if you would like a personalized tour of the building and grounds. We will be delighted to show you around.

Click the link below to take our virtual tour:
https://youtu.be/6DNaazx-cMU

In case of emergency:
We monitor for severe weather and conduct fire drills routinely. Announcements will be made when drills occur. In the event of an actual emergency, staff will provide instructions accordingly.

When you first arrive:

Please check in with the volunteer receptionist at the front desk. If no receptionist is available, proceed to the Nurse’s Station by following the main corridor straight ahead past the dining room, chapel, and rest rooms, through the next set of double doors toward the piano.

Patient suites:

Eight patient suites offer a variety of features meant to provide the highest level of comfort and ease for patients and their families and other visitors. All patient rooms are similar in layout and configuration, although furniture can be rearranged according to patient and family preference. Mementos and personalized touches can be added as desired, however please do not affix anything to the walls.

Standard accommodations include:

- Call light alerts to request clinical staff and volunteer assistance
- Fully adjustable beds for comfort and ease of care. Please keep the bed in the lowest position when the patient is unattended
- Custom recliner (lock wheels before transferring)
- Med-gases (oxygen, air, suction, located out-of-site in the cabinet next to the bed

- Adjustable tray table
- Personal storage including bedside tables, and armoire
- Tables, chairs, easy chair, ottoman, sleeper sofa

Patient bathrooms offer a fully tiled, open and barrier-free space with toilet, granite countertop sink & vanity, and a shower which is designed to accommodate wheelchairs, walkers, shower benches and more.

Telephone service: Each patient room has a private phone line with One hand-set extensions. Your personal phone number will be provided upon admission.

You must first dial "8" to place outgoing calls.
You may receive incoming calls to your room any time. If you don't want to receive calls directly, please tell our staff so they can screen them and take messages for you.
Electronics (TVs and computer access) include one wide-screen TV with remote. Channel listings are provided in each room. Each room also contains a CD player/radio (you may bring your own CDs, or borrow from our CD library at the reception desk), and free Wireless Internet access.

Individual room-temperature controls can be adjusted easily according to your preference. You may also feel free to open patio doors or windows — however, we ask that you close the interior door to the corridor when exterior door or windows are open.

Windows and doors allow beautiful views and access to natural light and ventilation to the outdoors. Adjustable window shades are for privacy. Please lock doors and windows when they are closed.

Semi-private patio: Patient beds can be wheeled outside in nice weather. Please ask staff for assistance.

Additional patient-care services:

The Spa and Therapy Room located on the East Wing is a special place where patients may be treated to a whirlpool bath; the submergible lift allows for easy and comfortable transfers; a salon-style sink can be used for hair care when a full-bath isn't desired.

Patient laundry is located just off the family room (past the children's play area). We encourage patients to dress in whatever they're most comfortable wearing and are welcome to bring in their own pajamas, etc. If and when they need to be laundered, we have everything necessary to do the wash right here.

Places to relax, reflect, and refresh:

The Family Room is located between the two patient wings near the Nurse's Station and offers a comfortable lounge area for families and visitors to relax and refresh with a variety of seating areas, a fireplace, TV, and more.

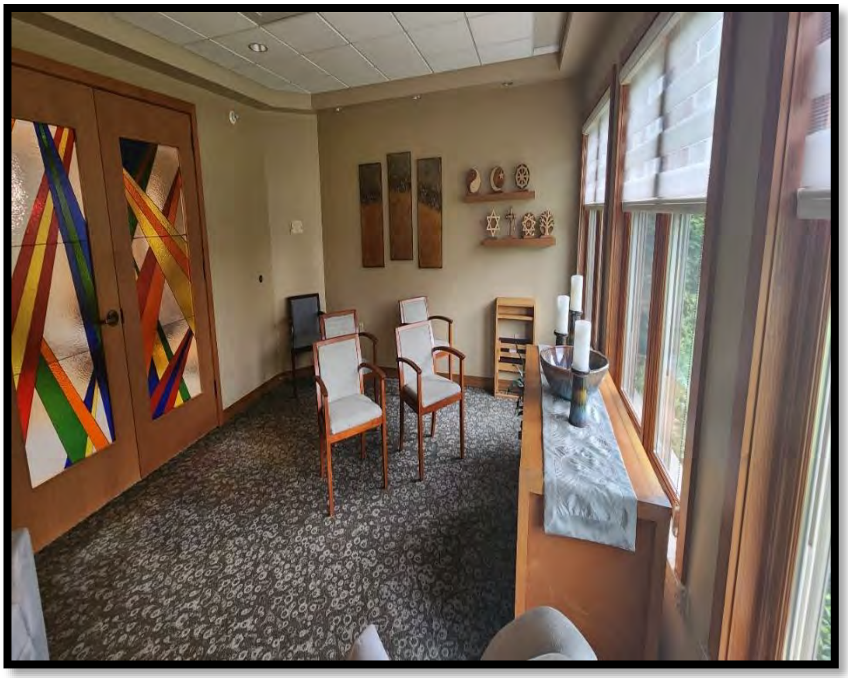
The Fireside Oasis family kitchenette features a full-size refrigerator, micro-wave oven, dishwasher, and tableware for your use and convenience. Family members and other guests are welcome to bring food in and use the dishes, utensils, refrigerator, microwave and dishwasher in the Fireside Oasis kitchenette, located in the family room. Additional utensils can be found in the dining room.

A special **Children's Play Area** including a number of books and toys is located in the same room, however, we ask that you please do not leave young children without adult supervision.

A Screened Porch is located directly off the family room and offers a fully furnished and protected outdoor setting for quiet relaxation during the warmer months of the year.

Another semi-private Quiet Space is located at the end of the west wing hallway.

Alcove desks in both patient wing corridors offer extra work surfaces for staff and visitors.



An Interfaith Chapel is located across from the dining room. This quiet contemplative space is open to patients and guests.

Kitchen & Dining services:

Our fully equipped commercial kitchen is managed by the Inpatient Center Chef, who along with trained staff and volunteers, prepare a variety of nutritious and appetizing meals for patients, visitors, and special events. Patient meals are served three times a day; however, additional food, snack items and beverages are available to patients and families 24 hours a day.

Family members and visitors are welcome to purchase lunch meals from the kitchen using the Special Menu posted in the dining room Monday through Friday. We ask that family please place orders by 10:30am so are sure to prepare enough. Meal Tickets are available at the Nurse’s station desk.

The Jones Family Dining Room is located just inside the main entrance across from the chapel. It offers an inviting place with free beverages including coffee, tea, juice, and soda available at all times. In warm weather, there’s additional seating outdoors on the patio.

Preparing for a Stay at the Inpatient Center

What to bring:

- ☐ All of your medications (in the original bottles, if possible)
- ☐ Eye glasses
- ☐ Hearing aides
- ☐ 2 changes of clothes
- ☐ 2 pairs pajamas or nightgowns
- ☐ 2 pairs of socks
- ☐ Slippers
- ☐ Sweater or robe
- ☐ Adult incontinence products—if you use them. *(We have more here but want to make sure that we get the right size for you)*
- ☐ Washbasin—if you already have one from Rainbow Hospice Care. *(You can use this to carry toiletries.)*
- ☐ Personal toiletries:
    - o Toothbrush & toothpaste
    - o Denture care items
    - o Shampoo
    - o Body wash
    - o Moisturizing lotion
    - o Razor *(especially if you prefer an electric razor)*
    - o Shaving cream
    - o Powder
- ☐ List of important telephone numbers
- ☐ Cell Phone and Charger
- ☐ Books or other recreational items as desired

6

Emergency Preparedness & Home Safety

Rainbow Hospice Care

Basic Home Safety

Electrical Safety

- Only three-pronged extension cords should be used for equipment requiring electricity.
- Use a three-pronged adapter when needed.
- Be sure electrical outlets are the required amperage and are grounded.
- Frequently check for exposed or faulty cords or wiring. Check for fraying or cracking.
- Do not expose electrical equipment to water or other liquids.
- Be sure electrical cords do not interfere with walkways.
- Electrical cords should not run under carpets or rugs.

Firearm Safety

- Safety for you and your hospice team is important. Please inform your team if you have firearms in the home.
- Firearms should be stored, unloaded, and in a locked place.
- Firearms should be stored in an area that children cannot reach.
- Firearms and ammunition should be stored separately.

Fire Safety

- Never smoke in bed or near oxygen equipment.
- Your home should be equipped with smoke alarms, at least one on each floor.
- Have a fire extinguisher near where fires may occur (fireplace, kitchen, etc.)
- Install smoke detectors on ceilings or high on walls and check them frequently. If the detector starts to beep intermittently, replace the battery immediately.
- Have a plan for evacuating the home in case of fire and have an alternate route available. Do not take anything with you − leave the house immediately.
- Keep the bedroom doors closed at night to delay the spread of fire and deadly gases.
- Incapacitated individuals should be placed in rooms with multiple escape routes, if possible. Before any emergency, a plan for assisting them out of the house should be discussed.
- If you cannot exit, stuff wet towels or clothing into door cracks. Stay near a slightly opened window. Cover your nose and mouth with a damp towel if the room is full of smoke, and get as low to the floor as possible.

- Do not leave candles burning unattended. Avoid burning candles when possible and utilize flameless candles.
- Ensure the lint filter on the dryer is emptied with each use.
- Check and clean dryer venting routinely.

Carbon Monoxide Alarms

- Ensure a carbon monoxide alarm is located on each level of your home.
- Replace carbon monoxide alarms that are older than 7 years.

Smoke Alarms

- Ensure at least one smoke alarm on every level of the home and inside and outside each sleeping area.
- Smoke alarms should be tested and cleaned monthly.
- Change batteries in smoke detectors twice a year and as needed. A good rule of thumb is to change the batteries when daylight savings time starts and ends.
- Replace smoke alarms that are older than 10 years.

Heating Safety

- Chimneys and furnaces should be cleaned and inspected yearly.
- Be sure furniture and other items that can catch fire are at least 3 feet from fireplaces or wall heaters.
- Avoid using space heaters when possible. If utilizing space heaters, use a heater approved by a national testing laboratory with a tip-over shut-off function.
- Avoid heating pads and electric blankets, when possible, especially for patients with impaired senses. If needed, use moist heat such as a hot water bottle.

Bathroom Safety

- Install grab bars securely around the shower or tub to assist in entering and departing.
- A tub or shower chair can increase stability.
- A toilet safety frame attached to the toilet seat can make it easier.
- Floors should be kept dry and non-slip carpeting used to prevent slippery conditions.

Walking Safety

- Wear shoes that are flat, preferably low-heeled shoes and non-skid soles.
- Keep shoes in good repair.
- Tack down carpeting. Do not use throw rugs or use only rugs with non-skid backing.
- Refrain from allowing furniture, clothing, or electrical cords to get in the way of your travel.
- Keep walkways clear and well-lit. Lamps and light switches should be conveniently located.
- Stairs should have non-slip treads and a securely mounted handrail.
- Wipe up spills. Make sure floors are dry before proceeding and avoid highly polished floors.
- Sidewalks and outdoor stairs should be shoveled, sanded, and/or salted during cold, wet weather. Your hospice team's safety is important, and they may be unable to visit if your driveway and access to your home are not kept clear.
- Turn on the lights before entering the room.

Stairway Safety

- Do not use loose rugs around the entry or exit to a stairway.
- Storage of loose items such as newspapers, boxes, or tools on stairways can cause you to trip or fall.
- Use a handrail and adequate lighting.
- Use non-slip strips securely fastened to the steps.
- Keep outdoor steps dry and free from ice and snow.

What to do if you fall

- Call Rainbow Hospice Care at 920-674-6255.
- A nurse visit will be made for a fall with or without suspected injury.
- If an injury is suspected, leave the patient in current position, and make them comfortable by covering them with a blanket and providing a pillow.
- Continue to monitor for changes in condition and report to Rainbow Hospice Staff immediately should change occur.

Home Safety Checklist

Check off each item that describes the situation in your home. Cross off items that do not relate to your home. Each item that is left unchecked represents a potential hazard.

Stairways, Halls, and Outdoor Steps

- ☐ Stairways with three or more steps have a strong handrail.
- ☐ Stairways and halls are free from boxes, toys, mops, brooms, tools, and other tripping hazards.
- ☐ Gates at the top and bottom of stairs prevent children from falling.
- ☐ The head and foot of stairs have no small or loose rugs.
- ☐ Stair carpeting or covering is fastened securely.
- ☐ Stairways and halls have adequate lights, controllable at either end.

Kitchen

- ☐ Matches are kept where children cannot get them.
- ☐ Knives and sharp instruments are kept in a special knife drawer or holder out of reach of children.
- ☐ Can openers don't leave sharp edges on cans.
- ☐ Lye, disinfectants, and cleaning products are kept out of reach of children.
- ☐ Pan handles are turned away from stove edges.
- ☐ Spilled grease, water, or bits of food are wiped up immediately.
- ☐ Potholders are within easy reach.
- ☐ A fire extinguisher is mounted near the stove.

Bathroom

- ☐ Tubs and showers are equipped with strong handholds.
- ☐ Tub floors have a non-slip surface installed.
- ☐ Poisons are clearly marked, sealed shut with adhesive tape, and kept out of reach of children.
- ☐ All medicines are out of reach of children and stored in a child-proof container.
- ☐ Lights are turned on, and labels are read before taking any medication.

Attic and Basement

- ☐ Ladder is strong, solid, and sturdily constructed.
- ☐ The stairway is sturdy and well-lighted.
- ☐ Children keep skates and play gear in a specific place.
- ☐ Walls and beams are free from protruding nails.
- ☐ Fuses and circuit breakers are the proper sizes.
- ☐ Rubbish and flammable materials are kept in covered metal cans until disposed of.
- ☐ Wastepaper is kept away from the furnace and stairs (stacked neatly in a box or bag) and cleared of possible basement seepage while awaiting disposal).

Living Room and Dining Room

- ☐ Furniture is placed to allow free passage.
- ☐ The furniture and woodwork are solid, in good repair, and free from splinters and rough spots.
- ☐ The fireplace screen fits snugly.
- ☐ Rugs are fastened or laid on nonskid pads.
- ☐ Rugs are kept from curling at the edges.
- ☐ Fire in the fireplace is extinguished at bedtime.
- ☐ Candles are in stable holders and carefully extinguished after use and before bedtime or leaving home.

Bedroom

- ☐ The smoke alarm has a fresh battery or secure electrical connections and is tested regularly.
- ☐ The carbon monoxide detector has a new battery or secure electrical connections and is routinely tested.
- ☐ Furniture is placed to allow clear passage between the bed and the door to avoid collisions in the dark.
- ☐ A light switch or lamp is within easy reach of the bed.
- ☐ A night light illuminates the bedroom and halls.
- ☐ Bureau and dresser drawers are closed when not in use.
- ☐ Bar across bunk beds to help prevent falls.
- ☐ Children are taught not to lean against windows or window screens.
- ☐ Low-sill windows are sturdily screened to prevent children from falling out.
- ☐ Smoking in bed is prohibited.
- ☐ Gas and electric heating devices are turned off at bedtime.

Stoves, Furnaces, and Heaters

- ☐ Stoves are located away from windows to avoid setting fire to curtains.
- ☐ Stoves and furnace pipes and flues are inspected and cleaned at least annually.
- ☐ Gas burners are properly adjusted and free from leaks.
- ☐ The water heater and all small gas or oil room heaters have vent pipes or flues to carry combustion gases outside the house.
- ☐ Water heaters or boilers have a safety valve and are checked annually.
- ☐ Flames from gas burners are protected from drafts.
- ☐ An insulating shield protects woodwork within 18 inches of the furnace, stove, or heater.
- ☐ Burnable materials are kept well away from stoves, furnaces, and heaters.
- ☐ An appropriate-size crescent wrench is stored near the shut-off valve of outside gas lines.

Porch, Yard, and Garage

- ☐ Handrails are sound and inspected periodically.
- ☐ Steps and walks are kept free from ice and snow.
- ☐ Yard and play spaces are free from holes, stones, broken glass, nail-studded boards, tools, and other litter.
- ☐ Tools and other dangerous articles are out of reach of children.
- ☐ Dangerous products and chemicals such as antifreeze, insecticides, cleaning fluid, and lubricants are kept in the original container in locked storage areas.
- ☐ Wires and low fences are brightly painted or marked with cloth strips to make them visible.
- ☐ Disposable materials are not burned outside.
- ☐ The lawn mower is equipped with proper safeguards.

Workshop

- ☐ Good ventilation exists, especially when sanding.
- ☐ Safety goggles and/or face masks are available, with eyewash.
- ☐ Baking soda is kept handy to neutralize acid burns.
- ☐ All electrical tools are grounded with three-wire plugs or clearly marked as doubled-insulated.
- ☐ The work area is clutter-free, including lumber scraps and oil rags.
- ☐ Lighting over the work area is adequate.
- ☐ All tools and accessories have a place and are in their place, except those used on a project.
- ☐ Guards are in place on all power tools.

Emergency Preparedness

Common sense is usually reliable during extreme weather changes or threatening situations. The following tips remind you of what to do when caring for someone during threatening weather conditions or disasters.

In extreme weather or natural disaster, it may be difficult for Rainbow Hospice Care personnel to visit immediately. We will be available by phone to assist you in every way possible. If the phone lines are down, stay calm and maintain your safety. Emergency personnel will be working to restore the system as rapidly as possible. Become familiar with your own safety and family disaster plan so that you will be prepared in the event of a disaster.

Emergency Communication Plan

- Make a communication plan with your family and caregivers.
- Keep emergency numbers posted where they can be easily seen.
- Consider if emergency numbers will be visible if you fall.
- Make sure you can easily reach a phone from your chair or bed.
- Consider a service like Lifeline if you may have difficulty accessing a phone.
- Contact 911 if you are in an emergency. Contact your hospice team as soon as it is safe.
- Your hospice team will inform you if extreme weather or other threatening situations disrupt visits or other hospice care services.

Evacuation Plan

- Have two ways out of each room.
- Plan a meeting place to meet after an evacuation. The meeting place should be near the front of your home, so firefighters know you are out.
- Practice your evacuation plan.
- Know to crawl low to the floor when escaping to avoid smoke.
- Know that once you are out, stay out.

Emergency Kit

- Put together an emergency kit with useful items in an emergency.
- Store the kit in an easily accessible location near evacuation paths.
- Emergency Kit Suggestions:

    - Water
    - Non-perishable food items
    - Can opener
    - Batteries
    - Flashlight and extra batteries
    - Duct tape
    - Blanket
    - First aid items (Band-Aids, ointment, bandages)
    - Cash
    - Screwdriver, hammer
    - Pens and paper
    - Toilet paper
    - Hand sanitizer
    - Candles, lighter/matches

Extreme Heat

- Drink plenty of fluids.
- Stay out of the sun and heat, preferably indoors, with curtains or blinds closed to cool the house.
- Use a fan or air conditioner to keep indoor temperatures moderated.
- Keep the air circulating.
- Apply cool cloths to the skin to cool the bed-bound patient.
- Increase the number of baths given.
- Try not to exert yourself physically.
- Minimal clothing is best to aid in body cooling through perspiration.

Extreme Cold

- Stay indoors where it is warm.
- Wear layers of clothing to maximize heat retention.
- Cover all exposed skin, including the face, during temperatures below zero to avoid frostbite.
- Close off unused rooms to maximize central heating and decrease heating costs.
- Cover windows with curtains to optimize heat retention indoors and reduce the effects of penetrating winds.

Tornadoes and Thunderstorms

- If threatening weather is coming, the patient and caregiver should seek shelter.
- If the patient is bed bound, move them to the farthest inside wall, away from windows and doors, if the bed can be moved.
- Cover windows with blankets to minimize the risk of injury from flying debris.
- Cover the bed-bound patient with blankets, mattresses, or cushions, to prevent any cuts or other injuries in the event of broken glass.
- Caregivers should seek shelter. While you may leave the patient briefly, if you are injured in a weather-related event, your patient will not have anyone to provide care after the storm.

Power Outage

- Have a flashlight and fresh batteries accessible during a power failure.
- Monitor the charge of your equipment's batteries and be aware of recharging capabilities.
- Switch oxygen over to portable tanks if needed.
- Contact your hospice team, if able, to inform them of the outage.

Fire

- Know how to safely operate fire extinguishers in your home.
- If the fire is smaller than a small waste basket, it is typically safe to extinguish.
- Evacuate if the fire is too large for a fire extinguisher or if the extinguisher is not easily accessible.
- Remember to GET OUT, STAY OUT and CALL 9-1-1
- Yell "Fire!" several times and go outside right away. If you live in a building with elevators, use the stairs. Leave all your things where they are and save yourself.
- Use your second way out if closed doors or handles are warm or smoke blocks your primary escape route. Never open doors that are warm to the touch.
- If you must escape through smoke, get low and go under the smoke to your exit. Close doors behind you.
- If smoke, heat, or flames block your exit routes, stay in the room with doors closed. Place a wet towel under the door and call the fire department or 9-1-1. Open a window and wave a brightly colored cloth or flashlight to signal for help.

- Once outside, go to your meeting place and send one person to call the fire department. If you cannot reach your meeting place, follow your family emergency communication plan.

If your clothes catch on fire:

- Stop what you're doing.
- Drop to the ground and cover your face if you can.
- Roll over and over or back and forth until the flames go out. Running will only make the fire burn faster.
- THEN Once the flames are out, cool the burned skin with water for three to five minutes. Call for medical attention.

Flood

- Make an evacuation plan if you live in an area prone to flash flooding or seasonal floods.
- Keep an emergency supply kit in an easily accessible location.
- Monitor weather when conditions are right for flood watches and warnings.
- Planning can help ensure that you are ready to evacuate in an orderly manner before rising waters impact your residence or evacuation routes.
- Do not drive through standing water on roadways.
- Contact your hospice team if you are concerned about imminent flooding. Hospice can assist in relocating the patient to a safe place.

7

Emotional Support & Wellbeing

Rainbow
Hospice Care

Emotional Wellbeing

Hospice care includes helping manage mental and emotional distress. Someone who is alert near the end of life might understandably feel depressed or anxious. It is important to address emotional pain and suffering. Encouraging conversations about feelings might help. Discuss any concerns with your hospice team.

A dying person may also have some specific fears and concerns. He or she may fear the unknown or worry about those left behind. Some people are afraid of being alone at the very end. This feeling can be made worse by the understandable reactions of family, friends, and even the medical team. When family and friends do not know how to help or what to say they sometimes they stop visiting. Or, someone who is already beginning to grieve may withdraw.

The simple act of physical contact—holding hands, a touch, or a gentle massage—can make a person feel connected to those he or she loves. It can be very soothing. Warm your hands by rubbing them together or running them under warm water.

Try to set a comforting mood. Remember that listening and being present can make a difference. Listen to the patient, they may or may not want visitors. There may be certain times of day that visitors should come, like mornings, if the person has more energy in the morning. Visitors can be exhausting, so listen to the patient and limit visitors when needed.

Music at a low volume and soft lighting can be soothing. In fact, music might improve mood, help with relaxation, and lessen pain. Listening to music might also evoke memories those present can share. For some people, keeping distracting noises like televisions and radios to a minimum is important. Others like the distraction of TV or other sounds.

Often, just being present with a person is enough. It may not be necessary to fill the time with talking or activity. Your quiet presence can be a simple and profound gift.

As a caregiver, emotional wellbeing is important to ensure that you can continue to provide care. Refer to Care for the Caregiver section for helpful tools.

Memories and Meaningful Moments

Take a moment to think about what is the most meaningful to you. When your loved one passes on, what will be important to you? What do you want to remember? Is there something you want to know? Are there recipes you want to have? Are there family traditions you want to continue? Are there moments you want to remember or create?

Slowing down and making a conscious effort to relish time with a loved one can create healing memories for you now and later on.

There are simple ways to find small moments to cherish the time you have:

- Sit quietly and hold hands.
- Play favorite music.
- Read a favorite book together.
- Pray together.
- Share great memories.
- Ask questions you've never thought to ask:
    - First loves.
    - First pets.
    - Childhood memories.
- Think about moving up and celebrating important events while your loved one can still enjoy them. Holidays, birthdays, anniversaries, weddings, baby showers…
- Make a reason to have a family get together. Create something to celebrate or just celebrate your loved one.
- Consider keeping an article of clothing that reminds you of your loved one.
- Spray a keepsake with some of their favorite cologne or perfume.
- When you are holding hands – snap a quick picture of your hands. Hands are unique to each of us and can evoke powerful memories.
- Do something your loved one enjoys (baking, fishing, quilting, reading, etc.).
- Finish a "bucket list" item for them or with them.
- Bring their favorite things to them to recreate great trips or memories (have a casino night, movie night with popcorn, tropical location themed night to replace or remember a trip).

Memorable Projects and Legacy Work

- A scrapbook (with pictures/keepsakes related to a particular time in your life, a loved one, a favorite vacation destination, etc.).
- Have new family pictures taken.
- Take generational pictures (for example all of the girls in the family - great-grandma to the littlest great granddaughter).
- Create collection of your favorite recipes.
- Have a blanket or teddy bear made out of your favorite T-shirts or other fabric items.
- Complete life review worksheet.
- Make handprints of you and/or your loved ones in plaster.
- Make a small thumbprint in air-dry clay for a necklace.
- Paint a thumbprint tree.
- Make a video montage (best advice, most cherished memories, stories about family history, etc.).
- Have cards written or gifts purchased for a future birthday, holidays, special occasions or events (wedding day, first baby, graduation).
- Have a poem or a song created specifically for your loved one(s).
- Complete a life review projects using books/outlines.
    - Hardcover Book - My Dad: His Story, His Words
    - Hardcover Book - My Mom - Her Story, Her Words
    - Audio/video

If you're struggling with where to begin, or if you need a little help along the way, talk with your hospice team.

Spiritual Wellbeing

Spiritual Wellbeing refers to the relationship that the patient, family and caregivers have to the inner workings of the spirit- what it takes that makes you WHOLE, HAPPY and FULFILLED.

Spiritual Wellbeing might include the religious rituals and experiences of the patient and family but is only one part of the equation. Spiritual Wellbeing includes how we see the world around us, how we relate to nature, the arts, music, friends, hobbies; in short, anything that brings joy and happiness to our deepest self.

Spiritual Counselors and Chaplains are able to assist the patient and family to address those concerns of the heart that help each of us feel whole and fulfilled. This might include doing a "life review", (possibly in the form of writing your life story), arranging for a "dream trip" or activity, (such as attending a sports activity or going to see a movie) bringing musicians or singers to the home/room of a patient who likes live music. It might mean arranging a ride in a "hot rod" of your dreams, or a cruise on the lake. The Spiritual Care Team might turn to the Volunteer team to assist in making these things happen for the patient and family.

Spiritual Wellbeing could involve the reading of a great book or good poetry to the patient, or assisting them in writing letters, going through old photos and helping the patient identify the persons and activities in those photos. Again, these activities could be seen as gifts to family members.

Spiritual Wellbeing could very well mean collaborating with the Pastor of the patient's church community, and allow for members of that faith community to visit if it is appropriate and welcomed by the patient and family. Prayers and rituals of the faith/denomination might be arranged as well. Church services that are videoed or "live-streamed" could be made available for those who can no longer physically attend their church services.

The Chaplains and Spiritual Counselors are prepared to assist with end of life issues and care and are well positioned to assist the patient's pastor in providing that end of life spiritual care. We do not take the place of your Pastor, but work along with your Pastor to provide for your Spiritual Wellbeing at the end of life.

Patients and families who do not have a church preference or are not connected to any particular faith expression may benefit from having Chaplain/ Spiritual Counselor visits. We may assist you in discussing those issues and ideas that bring you comfort and peace during this time of transition.

Anticipatory Grief

When someone is diagnosed with a terminal illness, the patient and family both experience a wide range of emotions, one of these emotions may be grief.

Anticipatory grief is what we call the actual and anticipated losses that occur prior to a death. Actual losses for the patient may include loss of mobility, loss of sense of self as a healthy, independent person, loss of status, loss of job, loss of social contacts, or loss of control.

Actual losses for the family may include loss of companionship, loss of freedom, loss of role distinction, loss of relationship with the patient, and loss of sleep.

The patient may also anticipate the loss of being present at future events, unfulfilled dreams, and the effect his or her death will have on the family.

The family members begin to identify changes in lifestyle, relationships, the loss of routines associated with care of the patient, future events at which the patient will not be present.

The nurse, social worker or chaplain will be available to help the patient and family talk about these losses and their impact.

Care for the Caregiver

A terminal illness has an effect on the whole family. Caring for a terminally ill family member can be rewarding but it can be, physically and emotionally, the most difficult job the caregiver and family will ever have. The Rainbow Hospice Care staff is there to help the entire family cope during this difficult time.

At times, during the illness, the patient may act angry or strange towards family members. Most often this is due to frustration and may mean, "Why did this happen to ME?" The anger is usually directed at the people the patient knows will always love and care for them in spite of what they say or how they act. Try to discuss your feelings with them but be aware that the patient may not realize that they are acting differently. Feel free to discuss your fears and feelings with the Rainbow Hospice Care staff.

Caring for a terminally ill patient can be physically demanding. It is very important to take care of yourself also. If you don't get enough rest and time for yourself, you will not be able to stay physically and emotionally able to care for the patient.

Plan time for yourself away from home.

Try to get at least six hours of uninterrupted sleep each night.

Take naps when the patient is sleeping during the day.

Maintain a balanced diet.

Lessen time spent on your regular responsibilities such as household chores.

Ask other family members and friends to help. Sometimes they are just waiting to be asked. They may be able to do some shopping for you or fix a meal. Just sitting with the patient and sharing some common memories may be enjoyable for all.

If you find you are getting exhausted, let your nurse know. She may be able to suggest an easier plan for caring for the patient. Rainbow Hospice Care has volunteers who are trained in caring and working with terminally ill patients and their families.

We also have Certified Nursing Assistants who are able to assist with patient's bathing and personal hygiene needs. There may also be some community option available to you. Ask your nurse or social worker to explore these with you.

The Rainbow Hospice Care program has social workers to provide support to the patient and family as they face changes in their roles and relationships. This support may include identifying community resources available and providing advice concerning financial problems associated with prolonged illness. The social worker can also provide assistance with completion of Advanced Directives.

Facing illness and death as a family makes it easier but not all families can be open and share their feelings. Each member of the family is unique and deals with the patient in his or her own way. Your nurse, social worker, minister or the Rainbow Hospice Care Spiritual Advisors may be able to bring the family together to talk, listen and help each other.

Children have some special needs when dealing with illness and the impending death of someone they love. Death may have different meanings to them depending on their age and stage of development. It is important to be honest with them and answer their questions in a way they can understand. Do not tell the child that the patient is going to "sleep" as the child may associate death with bedtime and sleep. Have the child/children spend time with the patient and involve them in helping to care for the patient. This will lessen their fears. Children will need extra comfort, affection and structure during this time. Try to stick as closely as possible to their normal routines.

For some patients and their families, a religion, a church community and their own personal relationship with God can be a strong source of support and strength. You may want your local clergy or the Rainbow Hospice Care chaplain to become more involved. Some patients and families may not find religion to be a source of help. Know that neither approach is better than the other. The Rainbow Hospice Care team will respect each person's needs and beliefs.

Your feelings as a caregiver

If you have decided to care for a terminally ill person in your home, you deserve enormous credit. The task is probably more difficult than you first imagined it to be. But at the same time, you are probably more capable than you ever thought yourself to be. You have a great deal of common sense and what you don't know, you can learn.

Whether you are providing care in your home or are commuting to provide care where your loved one lives, you have a big job. There are certain aspects of the situation that may become discouraging--no matter how much you want to help, no matter how much satisfaction helping brings you.

Here is a list of COMMON REACTIONS to being a caregiver, followed by some ideas about how to help you feel better:

Resentment at having to give care, always attending to someone else's needs. "I thought I'd finally have some time to myself when Susan grew up. Instead, I have less time than ever since Mom's stroke."

Exhaustion from the never-ending nature of the tasks. Personal care, cooking, and housework can feel like a treadmill-there are few places to stop and see what you have accomplished. "I work so hard, but there's always laundry waiting to be done, the next meal to fix."

Sadness that the role your loved one used to play in your life has changed. Whether you care for your spouse, parent, other relative, friend, or neighbor, chances are that this illness has affected your relationship. "I never expected to have to give my husband the kind of care I gave my children."

Frustration that you don't have time for your own needs and pleasures. "When will it be my turn? And will I be healthy enough to enjoy it when it comes?"

Guilt that you wish for more gratitude than your loved one can express. "She could at least say 'thank you' when I bring in the meal."

Anger that others don't offer more help. "Jean has always gotten lots of praise for being such a devoted daughter, but where is she now?"

Pain at seeing the person you care for deteriorate, being less able than in former times. "She was such an independent, capable woman. It hurts to see her in that wheelchair."

Exasperation at the health and human service systems, which are sometimes difficult to pin down, often require lengthy interviews and frequently cannot provide exactly what your friend or family member needs.

All of these factors can create STRESS. Unrelieved stress may lead to a decline in your own health and emotional well-being and it may affect other members of your family.

When is it too much stress?

Knowing the signs of stress can help you recognize when you have been demanding too much of yourself. Feeling irritable, worried, pessimistic, preoccupied, having physical symptoms, such as diarrhea or constipation, or being unpleasant to people you care about can be signs that you are experiencing too much stress.

Negative feelings, such as pain, anger, and resentment, can make us sick if we don't release them.

What can help?

Getting adequate rest and good nutrition prepares you to face each day. If caring for your friend or loved one prevents you from sleeping, perhaps another family member could come in one night a week to let you get a full night's sleep.

Exercising regularly, like taking a good walk, helps to relieve tension.

Getting away gives you needed time off for activities you enjoy, relaxing alone or with others. Ask someone else to take over for you on a regularly scheduled basis. Knowing that every Tuesday evening is yours can help.

Allowing others to help is a sign of strength, not weakness. If you do it all yourself, you risk running out of steam. Ask others to help you and let them know how good it feels to get even a little help. They may enjoy feeling useful.

Talking about your frustrations can be helpful. Telling someone about the things that are bothering you may not change the situation, but it can make you feel better.

Go easy on yourself. Getting upset with yourself for feeling sad or angry can make it all the harder. You are probably feeling just what others in similar situations feel.

Setting milestones that you can achieve. Plan to spend 15 minutes doing something important to you and then do it. Try not to link your sense of accomplishment to the health or mood of the person you care for.

Reorganizing your work to make it easier in any way possible to give yourself a change of pace.

Writing down your feelings in a notebook "for your eyes only" can help.

How to reduce your stress

There are many ways to release stress and negative feelings. Here are just a few:

Breathe deep, full breaths all the way down to your abdomen, then breathe out. Imagine the fresh air going through your mind, taking all tensions and negative feelings out of your body as you exhale.

Listen to music - take a few minutes to sit down, listen, and concentrate only on the sound of music you find especially relaxing. Tape recordings of the sound of the ocean or mountain streams are available in large stores which sell records and tapes.

Relax your body by tightening the muscles in your face very tightly and then relaxing them. Now do this with your neck, then shoulders, arms, abdomen, buttocks, legs, and feet--one muscle group at a time.

Imagine that all tension is leaving your body, starting at your head and working down to your toes.

Imagine the person you are angry with sitting across from you. Now start talking, putting your feelings into words. Let out the feelings that you've been holding in.

Mutual Support

Mutual support from others can reassure you that your feelings are normal. It can help you feel less alone. All over the country the idea of "support groups" has caught on.

People struck by cancer, parents of handicapped children, and many others are getting together to discuss feelings, problems and solutions. People even help each other arrange free time. They find that they are their own experts. They can help one another because they truly understand the situation. There may be an organized group in your community that can provide reassuring contact with others, information, and education.

Or you might ask a nurse or a social worker who comes to care for your loved one about this. Chances are there are others not far from you who have similar concerns. You might try talking by telephone if getting together in person is difficult.

Self-Care

Here are some things you can try to incorporate into your own self-care routine:

Daily self-care checklist

- ☐ Engage in positive self-talk.
- ☐ Practice three minutes of meditation.
- ☐ Drink eight glasses of water.
- ☐ Journal before bed.
- ☐ Add more vegetables to your diet.
- ☐ Choose one goal to focus on.
- ☐ Go outside.
- ☐ Take a break from technology.

Monthly self-care checklist

- ☐ Spend quality time with your partner.
- ☐ Practice your favorite hobby.
- ☐ Make sure your medication is renewed.
- ☐ Try a new type of exercise.
- ☐ Write down your monthly goals.
- ☐ Read a book.
- ☐ Nap when needed.
- ☐ Test out a new recipe.
- ☐ Review your monthly budget.

Self-care checklist by category

Psychological

- ☐ Set your bills to automatic payments.
- ☐ Turn off all electronics one hour before bed.
- ☐ Incorporate more vegetables and fruit into your diet.
- ☐ Visit a financial advisor.
- ☐ Book a therapy session.

Physical

- ☐ Sign up for a yoga class.
- ☐ Turn on some music and dance.
- ☐ Schedule your routine doctor’s visit.
- ☐ Go on a walk with a friend.
- ☐ Drink one full glass of water when you wake up.
- ☐ Take a 20-minute nap when you’re overtired.

Emotional

- ☐ Spend 30 minutes of quality time with your partner.
- ☐ Try a social media cleanse for 24 hours.
- ☐ Write a gratitude list.
- ☐ Take a break during the workday to meditate.
- ☐ Say “no” to an activity you don’t enjoy.

Intellectual

- ☐ Take an art or cooking class.
- ☐ Visit a new neighborhood in your area.
- ☐ Ask your manager for constructive feedback.
- ☐ Set up a monthly phone date with a friend.
- ☐ Read the opinions section of a newspaper.

Acknowledging You Need Assistance

As caregivers, we sometimes become so involved in the day-to-day efforts to keep things going we may forget to let others know we need additional assistance with providing care, or just need a break from the work of caring for someone.
Some ways to make your needs known include:

- *Work Options*. If you are a working caregiver, it is important to discuss your needs with your employer. Telecommuting, flextime, job sharing or rearranging your schedule can help to minimize stress. Increasingly, companies are offering resource materials, counseling, and training programs to help caregivers.
- *Involve Older Children*. Older children living at home may be able to assist you and/or your loved one. Such responsibility can help young people become more empathetic, responsible, and self-confident and give you needed support. Your hospice team can help with any needed caregiving education.
- *Ask Others to Help*. You can and should ask other family members to share in caregiving. A family conference can help sort out everyone's tasks and schedules. Friends and neighbors also may be willing to provide transportation, and help with shopping, household chores or repairs.
- *Create a list of things* that need to be done, such as grocery shopping, laundry, errands, lawn care, housecleaning, or spending time with your loved one or friend, and put it on the refrigerator or near the front door. If someone says, "let me know if there is anything I can do to help" you can point to the list.
- *Take a break from caregiving*. Even if it is only 15 or 20 minutes a day, make sure you do something just for you. Consider having hospice volunteers relieve you, while you take a walk or a nap.
- *Exercise*. Whether it is a 20 minute walk outside or taking a yoga class, exercising is a great way to take a break, decrease stress and enhance your energy.
- *Eat healthy*. Your health and nutrition is just as important as your loved ones, so take the time to eat well. If you are having difficulty doing that, ask for help and get others to fix meals for you.
- *Subscribe* to caregiving newsletters or list serves for support.
- *Attend a support group for caregivers*. Ask your hospice team for more information.
- *Seek professional help*. Many caregivers have times when they feel lonely, anxious, guilty, angry, scared, frustrated, confused, lost and tired. If you feel like these feelings are overwhelming you, call your hospice team for support.

Options for Care at Home

Families are usually the primary caregivers for hospice patients. Rainbow Hospice does not take the place of the family. Rainbow staff will come in on a scheduled basis to provide intermittent care and are always available on an On-call 24/7 basis.

There are several options to consider when additional help is needed. Caregivers can be hired anywhere from 1 hour a day to 24-hour live-in care. Any of the private caregivers are the responsibility of the patient and their family to hire and pay for. The hospice benefit does not cover this type of service. Your hospice social worker will be more than happy to discuss with you any of the options available.

Questions to ask agencies:

- What are your rates for care?
- What are the qualifications of the caregivers you provide? (PCW, CNA)
- Are there a minimum number of hours, or maximum?
- What type of guarantee do you provide as to the quality of your staff?
- Can we meet with a caregiver prior to hiring your services?

Questions for Live in Caregivers:

- What are the daily rates, how are they paid?
- What are the "finder fees" per agency?
- What type of people do you provide?
- Do they speak English?
- How long does it take to find someone?
- What do I do if there is a problem with a caregiver?
- How much do I provide for their comfort and lifestyle?
- How many days do they work, time off?
- What happens if the caregiver gets injured?

Social Media and Good Communication

Good communication can be hard work, especially when a loved one is ill. Social media can be a useful tool, but it can contribute to poor communication as well.

Planning for communication is not something that is common for most of us. When a family member has a terminal illness, a plan needs to be in place.

Some things to consider:

- Come together as a family and discuss plans for communication. Determine what type works and how everyone prefers to get information.
- How many family members and friends need to be kept in the loop? For large families a phone tree, email distribution group, or a private social media group might be useful.
- Who needs to know information and how often?
- Who is the point person for communication?
- What information is each person responsible for?
- Who needs to have input in decision making?
- Who is the main decision maker?
- Should there be a family spokesperson for all family and friends to communicate through?
- What types of information will be shared with friends and acquaintances versus family?
- What type of communication is most effective for your family?
- During significant events, who needs to know before the information is posted on social media?
- Take into consideration what you want shared "out there in the universe." It is said, whatever goes on the internet lives "out there" forever.
- Decide what details might be private and should only be shared with close relatives and what information should be shared with the public. Some people are private and don't want the details of their illness shared beyond family.
- Discuss your plans for making information public with each person so they do not post the news inadvertently before you are able to make all necessary calls. News of a loved one's death can be especially difficult to find out on social media.

Trying to keep everyone in the loop can be anxiety provoking and exhausting. Social media may seem like an easier way to keep everyone in the loop, but it is not always received well when close family finds out important news on social media rather than on the phone or in person.

There are many communication methods, websites, Apps, and social media options out there. Do your own research and determine what works best for you and your family and friends.
www.caringbridge.org
www.caretogether.com
Create a private group on www.facebook.com

Recommended Reading
Death & Dying

Four Things that Matter Most by Ira Byock MD

Four simple phrases- "Please forgive me," "I Forgive you," "Thank you," "I love you"- carry enormous power to mend and nurture our relationships and inner lives. These four phrases and the sentiments they convey provide a path to emotional wellbeing, guiding us through interpersonal difficulties to a life of integrity and grace.

Final Gifts by Maggie Callahan and Patricia Kelly

Through their stories we come to appreciate the near miraculous ways in which the dying communicate their needs, reveal feelings, and even choreograph their own final moments. We also discover the gifts of wisdom, faith, and love that the dying leave for the living to share.

When Breath Becomes Air by Paul Kalanithi

While on his way to completing his training as a neurosurgeon Paul Kalanthi at age thirty-six was diagnosed with stage IV lung cancer. This book explores with him how he went from being a zealous medical student to trying to better understand what truly makes life meaningful. Through his eyes, readers can see how facing the end often brings a new perspective on living.

Can We Talk About Something More Pleasant by Roz Chast

In her first memoir, New Yorker cartoonist Roz Chast brings her signature wit to the topic of aging parents. Spanning the last several years of their lives and told through four-color cartoons, family photos, documents, and a narrative as rife with laughs as it is with tears, Chast's memoir is both comfort and comic relief for anyone experiencing the life altering loss of elderly parents.

Grief & Loss

It's Okay That You're Not Okay: Meeting Grief and Loss in a Culture That Doesn't Understand by Megan Devine

A psychotherapist, Devine wrote her book after she lost her partner in a drowning accident. The title of Devine's book sets the table for the book's content. Grievers don't have to be okay; she gives permission to grieve their loss for the rest of their lives. One of my favorite quotes from her book follows, "When something cannot be changed, the 'enlightened' response is to pay attention. To turn toward it and say, 'I see you.' That's the big secret of grief: the answer to the pain is in the pain...it deserves to be heard."

How to Carry What Can't be Fixed: A Journal for Grief by Megan Divine

Megan Divine has carefully crafted a journal for grief and loss. This book guides users through their grief with exercises, information, and practical tips on how to navigate the world while grieving. It covers everything from processing the intensity of early grief to how to decline invitations you may not be ready for yet. Each page is filled with practicality, care, and compassion designed to help provide support when it's needed most.

Finding Meaning: The Sixth Stage of Grief by David Kessler

Kessler is considered one of the world's experts on grief. He has heard the stories of thousands and experienced his own losses both with the death of his mother as a child as well as the death of his son to an accidental drug overdose. This is a book of hope while walking alongside his readers in their pain. He wrote it as a response to how he made meaning after his son's death and has added a brief afterword that addresses the pandemic.

Understanding Your Grief: Ten Essential Touchstones for Finding Hope and Healing Your Heart by Alan D. Wolfelt, Ph. D.

Grief is a wilderness journey, according to Wolfelt. A long, mountainous hike that is uniquely yours. This is a comprehensive look at grieving that includes chapters on the misconceptions of grief, the feelings of loss, recognizing that you are not crazy, and how to nurture yourself. A companion journal is also available if you are interested in exploring the touchstones and how you are experiencing them on your grief journey.

Bearing the Unbearable: Love, Loss, and the Heartbreaking Path of Grief by Joanne Caccitore, Ph.D.

In this book Dr. Caccitore compassionately delves into the human experience that is grieving. She shares stories and insights from her own grief journey, and from those she has supported in her practice. Through these stories she paints a picture of grief that reflects the person and the loss rather than a formula. Her encouraging words help guide the reader to connect with their grief and honor their losses in ways that provide comfort and meaning.

Grieving is Loving: Compassionate Words for Bearing the Unbearable by Joanne Caccitore, Ph.D.

A companion book for her previous work, Bearing the Unbearable, this book is a compilation of stories, quotes, and poems intended to provide encouragement to the grieving. It is a great book to simply open and find a short reflection or insight on grief and loss. It helps the reader to embrace their grief, "Just one day, just one moment, one breath at a time…"

What's Your Grief? Lists to Help You Through Any Loss by Eleanor Haley & Litsa Williams

From what to look for in grief support to how to deal with guilt, this book provides tools to help the bereaved better understand their grief and ways to cope with the losses they are experiencing.

Always a Sibling: The Forgotten Mourners Guide to Grief by Annie Sklaver Orenstein

After her brother's death while he served in Afghanistan Annie Skalver Orenstein experienced firsthand what it is like to lose a sibling. Her experiences lead to years of research into sibling loss and what helps when we are grieving. In this book, she shares her own story and that of others she interviewed. Intertwined are ways to understand and cope with grief including helpful exercises designed to help grievers honor their grief and their loved ones.

Grief and loss for Children

Tear Soup: A Recipe for Healing After Loss by Pat Schwiebert and Chuck DeKlyen

This is the story of Grandy and the big loss she suffered and the pot of tear soup she made to guide her process of grieving. It provides the reader the opportunity to consider what belongs in their recipe for tear soup.

My Big Dumb Invisible Dragon by Angie Lucas

This is the story of how grief often arrives and takes over every aspect of our lives. In this story grief takes the form of an Invisible Dragon and provides examples of how we learn to make space for grief in our lives.

I Can't Believe They are Gone: A kid's *Grief Book That Hugs, Helps, and Gives H**ope by*** Karen Brough & Hiruni Kariyawasam

A family of mice has experienced a loss, and they are all responding differently. This book provides examples of how grief is unique to each individual and how despite those differences we can honor and support one another as we grieve.

Pocket Full of Sads by Brad Davidson & Rachel Mas Davidson

Bear is grieving and Rabbit is trying to help cheer him up. This story demonstrates, through colorful illustrations and an amusing story, how grief may impact our lives and how to support friends and family who are grieving.

The Invisible String by Patrice Karst & Joanne Lew-Vriethoff

One stormy night a mother and her children explore how even when our loved ones are out of sight, we can still feel them with us. This book helps children understand how the love we feel for those in our life connects us no matter how far away they go.

The Memory Box: A Book About Grief by Joanna Rowland & Thea Baker

The fear of forgetting or the fear that we will never feel happy again are normal when we lose a loved one. This story explores ways to cope with these feelings through crafting a memory box to help honor our loved ones and the grief we carry for them. In doing so it provides a practical tool for helping young grievers and their caregivers as they cope with the loss of a loved one.

It Won’t ever Be the Same by Koreigh Leigh Ph.D.

A comprehensive guide for teens that empowers them to better understand and navigate grief and loss. This book contains helpful information, activities, original art, and personal stories from teens who have experienced loss. It is a supportive toolbox for teens and their caregivers as they grieve and learn to live with loss.

Death & Dying for Children

What Happens When Someone I Love Can’t get Better: A Book to Prepare and *Cope with End of Life* – by Sarah Olsher & Jenni Rogers

From the natural end to all living creatures to how things at home may change when someone is on hospice, this book presents a clear picture of what happens when we die. Through colorful illustrations and compassionate language, the authors invite children and their caregivers to have meaningful conversation about end of life.

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Nearing Death

Rainbow
Hospice Care

Common Changes as Death Nears

Every person's journey is unique. This list provides common changes that can be expected during the end of life. Your hospice team will use these signs to help prepare you. Discuss any changes you see or concerns you have with your hospice team.

One to Three Months

- withdrawal from the world and people
- decreased food intake
- increase in sleep (spending more time in bed)
- less communication (less engaged in conversation)

(*Give permission to nap during conversations, offer small meals, begin asking more yes and no questions as they will likely not have energy to initiate or stay engaged in conversation*)

One to Two Weeks

- disorientation/confusion
- agitation
- skin color changes; pale/ashen
- talking with the unseen
- breathing changes/irregularities
- congestion
- sleeping but responding
- complaints of body being tired/heavy
- picking at clothes
- not eating, taking little fluids
- body temperature varying from hot to cold
- decreased blood pressure
- pulse increase

(Avoid correcting any confusion, validate their experiences and what they see, offer reassurance and calm peaceful presence, offer a fan pointed towards the ceiling if they seem warm)

Days or Hours

- intensification of one-to-two-week signs
- surge of energy
- eyes glassy, watering, half open
- irregular breathing, stop/start
- Forehead and extremities feel warm
- restlessness or no activity
- purple color to knees, feet, hands, blotchy skin – called "mottling"
- pulse weak and hard to find
- may be incontinent of urine or bowels

(*Offer cool compress to forehead, begin/consider repositioning, continue calm and peaceful presence and hand holding, offer mouth swabs for moisture*)

Minutes to Hours

- very shallow and irregular breathing
- rapid/quick respirations
- cannot be awakened
  (Offer calm and peaceful presence)

It’s OK for the Terminally Ill not to Eat

By Mary Glodowski

Caring for someone with a terminal illness includes dealing with many issues regarding changing health conditions. Nutrition is one of these issues.

Family members often have a psychological need to feed the dying patient. When someone doesn’t eat, times of sharing and socializing are lost, fear of survival occurs since people associate food with “getting better”. Family members work hard to prepare foods that are appealing. Frustration occurs among both the family and patient when only a few bites are eaten or nothing at all. Often terminally ill patients would prefer that their family focus less on their eating problems and more on end-of-life issues. This attitude might be extremely difficult for others to understand and accept.

When someone is in the advanced stages of terminal illness, it is normal to refuse food and liquids. The decreased intake can be due to one or more of the following: difficulty in swallowing, vomiting, weakness, reduced level of consciousness, affected taste buds or a general emotional withdrawal. A decreasing intake is a signal that the disease is worsening and the body is preparing for death by shutting down normal body functions. In other words, nature is assisting the person to die in a more comfortable way.

It is OK for the dying person not to eat or drink.

Past thinking that dehydration is painful is now giving way to new beliefs. A decreased intake of fluids might benefit the person by leading to: decreased urine output resulting in a lessened need for the urinal, commode or catheterization, decreased vomiting, decreased lung and mouth secretions, with less coughing and lung congestion and fewer choking episodes; and decreased fluid retention, which might lessen pressure pain. Fluid reduction serves almost as a natural anesthesia for the central nervous system. As the patient’s level of consciousness decreases, so does the perception of suffering.

One drawback of dehydration includes dry mouth and lips, which can be relieved by salt water rinses, ice chips and use of lip balm. Muscular twitching or restlessness might also occur.

The decision to artificially feed or hydrate someone who is terminally ill must be made by the patient, family and health care team. The risks and benefits must be evaluated as to whether the potential benefits outweigh the risks, whether the goal is to maintain quality of life and comfort rather than extend life or change the course of the disease, and whether such actions meet the wishes, values and beliefs of the patient.

(Mary Glodowski, R.D., works for the Hospice of Portage County, Inc., in Stevens Point)

When Death Occurs

There are many similarities between the process of birth and the process of death. We usually have some expectations as to what these events *should* be like. Just as someone may prepare for a home birth, your hospice team will help you prepare for a home death. And like any event that involves human nature, things don't always go according to plan. What is important to remember is that we are all born on time, and each of us will leave on time. The events surrounding our coming or going may not always be easily understood, but in the divine order of the universe, life and death go on.

Trust the circumstances of your loved one's passing. Many people do not want their loved one to die alone. For some people, though, this is exactly what is needed; it may be that this is the final gift that they are wanting to give, or that it is simply too difficult to leave in your presence. Just know that *not* being present may be just as important as being there.

What is next?

- Call Rainbow Hospice Care 920-674-6255. A nurse will come to your home to verify the death, notify the physician, and contact the funeral home when you are ready.
- The hospice staff will bathe your loved one for a final time. If you would like to help with this, you may. Just simply speak to the nurse.
- You may want to have a chaplain called.
- You may wish to have family or friends come.
- You may want private time to sit, lay or talk with your loved one.
- Some people are comforted by music or candles.

Within the hospice philosophy, death is not viewed as an emergency. There is no immediacy at this time. Follow your heart to know what will give you comfort and take the time to do what *you* need to do.

9

General Hospice Information

Rainbow Hospice Care

Patient and Family Rights and Responsibilities

Rainbow Community Care, Inc. (RCC) is committed to providing exceptional and compassionate care and services. Should you have any concerns regarding your care, please do not hesitate to discuss them with any member of your hospice care team. If you feel your concerns are not adequately addressed, please contact the RHC at (920) 674-6255. Neither you, nor your legal representative, will be subjected to discrimination, reprisal or any negative consequences for exercising your rights.

At RCC you have the right to:

- Treatment without discrimination
- Participate in decisions about your care
- Care that supports you and your family
- Respect, personal dignity and confidentiality
- Receive the safest possible care, free from mistreatment of any kind
- Information regarding payment for services
- Express concerns and/or complaints

Treatment without discrimination

You have the right to:

- Treatment, regardless of race, creed, color, national origin, ancestry, religion, gender, sexual orientation, marital status, age, disability, source of payment, diagnosis, resuscitation status or any other protected status under law.
- Respect for cultural, spiritual and personal beliefs and preferences, within the limits of the law and without compromising your care or the care of other patients.

Participate in decisions about your care

You have the right to:

- Receive information in a manner that you can understand.
- Be fully informed regarding your condition, including any significant changes in your health care needs or status.
- Be involved in developing, managing and changing your hospice plan of care.
- Select or refuse treatment, care or services.
- Choose your attending physician.
- Prepare an advance directive, in accordance with state law.
- Be informed of criteria for discharge – *see Discontinuation of Services Policy*.

Care that supports you and your family

You have the right to:

- Receive effective pain management and symptom control for conditions related to your terminal illness.
- Request a consult with the RHC Ethics Committee for difficult ethical issues.
- Receive visitors at any hour, including children of any age, and to decide who may visit you.
- Receive visits in person, virtual or by phone

Respect, personal dignity and confidentiality

You have the right to:

- Be treated with courtesy, respect and full recognition of your dignity and individuality and to choose physical and emotional privacy in treatment, living arrangements and the care of personal needs.
- Privately communicate with others without restrictions.
- Have your health information be treated as private and confidential. Details of your condition and treatment will not be shared except with those who are allowed to receive the information.
- Request and receive a copy of your medical records. Access to or release of your medical records is handled in accordance with the Health Information Portability and

Accountability Act (HIPAA) – see Notice of Privacy Practices.

Receive the safest possible care, free from mistreatment of any kind

You have the right to:

- Be free from mistreatment, neglect, or verbal, mental, sexual or physical abuse, including injuries of unknown source and misappropriation of your property. Any such allegations against someone furnishing services on behalf of RHC are reported immediately to the hospice administrator.
- Be free from restraints and seclusion except as authorized in writing by the attending physician to provide palliative care for a specified and limited period of time and documented in the plan of care.

Information regarding payment for services

You have the right to:

- Be informed, prior to admission, of the types and scope of hospice services that RHC provides, including contracted services and specialized services for unique patient groups such as children, as well as specific limitations on those services.
- Be informed of the items and services available and for which you may be charged, and the amount of charges for those services.

Express Concerns and/or Complaints

You have the right to:

- Bring concerns, either verbal or in writing, to the attention of anyone providing services on behalf of RHC.
- Express complaints to RHC, without fear of reprisal, about the services provided and to have the complaint investigated in accordance with an established procedure.
- Submit a complaint or question to the State of Wisconsin:

  Department of Health Services

  Division of Quality Assurance

  Attn: Hospice Complaint Coordinator

  P.O. Box 2969

  Madison, WI 53701-2969

  Online: www.dhs.wisconsin.gov

  Toll-Free Hotline: (800) 642-6552

- Receive patient advocacy services from the Board on Aging and Long-Term Care (BALTC): (800) 815-0015.
- If a Medicare patient, report concerns to **LIVANTA:** (888) 524-9900; TTY (888) 985-8775.

In addition to your rights, RHC patients and families also have responsibilities:

Responsibilities include, but are not limited to:

- Providing **accurate and complete information** about your health and your health care.
- Providing **copies of any relevant advance directives** (e.g., Power of Attorney for Health Care)
- Providing **accurate, complete and up-to-date health insurance and financial information**, as necessary and related to your hospice plan of care.
- Actively **participating in developing and managing your plan of care** with your care team.
- **Informing RHC of any changes** in physician involvement, treatments or medications.
- **Asking questions** when you do not understand your care, treatment or services provided to you.
- **Contacting RHC for pre-approval** prior to receiving any interventions, treatments, medications, or procedures related to your terminal illness. If you do not receive pre-approval, you assume financial responsibility for all costs associated with the services received.
- **Treating all RHC staff with respect, courtesy and tact.** This applies to you, your caregivers, family and visitors. RHC does not permit any form of harassment, sexual or otherwise, intentional or unintentional, in the work environment.
- **Maintaining a safe environment** for you, your caregivers and staff.
- **Notifying RHC if you plan to leave the service area** for any reason.
- **Following RHC rules and policies.** Intentional disregard of your responsibilities could lead to discharge from RHC services as further described in the *Discontinuation of Services Policy*.

NOTICE OF PRIVACY PRACTICES

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

Rainbow Hospice Care takes the privacy of your health information seriously. We are required by law to maintain that privacy and to provide you with this Notice of Privacy Practices. This notice describes Rainbow Hospice Care's legal duties and privacy practices and your privacy rights with respect to your health information. We will follow the privacy practices described in this notice. Rainbow Hospice Care, Inc. is required to notify you or your representative in a timely manner, if your protected health information is used in a manner not permitted by privacy laws. If you have any questions about any part of this notice, or if you want more information about the privacy practices of Rainbow Hospice Care, please contact Rainbow Hospice Care, Inc. at (920) 674-6255.

HOW RAINBOW HOSPICE CARE MAY USE AND DISCLOSE YOUR HEALTH INFORMATION FOR TREATMENT, PAYMENT OR HEALTH CARE OPERATIONS

The following categories describe different ways that Rainbow Hospice Care uses and discloses your health information. For each category, an explanation of the category is provided, in some cases with examples. Not every use or disclosure in a category will be listed. However, all of the ways we are permitted to use and disclose your health information will fall into one of these categories.

Treatment. We may use and disclose your health information to coordinate care within Rainbow Hospice Care and with others involved in your care, such as your attending physician, members of the Hospice interdisciplinary team and other health care professionals who have agreed to assist in coordinating your care. For example, the interdisciplinary team members may leave messages on your answering machine to set-up appointments. We may disclose your health information to a physician involved in your care who needs information about your symptoms to prescribe appropriate medications. We also may disclose health information about you to individuals outside of Rainbow Hospice Care whom are involved in your care, including family members, other relatives, close personal friends, pharmacists, suppliers of medical equipment or other health care professionals.

Payment. We may use and disclose your health information to receive payment for the care you receive from Rainbow Hospice Care. For example, we may be required by your health insurer to provide information regarding your health care status, your need for care and the care that Rainbow Hospice Care intends to provide to you so that the insurer will reimburse you or the Hospice.

Health Care Operations. We may use and disclose health information for its own operations to facilitate the functioning of Rainbow Hospice Care and as necessary to provide quality care to all of our patients. For example, Rainbow Hospice Care may use your information for quality assessment and performance improvement activities,

including auditing, medical reviews or compliance programs. We may use your information as part of performance evaluations, training programs or supervised student training programs. Other Health Care Operations may include fundraising, business management, planning or general administrative activities.
Electronic Health Care Exchange In compliance with federal and state laws, we may make your Protected Health Information available electronically through an electronic health information exchange to other health care providers and health plans that request your information for purposes of Treatment, Payment, and Health Care Operations; and to public health entities as permitted by law. Participation in an electronic health information exchange also lets us see other providers' and health plans' information about you for purposes of Treatment, Payment, and Health Care Operations.

How Rainbow Hospice Care May Use or Disclose Your Health Information Without Your Written Authorization

The following categories describe the ways that Rainbow Hospice Care may use and disclose your health information without your authorization. For each type of use and disclosure, we will explain what we mean and present some examples.

Inpatient Center Directory. We may disclose certain information about you, including your name, your general health status, your religious affiliation and where you are in Rainbow Hospice Care's Inpatient Center, in our directory while you are in the inpatient center. We may disclose this information to people who ask for you by name. Please inform us if you do not want your information to be included in the directory.

Fundraising Activities. We may use information about you, including your name, address, telephone number and the dates you received care, in order to contact you to raise money for Rainbow Hospice Care. We may also release this information to a related Hospice foundation. If you do not want us to contact you, notify the Administrative Assistant for Rainbow Hospice Care, Inc. at (920) 674-6255 and indicate that you do not wish to be contacted.

Appointment Reminders. We may use and disclose your health information to contact you as a reminder that you have an appointment for a home visit.

Treatment Alternatives. We may use and disclose your health information to tell you about or recommend possible treatment options or alternatives that may be of interest to you.

Required by Law. We may use and disclose your health information when that use or disclosure is required by Federal, State or local law. For example, we may disclose medical information to respond to allegations of abuse or a court order.

Public Health Risks. When required by law, we may disclose your health information to public health authorities for reporting communicable diseases, aiding in the prevention or control of certain diseases and reporting problems with products and reactions to medications to the Food and Drug Administration.

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

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

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

Law Enforcement. As permitted or required by State law, we may disclose your health information to a law enforcement official for certain law enforcement purposes. For example, We may disclose your health information to a law enforcement official for purposes such as identifying or locating a suspect, fugitive, or missing person, or complying with a court order or other law enforcement purposes. Under some limited circumstances we will request your authorization prior to permitting disclosure. We may disclosure your information if there is suspicion that your death was the result of criminal conduct.

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

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

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

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

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

Serious Threat to Health or Safety. We may, consistent with applicable law and ethical standards of conduct, disclose your health information if we, in good faith, believe that such disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety or to the health and safety of the public.

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

Worker's Compensation. Both State and Federal law allow the disclosure of your health care information that is reasonably related to a worker's compensation injury to be disclosed without your authorization. These programs may provide benefits for work-related injuries or illness.

Breach Notification

We are required to notify you in the event we discover a breach of unsecured PHI unless there is demonstration, based on a risk assessment, that there is a low probability that the PHI has been compromised. You will be notified no later than 60 days after the discovery of the breach. Such notification will include information about what happened and what can be done to mitigate any harm.

When Rainbow Hospice Care May Not Use or Disclose Your Health Information

Except as otherwise permitted or required by this Notice, we will not use or disclose your health information unless you provide written authorization. If you or your representative authorizes the use or disclosure of your health information, you may revoke that authorization in writing at any time. If you revoke your authorization, we will no longer use or disclose health information about you for the reasons covered by your written authorization, except to the extent that Rainbow Hospice Care has taken action in reliance thereon. You understand that we are unable to take back any disclosures we have already made under the authorization, and that we are required to retain our records of the care that we have provided to you.

Your Health Information Rights

Right to request restrictions. You have the right to request restrictions on certain uses and disclosures of your health information. You have the right to request a limit on our disclosure of your health information to someone who is involved in your care or the payment of your care. We are not required to agree to your request, unless your request is for a restriction on a disclosure to a health plan for purposes of payment or health care operations (and is not for purposes of treatment) and the medical information you are requesting to be restricted from disclosure pertains solely to a health care item or service for which you have paid out of pocket in full. If you wish to make a request for restrictions, please contact the Privacy Officer for Rainbow Hospice Care, Inc. at (920) 674-6255.

Right to receive confidential communications. You have the right to request that we communicate with you in a certain way. For example, you may ask we only conduct communications pertaining to your health information with you privately with no other family members present. If you wish to receive confidential communications, please contact any Social Worker for Rainbow Hospice Care, Inc. at (920) 674-6255. We will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.

Right to inspect and copy your health information. You have the right to inspect and copy your health information, including billing records. A request to inspect and copy records containing your health information may be made to the Privacy Officer for Rainbow Hospice Care, Inc. at (920) 674-6255. If you request a copy of your health information, Rainbow Hospice Care may charge a reasonable fee for copying and assembling costs associated with your request.
You have the right to request that we provide you, an entity or a designated individual with an electronic copy of your electronic health record containing your health information, if we use or maintain electronic health records containing patient health information. Rainbow Hospice Care may require you to pay the labor costs incurred by us in responding to your request.

Right to amend health care information. You or your representative has the right to request we amend your records, if you believe that your health information is incorrect or incomplete. That request may be made as long as the information is maintained by us. A request for an amendment of records must be made in writing to the Privacy Officer for Rainbow Hospice Care, Inc. at 147 West Rockwell Street, Jefferson, WI 53549. We may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your health information records were not created by us, if the records you are requesting are not part of our records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy or if, in our opinion, the records containing your health information are accurate and complete.

Right to an accounting. You or your representative have the right to request an accounting of disclosures of your health information made by Rainbow Hospice Care for certain reasons, including reasons related to public purposes authorized by law and certain research. The request for an accounting must be made in writing to the Privacy Officer for Rainbow Hospice Care, Inc. at 147 West Rockwell Street, Jefferson, WI 53549. The request should specify the time period for the accounting starting on or after April 14, 2003. Accounting requests may not be made for periods of time in excess of six (6) years. We would provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

Right to express a complaint. You or your personal representative has the right to express complaints to Rainbow Hospice Care, Inc. and to the Secretary of the U.S. Department of Health and Human Services regarding our patient privacy policies and procedures or our compliance with such policies and procedures. Individuals have the right to complain about our breach notification processes.
Any complaints to Rainbow Hospice Care should be made in writing to the Privacy Officer for Rainbow Hospice Care, Inc. at 147 West Rockwell Street, Jefferson, WI 53549. We encourage you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

Right to a paper copy of this notice. You or your representative has a right to a separate paper copy of this Notice at any time, even if you or your representative has received this Notice previously. To obtain a separate paper copy, please contact the Administrative Assistant for Rainbow Hospice Care, Inc. at 147 West Rockwell Street, Jefferson, WI 53549. The patient or representative may also obtain a copy of the current version of Rainbow Hospice Care, Inc.'s Notice of Privacy Practices at its website, www.RainbowCommunityCare.org.

CHANGES TO THIS NOTICE

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

IF YOU HAVE ANY QUESTIONS REGARDING THIS NOTICE

We have designated the Privacy Officer for Rainbow Hospice Care, Inc. as its contact person for all issues regarding patient privacy and your rights under the Federal privacy standards. You may contact this person at 147 West Rockwell Street, Jefferson, WI 53549 or (920) 674-6255.

COMPLAINTS

You or your personal representative has the right to express complaints to Rainbow Hospice Care, Inc. and to the Secretary of the U.S. Department of Health and Human Services if you or your representative believes that your privacy rights have been violated. Any complaints to Rainbow Hospice Care should be made in writing to the Privacy Officer for Rainbow Hospice Care, Inc. at 147 West Rockwell Street, Jefferson, WI 53549. We encourage you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

EFFECTIVE DATE: This Notice is effective October 1, 2020

ADVANCE DIRECTIVES

POLICY

Rainbow Community Care (RCC) complies with all State and Federal laws regarding advance directives and informs and distributes written information to the patient on his or her right to formulate advance directives. The provision of hospice care is not conditioned upon whether or not the individual has executed an advance directive.

PROCEDURE

1. During the admission interview, and prior to receiving care, the RHC nurse or social worker provides written information and instruction on advance directives to the patient. If the patient is unable to understand this information, it is given to the patient’s legal health care representative or proxy. The written information given to the patient and/or legal representative includes:

    a. RCC’s policies on the implementation of the patient’s advance directives including any limitations; and
    b. A description of the patient’s rights under State law, including the patient’s right to formulate an advance directive and the right to accept or refuse medical or surgical treatment, including resuscitation.

2. In the administrative section of the patient's clinical record, the RHC staff documents that the patient has received written information related to advance directives and whether the patient has or has not executed an advance directive.

3. If available, a copy of any advance directive is placed in the patient's clinical record and the patient's wishes, including his or her resuscitation status, are communicated to members of the RHC Interdisciplinary Team (IDT) to be included in care planning for the patient.

4. If the opportunity to formulate an advance directive is declined at the time of admission, the patient may execute one at a later date. The social worker provides the patient with appropriate forms and ensures that they are properly completed.

5. If the patient chooses DNR status, a signed order is obtained from the attending healthcare professional defined as a physician or an advanced practice registered nurse. A copy is placed in the patient's clinical record and the original retained by the patient.

6. The SW or designee directed by the attending healthcare professional, shall provide the patient with written information about the resuscitation procedures that the patient has chosen to forego and the methods by which the patient may revoke the do-not-resuscitate order.

7. A bracelet may be signed by the attending healthcare professional indicating DNR. This bracelet must be on the patient's wrist to be honored by EMS.

8. RHC will abide by individual facility protocol for ensuring patient resuscitation status is clearly identified.

9. Education is provided to RHC staff and the community regarding advance directives, advance care planning, and patient rights regarding advance directives.

MEDICATION MANAGEMENT AND DISPOSAL OF CONTROLLED SUBSTANCES

POLICY

Rainbow Community Care (RCC) instructs patients/caregivers in the safe use and disposal of controlled substances in accordance with State and Federal regulations.

DEFINITION

Controlled substances are drugs that are regulated by State and Federal laws that aim to control the danger of addiction, abuse, physical and mental harm, the trafficking by illegal means, and the dangers from actions of those who have used the substances. Such drugs may be declared illegal for sale or use but may be dispensed under a physician's prescription.

PROCEDURE

1. At the time when controlled substances are first ordered, the hospice nurse:

    a. Assesses for
        i. patient safety risk factors related to controlled substances including patient and caregiver history of drug diversion and potential for drug diversion.
        ii. appropriate quantity based on patient's condition, diagnoses, and safety risk factors. Provides a copy of the hospice's written policies and procedures on the management and disposal of controlled substances to the patient or patient representative and family.
        iii. safe medication administration including patient and/or caregiver ability to safely administer medication.
    b. Discusses the hospice's policies and procedures for managing the safe use and disposal of controlled substances with the patient or representative and the family in a language and manner that they understand to ensure that these parties are educated regarding the safe use and disposal of controlled substances; and
    c. Documents education provided on written policies and procedures for managing controlled substances in the clinical record.

2. Patient/caregiver education regarding RCC's policies and procedures on controlled substances may be in the form of written educational information on the safe use and disposal of controlled substances.
3. Education/information provided to the patient/caregiver related to controlled substances is documented in the patient's clinical record.
4. The RN Case Manager, or designee, identifies and documents any misuse of controlled substances and notifies the patient's attending physician or hospice physician, the pharmacist, and their supervisor or designee.
5. For suspected or actual diversion of controlled substances and the Interdisciplinary Team (IDT); in consultation with the hospice physician, the patient's attending physician (if there is one), and the pharmacist; determines the appropriate course of action. The CEO or designee should be informed of suspected and actual diversion for investigation and reporting, including reporting the diversion to appropriate authorities.

Disposal of Controlled Substances

1. When controlled substances are no longer needed by the patient, including upon order for the discontinuation of a drug, patient death, or when wasting a controlled substance, the RCC nurse will:

    a. Review RCC's policies and procedure for management and disposal of controlled substances with the patient and/or representative and
    b. Review literature available for appropriate disposal of medication per RCC policy in accordance with all State and Federal regulations, including but not limited to DEA, EPA and state DNR requirements.

2. Private Residence –
    a. The preferred method of disposal for controlled substances is <u>disposal by the RCC nurse with a witness observing the count and disposal process.</u>
        i. The patient or other individual must be present during entire disposal process.
        ii. Both the nurse and witness should document medication disposal using Controlled Substance Destruction Record including controlled substance type, unit measure and amount disposed.
        iii. Both the nurse and witness should sign verifying disposal of controlled substances documented on the Controlled Substance Destruction Record.
    b. Alternative options for disposal
        i. The patient or other individual lawfully entitled to dispose of the patient's property can dispose of controlled substances by removal to Drug Collection Site.
    c. The patient or other lawfully entitled individual can destroy the controlled substance(s) in accordance with written EPA recommendations provided. (see addendum – EPA Disposal of Medicine)

3. Contracted Facilities – the RCC nurse may witness the disposal of medication in these settings. The facility staff should follow their routine protocol for medication disposal in accordance with State and Federal requirements.

4. Inpatient Center – The Inpatient Center method of disposal for controlled substances is disposal by the RCC nurse or other authorized individual with a witness observing the count and disposal process.
        i. A witness must be present during entire disposal process.
        ii. Both the nurse and witness should document medication disposal using Controlled Substance Destruction Record including controlled substance type, unit measure and amount disposed.
        iii. Both the nurse and witness should sign verifying disposal of controlled substances documented on the Controlled Substance Destruction Record.

5. The RCC nurse should not destroy medication except as described above.
6. The RCC nurse should not remove medication from any setting.
7. The RCC nurse should document disposal education/instructions and activities.

DISCHARGE FROM HOSPICE CARE

POLICY:

Rainbow Community Care (RCC) follows a consistent plan for discontinuance of services and supports the patient/caregiver with referrals and planning for continued care as appropriate.

PROCEDURE:

1. RHC provides ongoing discharge planning throughout hospice services.

2. RHC may discharge a patient from services if:
   a. If the patient moves outside the geographical area serviced by the hospice or transfers to another hospice;
   b. If the patient no longer meets the eligibility requirements for hospice care;
   c. If the patient chooses to receive treatment from an inpatient facility with which RHC does not have and/or cannot obtain a written agreement; and/or
   d. For cause, if the hospice determines that the patient's (or other persons in the patient's home) behavior is disruptive, abusive, or uncooperative to the extent that the delivery of care to the patient or the ability of the hospice to operate effectively or safely is impaired. (refer to PC.D20 *discharge for cause letter* and PC.D20 *discharge for cause checklist*)

3. When a patient is discharged from hospice (and is not transferring to another hospice), he or she is no longer covered under the Medicare hospice benefit, resumes Medicare coverage of the benefits that were waived by the election of hospice care and may, at any time, elect to receive hospice care again in the future if he or she meets the eligibility requirements.

4. Prior to discharge, the hospice obtains a written physician's discharge order from the hospice physician and consults with the patient's attending physician (if there is one), documenting his or her review of the discharge decision in the discharge note.

5. When the patient is discharged from hospice, the hospice provides a copy of the clinical record (if requested) and the hospice discharge summary to the patient's attending physician. This discharge summary is filed in the clinical record and includes:
   a. The reason for the discharge;

   b. A summary of services provided to the patient; including treatments, and symptom and pain management;
   c. A copy of the patient's current plan of care, including the current drug profile;
   d. The patient's latest physician orders; and
   e. Any other documentation that will assist in post-discharge continuity of care.

6. Upon patient discharge, a Notice of Termination or Revocation (NOTR) is completed on National Government Services (NGS) FISS/DDE system for all Medicare patients within 5 calendar days of discharge.

7. If the Interdisciplinary Team (IDT) determines that the patient no longer meets the hospice's eligibility requirements, RHC will:
   a. Present the patient or legal representative with a **"Discontinuation or Termination of Services"** for signature. This notice will explain that the patient is being discharged from RHC services.
   b. Along with the written notice of discharge, and no later than 2 days before all covered services end, present the patient or legal representative with:
      i. A **"Notice of Medicare Provider Non-Coverage"** which will give the date of discharge and instructions on the appeal process as well as phone numbers of the Quality Improvement Organization (QIO). RHC's QIO is Livanta.
      ii. An **"Explanation of Non-Coverage"** which will give a detailed explanation of why RHC has determined that Medicare coverage for the current hospice services should end.
   c. Provide ongoing conversation with patient or representative leading up to discharge;
   d. Plan for any necessary family counseling;
   e. Continue to educate the patient/representative;
   f. Provide necessary referrals for services needed for patient and family after discharge;
   g. Notify the patient's attending physician (if there is one) of the discharge date as soon as it is determined.
   h. Ensure the patient has a necessary supply of medications and supplies.

8. A patient being discharged for no longer meeting the hospice's eligibility requirements has the right to appeal the decision for discharge. *This is the only type of discharge that a patient can appeal.*

a. If an appeal is made, and once the patient or family has contacted the QIO, the QIO will then contact RHC and request records. These records must be faxed to them no later than the close of business that day.

b. Livanta is the Beneficiary and Family Centered Care QIO (BFCC-QIO) for Wisconsin
    i. LIVANTA 1-888-524-9900 (TTY: 1-800-985-8775)
    ii. esMD is preferred method for record transmittal see addendum PC.D20 Addendum Livanta FAQ.
    iii. Website: https://www.livantaqio.com/en
    iv. Fax: refer to record request for fax
    v. Mailing Address:
    Livanta LLC
    BFCC-QIO Program
    10820 Guilford Road, Suite 202
    Annapolis Junction, MD 20701-1105
    vi. Additional information can be found at Code of Federal Regulations 422.626.

c. The QIO will review the records and make a decision to agree with the provider or with the patient.
    i. If the decision is to agree with RHC and recommend discharge, the QIO will contact the family regarding their decision. The discharge date on the written notice for discharge will stand. The patient has the right to appeal the QIO's decision by submitting a Level 2 appeal to the QIC (Qualified Independent Contractor).
    ii. If the decision is to agree with the patient, and the QIO found that there is no reason for discharge, that patient still meets Medicare criteria and will remain on hospice. A note will be made on the written notice of discharge stating the QIO overturned the decision to discharge and patient still meets Medicare criteria. The form will be signed by the person completing it and filed in the patient's clinical record. RHC may appeal the QIO's decision by submitting a Level 2 appeal to the QIC.
    iii. For information on Level 2 appeals, visit https://www.hhs.gov/about/agencies/omha/the-appeals-process/level-2/parts-a-and-b/index.html

d. If at any time during the discharge process the patient/representative wishes to continue receiving hospice care beyond the expected discontinued date, Medicare may not pay, RHC will issue an **"ABN (Advanced Beneficiary Notice)"**.

9. When a person is being discharged for cause, RHC will:
    a. Advise the patient/representative that discharge for cause is being considered;
    b. Make a serious effort to resolve the problem or problems;
    c. Ascertain that the patient's proposed discharge is not due to the patient's use of necessary hospice services;
    d. Document the problems and efforts to resolve them in the patient clinical record;

REVOCATION OF THE MEDICARE HOSPICE BENEFIT

POLICY

A patient or his/her representative may revoke election of the Medicare hospice benefit at any time and for any reason during an election period.

PROCEDURE

1. To revoke the election of hospice care, the patient or representative must sign a revocation statement indicating that Medicare coverage for hospice care is revoked and the date that the revocation is effective. A verbal revocation of benefits is NOT acceptable.

2. The patient/representative may not designate an effective date earlier than the date the revocation is signed.

3. The patient is advised that he or she may re-elect Medicare coverage for hospice care at any time if eligibility requirements are met.

4. Only the patient or his/her representative may revoke a Medicare election. Rainbow Community Care (RCC) may not revoke a patient's Medicare election, nor pressure the patient to do so for any reason or under any circumstances.

5. Reasons a patient may choose to revoke the Medicare hospice benefit may include, but are not limited to the following reasons:
    a. Moving out of RCC's service area;
    b. Dissatisfaction with the RCC's services;
    c. Choosing to receive care at an inpatient facility with which RCC does not have a written agreement; and/or
    d. Choosing to seek curative care for treatment of the terminal illness.

6. When a revocation occurs, RCC sends a discharge summary to the attending healthcare professional that includes, at a minimum:
    a. The reason for the revocation;
    b. A summary of the patient's stay including treatments, symptoms, and pain management;
    c. A copy of the patient's current plan of care including medication profile, DNR, and advance directives;
    d. The patient's latest physician orders; and
    e. Any other documentation that will assist in post-discharge of continuity of care.

7. The patient's clinical record is forwarded to the attending physician, if requested.

8. The RN Case Manager or designee notifies the patient's attending healthcare professional of the revocation decision and effective date.

9. When a patient revokes the Medicare hospice benefit, he or she loses the remaining days in the current benefit period and, if readmitted, goes into the next benefit period.

10. Upon patient revocation, a Notice of Termination or Revocation (NOTR) is completed on National Government Services (NGS) FISS/DDE system for all revocations for Medicare patients within 5 calendar days of discharge.

Nondiscrimination Notice

Rainbow Community Care complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. Rainbow Community Care does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

Rainbow Community Care provides free aids and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters.
- Written information in other formats (large print, audio, accessible electronic formats, other formats).
- Free language services to people whose primary language is not English, such as:

    - Qualified interpreters

- Information written in other languages

If you need any of these services, contact Michelle Smith.

If you believe that Rainbow Community Care has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can file a grievance with: Michelle Smith – Director of Human Resources, 147 Rockwell St. Jefferson, WI, 920-674-6255, michelle.smith@rainbowhospicecare.org. You can file a grievance in person or by mail, fax, or email. If you need help filing a grievance, Michelle Smith is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at https://ocrportal.hhs.gov/ocr/portal/lobby.jsf, or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Avenue, SW
Room 509F, HHH Building
Washington, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)

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

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-920-674-6255.

LUS CEEV: Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. Hu rau 1-920-674-6255.

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-920-674-6255.

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 1-920-674-6255.

ملحوظة: إذا كنت تتحدث اذكر اللغة فإن خدمات المساعدة اللغوية تتوفر لك بالمجان اتصل برقم 1-920-674-6255.

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-920-674-6255.

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-920-674-6255.

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1-920-674-6255.

Wann du schwetzscht, kannscht du mitaus Koschte ebber gricke, ass dihr helft mit die englisch Schprooch. Ruf selli Nummer uff: Call 1-920-674-6255.

ໂປດຊາບ: ຖ້າວ່າ ທ່ານເວົ້າພາສາ ລາວ, ການບໍລິການຊ່ວຍເຫຼືອດ້ານພາສາ, ໂດຍບໍ່ເສັຽຄ່າ, ແມ່ນມີພ້ອມໃຫ້ທ່ານ. ໂທຣ 1-920-674-6255.

ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-920-674-6255.

UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 1-920-674-6255.

ध्यान द□: य□द आप □हदी बोलते ह □तो आपके लिए मुफ्त म□ भाषा सहायता सेवाएं उपलब्ध ह।□ 1-920-674-6255.

KUJDES: Nëse flitni shqip, për ju ka në dispozicion shërbime të asistencës gjuhësore, pa pagesë. Telefononi në 1-920-674-6255.

PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-920-674-6255

Your Right to an Interpreter

You have the right to an interpreter at no cost to you. Please point to your language. An interpreter will be called. Please wait.

Albanian

Shqip

Keni të drejtën për përkthyes falas gjatë vizitës mjeksore. Ju lutem tregoni me gisht gjuhën që flisni. Ju lutem prisni, do t’ju gjejmë një përkthyes për viziten mjekësore.

Polish

Język Polski

Macie prawo do korzystania z usług polskiego tłumacza. Usługa ta jest na nasz koszt. Proszę wskazać swój język. Proszę czekać. Łączymy z tłumaczem.

Arabic

عربي

يحق لك الحصول على خدمات ترجمة
فورية دون أي مقابل. يُرجى منك أن
تشير بإصبعك الى لغتك كي نستدعي
المترجم الفوري. يُرجى منك الانتظار
لحين استدعاء المترجم.

Chinese - Simplified

中文

Cantonese	Mandarin	Toisanese	Taiwanese/Fukienese	Min
广东话	国语	台山话	台湾语/福建话	闽语

你有权利要求一位免费的传译员。请指出你的语言。传译员将为你服务，请稍候。

Chinese - Traditional

中文

Cantonese	Mandarin	Toisanese	Taiwanese/Fukienese	Min
廣東話	國語	台山話	台灣語/福建話	閩語

你有權利要求一位免費的傳譯員。請指出你的語言。傳譯員將為你服務， 請稍候。

Russian

Русский

Вы имеете право на услуги бесплатного переводчика. Укажите, пожалуйста, на Ваш язык. Переводчик будет вызван. Пожалуйста, подождите.

French

Français

Vous avez droit gratuitement aux services d’un interprète. Veuillez indiquer votre langue. Nous allons contacter un interprète. Veuillez patienter si’il vous plaît!

German

Deutsch

Sie haben kostenlosen Anspruch auf eine/n Dolmetscher/in. Bitte deuten Sie auf Ihre Sprache. Ein/e Dolmetscher/in wird gerufen. Bitte warten Sie.

Spanish

Español

Usted tiene derecho a un intérprete gratis. Por favor, señale su idioma y llamaremos a un intérprete. Por favor, espere.

Tagalog

Tagalog

Ikaw ay may karapatan na magkaroon ng tagapagsalin na walang bayad. Ituro ang iyong wika. Ang tagapagsalin ay tatawagin. Maghintay.

Vietnamese

Tiếng Việt

Quý vị có quyền được một thông dịch viên miễn phí. Xin chỉ vào ngôn ngữ của quý vị. Chúng tôi sẽ gọi một thông dịch viên. Vui lò ng chờ trong giây lát.

Hindi

हिंदी

आपको बिना कोई शुल्क दिए दुभाषिया सेवा पाने का अधिकार है। कृपया अपनी भाषा को इंगित करें। दुभाषिया को बुलाया जाएगा। कृपया प्रतीक्षा करें।

Hmong

Hmoob

Koj muaj cai txais kev pab txhais lus dawb tsis them nyiaj. Thov taw tes rau koj hom lus nov. Mam hu tus txhais lus. Thov nyob tos.

Korean

언어

여러분은 무료로 전문 통역자의 도움을 받을 권리가 있습니다. 왼쪽의“한국어”를 손가락으로 가리켜 주십시요. 전문 통역자에게 연결될 것입니다. 잠시만 기다려 주십시요.

Laotian

ລາວ

ທ່ານມີສິດຂໍນາຍແປພາສາໂດຍບໍ່ເສັຽຄ່າ.

ກະຣຸນາຊີ້ໃສ່ພາສາຂອງທ່ານ.
ນາຍພາສາຈະຖືກເອີ້ນມາ.
ກະຣຸນາລໍຖ້າ.

Source: http://www.masslegalservices.org/content/multilingual-interpreter-rights-and-requests-help-posters-and-cards

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Notes

Rainbow Hospice Care

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CAREGIVER TRAINING TO CARE FOR THE PATIENT
Education Checklist

Patient Name:

Pain	Education Needed: RHC Staff Mark "X" if Education is Needed.	Family Request: Place an "X" here if you would like additional education on this topic	Education Provided on (initial and date)	Additional Education Provided (initial and date)	Mark "X" if no further education is needed
Pain Medication - in the home for patient					
Pain Medication - Side Effects					
When to Give Pain Medication					
How/When to call RHC regarding Pain					
Breathing - Shortness of Breath (Dysnpea)					
Signs of Shortness of Breath					
Medications for Shortness of Breath					
Side effects of these medications					
When to give medications for Shortness of Breath					
Other interventions for Shortness of Breath					
How/When to call RHC regarding Shortness of Breath					
Restlessness/Agitation					
Signs of Restlessness and agitation					
Medications for Restlessness and agitation					
When to give medications for Restlessness and Agitation					
Other interventions for Restlessness and Agitation					
How/When to call RHC regarding Restlessness and Agitation					
How to safely move your family member					

Constipation	Education Needed: RHC Staff Mark "X" if Education is Needed.	Family Request: Place an "X" here if you would like additional education on this topic	Education Provided on (initial and date)	Additional Education Provided (initial and date)	Mark "X" if no further education is needed
Signs of Constipation					
Medications for constipation					
When to give medications for constipation					
Other interventions for constipation					
How/When to call RHC regarding constipation					

Anxiety and Sadness					
Signs of Anxiety					
Medications for anxiety					
When to give medications for anxiety					
Signs of Sadness					
How to contact RHC for direction regarding sadness					

OTHER TOPICS (For other topic ideas, see Patient Resource Manual Table of Contents):
