



triniti

Home Health + Hospice

A Cassia | Guardian Angels Affiliation

Hospice Caregiver Training Booklet

Introduction

This booklet was designed to help the families/caregivers of Trinita hospice patients care for their loved ones.

The information provided below is intended to prepare caregivers for the following situations:

1. How to respond to changes in eating and drinking.
1. How to help your family member if they have trouble breathing.
2. What to watch for side effects of pain medication and when to give more pain medication.
3. What to do if your family member becomes restless or agitated.
4. What to do to relieve pain and discomfort.
5. How to respond to changes in bowel movements or urination.
6. How to care for skin and wounds.

Each of us experience a unique end of life path. There are, however, common symptoms, issues, and behaviors we all tend to experience. Our hope is that by providing this booklet to families, you will be able to communicate effectively with the hospice team and have the **training** needed to support your loved one through their journey.

Trinita hospice provides physical, emotional, and spiritual support for those experiencing life-limiting illness and compassionate support for your loved ones. Our interdisciplinary team includes the patients primary care physician and our hospice physician, nurses, social worker, chaplain, certified nursing assistants, massage therapist, music therapist, & volunteers. As a faith-based agency, we pride ourselves on using spiritual care to bring peace, strengthen connections, and create meaningful relationships between the hospice patient, their family, and God.

Thank you for partnering with Trinita hospice to serve your loved one. We respectfully ask that you take the time to complete the Consumer Assessment of Healthcare Providers and Systems **(CAHPS) Hospice Survey**, that will be mailed to you 2-3 months following the passing of your loved one. This survey impacts our publicly reported patient satisfaction scores and is very important to us. We hope this caregiver training booklet has provided you with the information you needed and that your overall rating of Trinita Hospice will be 10, best hospice care possible.

Trinita Hospice Team is available 24/7. Our main phone number rolls over to our *After-Hours* answering service and On-Call staff every evening at 4:30pm until 8:00am the following day, and Saturday through Sunday. You can reach us at one number anytime day or night, **763-241-0654**.

Eating and Drinking

Goals:

- Enjoy eating and drinking with safe and comfortable swallowing for as long as possible.
- Reduce choking and coughing.

Training for caregiver:

- The ability to eat, drink and swallow declines as the body changes.
- Refusing to eat or drink is a natural part of the dying process.
- Appetite may vary greatly and is often fleeting.
- Often just a bite or sip will satisfy the craving.
- Constipation is often a result of poor appetite and is expected.
- Dehydration is also expected and a normal part of the process.
- IV fluids may or may not offer comfort, a dying body likes to be dry and quiet.

What to do:

1. Offer foods and fluids they enjoy but allow them to refuse.
2. Respond to requests as soon as possible, before the desire is gone.
3. Follow the recommendations of your hospice team to position your loved one in a safe way for eating and drinking. Make sure they are sitting up and alert before attempting to eat or drink.
4. Soft foods may be more enjoyable. Try yogurt, ice cream, and popsicles if your loved one can tolerate thin liquids.
5. Stop feeding or drinking if your loved one is coughing, choking, or they turn their head away.
6. If the mouth is dry, use an oral sponge to moisten.

Breathing

Goals:

- Breathe easily without discomfort.
- Quick relief from breathing difficulties.

Training for caregiver:

- Breathing should be easy; however, pain and discomfort can cause shortness of breath.
- Medication is the fastest and most effective way to relieve shortness of breath.
- Oxygen levels will drop when your loved one is actively dying, this does not necessarily cause anxiety or become uncomfortable.
- Oxygen support is generally not needed, if breathing is comfortable.
- Morphine is often the most effective medication for breathing discomfort.

What to do:

1. Listen, if they mention breathing it may be becoming harder to breathe.
2. Check the positioning and elevate the head of the bed if able.
3. Check the environment, provide a fan and/or cool the room temperature.
4. If using oxygen, make sure it is used properly. Check the tubing for kinks, check the flow, and follow all safety precautions.
5. Ask for additional medication that may be available as needed (PRN).
6. If no improvement, call hospice for assistance.
763-241-0654.

Medication Management for Hospice

Goals:

- Use the right amount of medication to achieve the desired effect, which provides the best quality of life.
- Increase confidence with administering and/or asking for medications.

Training for Caregiver:

- Reducing or eliminating medications that are no longer effective or necessary is important to provide the best comfort management.
- The nurse is watching for constipation, drowsiness, nausea, changes in vital signs, and any allergic reactions.
- Medications are required because the patient is dying, the patient is not dying because of the medications.
- People can live longer and better with good symptom management.
- Less medication is often needed when symptoms are prevented and treated quickly.
- PRN is a Latin abbreviation referring to medication that is used “as needed”. There may be medications that are scheduled, and some that are PRN, or both.
- The common medications used in hospice are often designed to work together.
- There are many ways to give/take medications, including oral, sublingual, rectal, and injectable.
- Medications are a tool in our toolbox. It may take a few trials to find the right combination and amount for total comfort.
- These medications are commonly used for pain/shortness of breath, Morphine, Oxycodone, Methadone, Hydrocodone, Dilaudid, Tramadol. ***Patients with advanced pain rarely become addicted to these medications per Stanford School of Medicine.***

- These medications are commonly used for anxiety or agitation: Lorazepam. Valium.

What to do:

1. Follow the medication plan and take scheduled medications consistently for maximum benefit.
2. Do not discontinue scheduled medication without alerting your hospice nurse first. 763-241-0654.
3. Use the PRN medications for breakthrough symptoms not managed by the scheduled medications.
4. Keep track of any PRN medications used and when they were taken.
5. Use a pill box to help organize the scheduled medications.
6. Keep medications out of reach of children & pets.

Restlessness & Agitation

Goals:

- Manage the signs of physical and emotional anxiety and agitation.
- Increase adequate and peaceful sleep.

Training for caregiver:

- Restlessness, agitation, and anxiety are normal, expected, and common responses to end of life.
- Anxiety can be very subtle, or it can be obvious.
- Pain and anxiety often feed off each other and may need to be treated simultaneously.
- Some patients experience forgetfulness, confusion, and/or even hallucinations which can cause agitation.
- Be aware of signs of anxiety including talking about the same subject over and over, looking worried, physical tension, increased distractions, not following conversations, not acting themselves but being more quiet, withdrawn, or irritable, not sleeping well.
- Be aware of signs of agitation including restlessness, pacing, calling out, reaching, trying to re-position, hallucinations, and/or distressing dreams.

What to do:

1. Ask questions about how they are feeling or what they are thinking.
2. Check to make sure all their needs are met. Are they hungry or thirsty? Do they need to urinate, or have a dirty brief?
3. Is there something they are worried about that they can share with you?
4. Sit and listen. Be patient, ask open ended questions to reveal what might be bothering them.
5. Repeat what you are hearing and ask for clarification.

6. Consult with your hospice nurse to help determine when medications might be beneficial. 763-241-0654.
7. Adjust the environment, dim lights, soft music, offer prayer, or read a book.

Pain and Discomfort

Goals:

- Recognize and manage pain and discomfort.
- Provide relief safely and effectively for consistent comfort.

Training for caregiver:

- Pain is different for everyone.
- Pain consumes the energy that can be used for other activities.
- Fear of pain and pain medications can be bigger than the pain itself.
- Pain management can include multiple options which target the pain from different angles.
- Some pain medications are long-acting and are combined with short-acting medications for break through pain.
- Some patients pain increases with movement or during cares, which can be anticipated and reduced.
- Some signs of pain include complaining of pain or moaning, grimacing, tension, laying in a curled ball, restlessness, and/or agitation.
- Repositioning may help with discomfort.

What to do:

1. Give routine medication prescribed by your hospice team.
2. Use PRN medication as instructed.
3. Keep track of PRN doses and let your hospice nurse know.
4. Give pain medication 20-30 minutes prior to cares or activities.
5. Do not wait, if pain continues to increase and cannot be managed, call your hospice to report it. Hospice is available 24/7. 763-241-0654.

Bowel Movements and the need to Urinate

Goals:

- To prevent constipations and have a comfortable bowel movement at least every 3 days.
- To prevent or manage issues that arise with urination.

Training for caregiver:

1. Incontinence of bowel and/or bladder is a normal consequence of the dying process and is expected.
2. Both being unable to urinate or becoming constipated can be uncomfortable and cause restlessness and agitation.
3. The amount of urine will decrease and get darker in color as people drink less and is expected.
4. Hospice nurses are the best at managing constipation.
5. Some medications cause constipation, and this will be managed by your hospice nurse.
6. Common medications for constipation include: MiraLAX, Senna tablets, Bisacodyl tablets, and Bisacodyl suppositories.

What to do:

1. Help them to the commode or toilet at least 3 times a day or as needed.
2. When using briefs or pads check every 2-3 hours for wetness and change to prevent skin issues.
3. Use prescribed bowel medication as ordered.
4. If no BM by noon on day 3, call hospice for further instructions. 763-241-0654.
5. Keeping a log of bowel movements can be helpful.

Catheter Care

- Urinary catheters are frequently used in hospice and are often more comfortable for both patient and caregiver.
- When a catheter is in place, make sure it stays anchored. Pulling or tugging on the tubing can cause discomfort.

- Wash the entire genital area and catheter thoroughly daily with soap and water.
- Inspect the tubing with turning or repositioning to make sure there are no kinks or twists.
- If there is no urine in the bag, check again for twists or kinks.
- Still no urine and patient uncomfortable, call hospice. 763-241-0654.

Skin & Wound Care

Goals:

- Maintain skin integrity for as long as possible.
- Provide comfort for any breakdown that does occur.

Training for caregiver:

1. Skin will change during the dying process, including color, moisture, and temperature.
2. Skin breakdown cannot always be avoided, but prevention is the best comfort measure.

What to do:

1. Look for red spots, scrapes, bruises, dryness, rash and notify your hospice nurse if you see any of those issues.
2. Keep skin clean and dry.
3. Oils and lotions are okay, and essential oil massage (M-technique) can be taught to the caregivers (ask your hospice nurse or aide).
4. Repositioning every 2-3 hours is a great way to prevent skin breakdown.
5. Some patients need comfort medications before turning or repositioning, this is normal.
6. Respond to the skin temperature as you would your own, if hot remove blankets, if cool cover up.

In accordance with the hospice Medicare Benefit, Trinita provides 13 months of bereavement care for families following the passing of your loved one. You will receive calls, cards, and additional education to support you after your loved one is gone. Don't hesitate to reach out to your hospice team at any time for more education, training, or resources during this difficult time.

Reminder that hospice primary caregivers will receive a CAHPS Hospice Survey, look for a mailing from the following company:



We would very much appreciate it if this survey were completed in detail, the scores are publicly reported to help families seek out hospice agencies with the best service.

Lastly, we pray for peace and hope for all our hospice clients and caregivers.

Romans 15:13 *"I pray that God, the source of hope will fill you completely with joy and peace because you trust in him".*



triniti

Home Health † Hospice

A Cassia | Guardian Angels Affiliation

403 Main St. Elk River, MN 55330 (763) 241-0654
www.triniticaring.org