



FINAL *Journey*

What to Expect and
How to Comfort
Your Dying Loved One



INTRODUCTION

This booklet is based on the **CARES** Tool, a guide to help medical teams better care for the dying and their family. It is based on the most common needs of the dying:

*C*omfort

*A*irway

*R*estlessness

*E*mootional support

*S*elf-care

Our goal is to teach you about body changes that will happen as your loved one dies. This guide can help you know what is normal and what could be a sign of possible suffering. Please keep in mind that the doctors, nurses, social workers, chaplains and the staff are here to help. We are committed to keeping your loved one comfortable.

Our prayers and thoughts are with you. Please call on us at any time.

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COMFORT

Pain can be a problem when caring for the dying. You know your loved one best. If you feel they may be in pain, please tell the nurse. Our goal is to keep your loved one comfortable and for you to have as much time with them as you can.

- The nurse will give pain medicine as needed.
- The nurse will answer any questions you have about these pain medications.

If you see any muscle twitching or jumping on your loved one's arms or legs, please tell the nurse because the pain medication may need to be changed.

Nurses will be working with you to make changes in your loved one's care. They will help you with choices that can be made about:

- Blood work
- Monitors
- Turning
- Bathing
- Stopping medicines

If you want to help with the care for your loved one, please let the nurse know.

Fluids both by mouth and given directly into a vein (IV) can make it hard to breathe and add to swelling. Nurses and doctors will talk to you about slowing down or stopping IV fluids and focusing on keeping the mouth moist. Often just keeping the mouth moist will satisfy feelings of thirst.

Food is a very big part of many cultures. It shows love and the wish to comfort. If your loved one is able to eat, check with the nurse for any restrictions.

- Many people often find just the smell of their favorite foods comforting.
- If your loved one can handle a normal diet, feel free to bring in their favorite foods.
- Not wanting to eat is a natural part of the dying process. The brain makes soothing chemicals at this time so that the dying do not feel hungry. The body is working very hard to keep the heart beating and to keep breathing, and blood flow to the stomach and gut is greatly reduced so that food cannot be properly digested.
- They may only be able to eat a bite or two. Do not force them to eat, as they may throw up and this can cause further breathing problems. They will not die of starvation. They are dying from their disease.

People differ in how they go through the dying process:

- Some sleep more and may respond less to you.
- Some people may become restless and agitated.

COMFORT

Continued

The nurse can give medications to help them relax, can offer calming ideas and may suggest the family participate by:

- Speaking softly and warmly
- Trying to be reassuring
- Letting your loved one know you are present
- Playing familiar music
- Setting up a calm environment with soft lighting
- Providing familiar or soothing pleasant smells such as lavender or essential oils

Anything brought in from the outside should be discussed with the bedside nurse to assure it complies with hospital policies.

Other common changes during this time may be:

- Loss of bladder and bowel function
 - Urine becomes dark and is made in smaller amounts as the kidneys shut down.
 - The making of urine often stops several hours before death.
 - The nurse may need to place a soft flexible tube (catheter) into the bladder to collect the urine.
 - Loss of bowel control is common when muscles in the body start to relax.
 - The nurse may need to pad the bed or place protective garments on your loved one.
- Skin changes occur such as cooling, increased moisture and bluish discoloration.
 - Bruise-like patches may appear on the toes, fingers, hands, feet and knees because blood flow to these areas has slowed.
 - The body usually becomes cold. In some cases, patients will get a high fever that does not come down with medication. Changes in temperature happen because the brain cannot manage body temperature as it shuts down during the dying process.
 - Nurses will help with ice packs or blankets as needed.

Your nurses can help you learn more about what happens in the dying process and how you can offer comfort.

AIRWAY

Breathing changes during the dying process:

- It can become irregular, shallow or slow then speed up.
- It can stop for short periods of time, then restart. This is due to decreased brain function. The breaths will stay irregular until they stop completely.
- It can sound like gasping, but your loved one is not suffering.
 - They do not know that they are doing it.
 - This could go on for hours or days, even after a breathing tube is removed.
- Gurgling may be heard as the dying person becomes too weak to clear their throat and fluids pool.
 - The nurse can:
 - Reposition your loved one so they can breathe easier.
 - Give additional medication to help reduce the gurgling, as well as anxiety and pain.
 - Set up a gentle suctioning system if needed.

You can help the most by:

- Speaking softly and warmly
- Trying to be reassuring
- Letting your loved one know you are present
- Playing familiar music
- Setting up a calm environment with soft lighting

It can be very hard to watch your loved one breathe irregularly, have increased secretions and possibly even have spasm-like chest wall movement.

- Talk to the nurse about your concerns and they can reposition, medicate, and/or educate you and your loved ones as appropriate.
- Low amounts of oxygen may improve comfort, while face masks or higher flow oxygen can be uncomfortable and are not recommended at this time. Ask the nurse for advice.

Your loving presence and comforting voice provide the best care to help your loved one relax and breathe easier.

Very often the last breath your loved one takes in will be followed by one last delayed breath out as all of the air in their lungs is released. This can be scary if you are not ready for it. Unfortunately, this is not a sign that your loved one is trying to breathe again.

RESTLESSNESS AND DELIRIUM



About 80 percent of patients become confused (delirious) during the dying process. Commonly, this is caused by the loss of oxygen to the brain as the body is shutting down.

During this time, your loved one may return to a time in their memory when they were happiest and healthiest. This may be a time at home or on vacation. You do not need to remind them where they really are.


You may see unusual restlessness or arm and leg movements. Some possible causes include:

- A full bladder
- Pain or other symptoms
- Unfinished business
- Need for reassurance that you will be OK without them

The nurse may be able to make your loved one more comfortable by:

- Inserting a tube into the bladder to drain any urine
- Giving your loved one medication to treat their symptoms

You may be able to help by:

- Bringing in familiar, pleasant smells
 - Playing their favorite music or reading their favorite book — consider the fact that hearing is the last sense to be lost in the dying process
 - Providing their favorite clothes
 - Reducing stimulation by lowering lights and avoiding loud noises
 - Reassuring them that their life has meaning and they will be remembered
 - Ruling out any unfinished business within the family. Your loved one may be holding on so they can be present at a wedding or graduation, or they may want to avoid dying on a special holiday.
 - Consider addressing your loved one's concerns by having a special or separate graduation or wedding in their room.
 - Assure them that tasks or issues they are concerned about will be managed.
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RESTLESSNESS AND DELIRIUM

Continued

- You may need to give them permission to die; this may be the most difficult thing you will ever do.
 - Reassure your loved one that you will be OK without them.
- Telling your loved one the following may help them rest easier:
 - Please forgive me¹
 - I forgive you¹
 - Thank you¹
 - I love you¹
 - Goodbye
- Just being present is one of the most loving acts you can provide.

Some patients become very anxious and may need to be sedated. If your loved one needs sedation to relax, they will not be able to speak to you or interact. While this can be hard for family, you must think about what is best for your loved one. This is the time your loved one's needs are placed ahead of your own.

There is often a period of alertness just days or hours before a person dies. They may become suddenly awake, talkative, and may ask for a favorite food or something special. This "awake time" may last moments to hours, after which they will again become unresponsive. There is no complete explanation why this happens.

- Make the most of this chance to talk and interact with your loved one.
- Understand this is often their last surge of energy before they die, and unfortunately is not a sign that they are getting better.

EMOTIONAL AND SPIRITUAL SUPPORT

It is very hard to predict when your loved one will die. There are certain milestones that are commonly seen as death gets closer:

- They will sleep more than they will be awake.
- They will withdraw and communicate less.
- They will stop making urine.
- Their feet, knees and finger tips will become discolored.
- Their breathing will become irregular and often stop for several moments.

We believe your loved one will be comforted just by your presence and touch, even if they cannot outwardly respond.

Let the staff know if you want more privacy. They are here to help, not get in your way. Clinical social workers are available to help. They have additional resources and can provide emotional support if needed. Let the nursing staff know if you need anything.

Our hospital chaplains can also provide spiritual care and support according to your faith's tradition, or just be present and listen. Let the nursing staff know if you would like a hospital chaplain to visit or to have a member of your faith community called.

Work with the staff to arrange any desired:

- Rituals
- Ceremonies
- Prayer sessions
- Music
- Funeral arrangements
- Letters for family to travel or written excuses from work

We want to help you celebrate the life of your loved one:

- Ask the nurse about legacy ideas.
- Bring in favorite clothes, food, music, etc.
- Share your favorite stories/memories with your family and staff.
- Do not be embarrassed to laugh as you share stories about your loved one.
- Remember and share the joy that having your loved one in your life has brought you.

EMOTIONAL AND SPIRITUAL SUPPORT

Continued

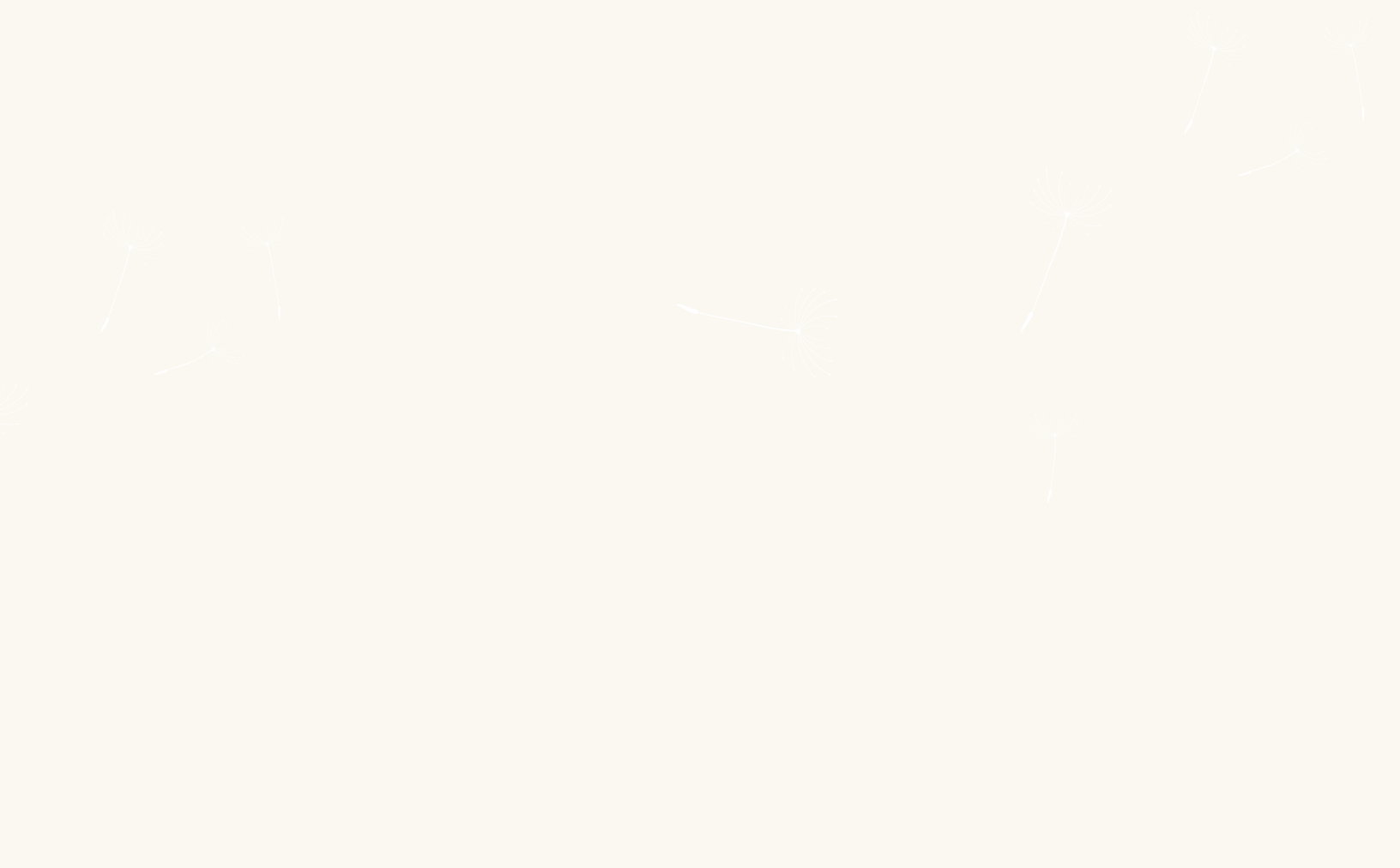
Death can be very spiritual and meaningful. You may want time to:

- Reflect
- Meditate
- Pray
- Say goodbye
- Just sit quietly and be with your loved one

Check with the nurse if you have any questions or concerns.

Feel free to touch and hold your loved one.

- Curl up next to them if this would support you and them.
- Death is not contagious and your loved one will appreciate being treated normally.



SELF-CARE

Having someone you love die is very painful.

- Nurses, chaplains, clinical social workers and child life specialists are available and can offer support, as well as provide information on grief and bereavement. Your bedside nurse can help by reaching out to the appropriate team members.
- You may invite a member of your own faith community to provide spiritual support.
- Try to get rest and eat. You will need your strength.
- Ask your nurse for any additional information you may need.

It is hard to stay focused when you are grieving.

- You may be too upset to make phone calls.
- Consider making funeral arrangements when you are calm, and not immediately after your loved one has died.
- Let staff know how they can help.

It may be difficult to leave the bedside of your loved one out of fear they will die when you are gone. Know that the last loving thing the dying can do is to pick the time they will die.

Often it is when family members have stepped out.

- Some believe the dying choose their time in an effort to protect their family and a desire to be remembered more positively.

You have done the very best you can to support and comfort your loved one.

- A power greater than you will decide what will happen.
- Try to celebrate the time you were given.

Let us help you make this final journey for your loved one as special and as compassionate as possible. Please let us know how we can help you further.

RECOMMENDED READING:

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NOTES

A series of horizontal dotted lines for writing notes.



