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Providing Care for a Person with Cancer as They Near Death

The caregiver should know what to expect and what they can do as the person with cancer gets close to death. This knowledge can help them provide the best care possible and help the person with cancer say goodbye.

This can be a time to focus on physical, spiritual, emotional, and family concerns. Patients and family members often have questions about what might happen during the last stage of life. Understanding what to expect both physically and emotionally might help them live more fully.

- What to Expect When a Person with Cancer Is Nearing Death
- Saying goodbye

What to Expect When a Person with Cancer Is Nearing Death

The end of life is different for everyone. No one can predict how long the final stage of life will last or when death will happen. Sometimes death comes quickly. Other times the dying process takes longer and the person may linger.

- Changes in body function
- Possible changes in consciousness

- Changes in appetite
- Possible changes in metabolism
- Possible changes in secretions
- Possible changes in circulation and temperature
- Possible changes in senses and perception
- Possible changes in breathing
- Possible changes in elimination
- Signs that your loved one has died
- What to do when you think your loved one has died

It's hard to know exactly what will happen in the final stage of life and especially near death. There are some common symptoms that most often happen in people with cancer who are dying. All might not happen, but it may help you to know about them.

Changes in body function

- Extreme weakness. May have trouble moving around in the bed and might not be able to get out of bed.
- May not be able to do much for themselves. They may need help bathing, brushing their teeth, and dressing. They may need to use a bedpan or bedside toilet, if they can get up.
- Less interest in food, often eating or drinking very little
- Trouble swallowing pills and medicines
- Lips may appear to droop
- Might not be able to focus on what's going on around them
- Might not be able to help with their own care
- Sudden movement of any muscle, jerking of hands, arms, legs, or face

What caregivers can do

- Help the patient turn and change positions every 1 to 2 hours. It's best to time any position changes to about 30 minutes after pain medicine is given.
- Speak in a calm, quiet voice and avoid sudden noises or movements to reduce the chances of startling the patient.
- If the patient has trouble swallowing pills, ask about getting liquid pain medicines or a pain patch.
- If the patient is having trouble swallowing, do not give them solid foods. Try ice

chips or sips of liquid.

- Do not force them to drink. Near the end of life, some dehydration is normal.
- Apply cool, moist washcloths to head, face, and body for comfort.

Possible changes in consciousness

- More sleeping during the day
- Hard to wake from sleep
- Confusion about what time it is, where they are or who the people around them are
- Restless, might pick or pull at bed linen
- May talk about things unrelated to the events or people present
- May be more anxious, restless, afraid, and lonely at night.
- After a period of sleepiness and confusion, may have a short time when they are mentally clear before going back to sleep

What caregivers can do

- Plan to be with them when they are most alert or during the night when your presence may be comforting.
- Remind them who you are and what day and time it is.
- Continue pain medicines up to your loved one's death.
- If your loved one is very restless, try to find out if they are having pain. If it appears
 they are, give breakthrough pain medicines as prescribed, or check with the doctor
 or nurse if needed.
- If your loved one is confused, use calm, confident,gentle tones so you don't startle or frighten them.
- Gentle touching, caressing, holding, and rocking are usually helpful and comforting.

Changes in appetite

In the last stage of life, many people lose their desire to eat or drink. This is not unusual. People also don't need to eat and drink as much. Loss of appetite can be caused by changes in the body happening now. Try not to get upset when they don't feel like eating or aren't eating as much as they used to.

What caregivers can do

- Avoid family food battles
- Let them eat what and when they feel like it
- Try to keep their favorite foods and drinks around, but know their tastes can change day to day.
- If the smell of food bothers them, offer foods that are cold or at room temperature.
- If they have nausea or pain, help them take medicines given to them as directed
- Try not to get upset when they don't feel like eating or aren't eating as much as they used to
- Let them know that your efforts to get them to eat more are because you love them
- Ask how you can best support them and spend time together in ways that don't involve eating

Possible changes in metabolism

- Mouth may dry out
- Might no longer need some of their medicines (such as vitamins, replacement hormones, blood pressure medicines, and diuretics), unless they help make them more comfortable.

What caregivers can do

- Put lip balm, lubricant, or petroleum jelly (Vaseline®) on your loved one's lips.
- Try giving ice chips from a spoon, or sips of water or juice from a straw.
- Check with the doctor to see which medicines may be stopped. Medicines for pain, nausea, fever, seizures, or anxiety should be continued to keep your loved one comfortable.

Possible changes in secretions

- Mucus may collect in the back of the throat. This may cause a rattling sound with breathing that's very distressing to hear. But know that this isn't usually uncomfortable for your loved one.
- · Secretions may thicken and build up due to less fluid intake and because your

loved one can't cough

What caregivers can do

- If mouth secretions increase, keep them loose by adding humidity to the room with a cool mist humidifier.
- If your loved one can swallow, give them ice chips or sips of liquid through a straw. This may help thin secretions.
- Change your loved one's position turning them to the side may help secretions
 drain from the mouth. Continue to clean your loved one's teeth and mouth with
 water and a soft toothbrush or foam mouth swabs.
- Certain medicines may help. Ask your doctor or nurse about them.

Possible changes in circulation and temperature

- Arms and legs may feel cool to the touch as circulation slows down
- Skin on arms, legs, hands, and feet may darken and look blue or mottled (blotchy)
- Other areas of the body may become either darker or paler
- Skin may feel cold and either dry or damp
- Heart rate may become fast, faint, or irregular
- Blood pressure may get lower and become hard to hear

What caregivers can do

- Keep your loved one warm with blankets or light bed coverings.
- Don't use electric blankets, heating pads, etc.

Possible changes in senses and perception

- Vision may become blurry or dim
- Pupils may not change size
- May have trouble closing eyelids
- Hearing may decrease, but most people can hear you even after they can no longer speak.

What caregivers can do

- Leave indirect lights on as vision decreases.
- Always assume your loved one can hear you.
- Continue to speak with and touch your loved one to reassure them of your presence. Your words of affection and support are likely to be understood.

Possible changes in breathing

- Breathing may speed up then slow down
- Your loved one may grunt while breathing
- Neck muscles may look tight to help breathe
- Mucus in the back of the throat may cause rattling or gurgling with each breath
- Your loved one may have periods up to 30 seconds when they don't breathe, then start breathing again

What caregivers can do

- Put them on their back, or slightly to one side.
- Raising your loved one's head may give some relief.
- Use pillows to prop your loved one's head and chest up or raise the head of the bed.
- Any position that seems to make breathing easier is OK, including sitting up with good support. If your loved one is a small person, they may be more comfortable in your arms.

Possible changes in elimination

- Urine may become darker and decrease in amount
- Your loved one may lose control of their urine and stool

What caregivers can do

- Pad the bed beneath your loved one with layers of disposable waterproof pads.
- If your loved one has a catheter to collect urine, the nurse will teach you to care for it.
- Bathe your loved one as they can tolerate it this could be a sponge bath or simply washing certain parts of the body.

Signs that your loved one has died

- Breathing stops
- Blood pressure cannot be heard
- Pulse stops
- Eyes stop moving and may stay open
- Pupils of the eyes stay large, even in bright light
- May lose control of their bowels or bladder

What to do when you think your loved one has died

An important note: If you call 911 or Emergency Medical Services (EMS), even after an expected death at home, the law might require that EMS try to revive the patient or take them to a hospital. This can complicate the situation and delay funeral plans. Be sure that family and friends know exactly who to call, so that they don't dial 911 in confusion or panic.

Try to have a plan for what to do just following your loved one's death. This can help caregivers and other people who are with the loved one when they die. If your loved one is in hospice, the hospice nurse and social worker can help you. If your loved one is not in hospice, talk with the doctor so that you will know exactly what to do at the time of death.

If your loved one dies at home and is not under hospice care, caregivers are responsible for calling the right people. Regulations or laws about who must be notified and how the body should be moved differ from one community to another. Your doctor or nurse can get this information for you.

If a hospice or home care agency is involved, call them first. If you've completed funeral arrangements, calling the funeral director and doctor are usually all that you have to do.

It's all right if you want to sit with your loved one for a while. There's no rush to get anything done right away. Many families find this is an important time to pray, talk together, and share their love for each other and for the person who has passed away.

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Saying Goodbye

Saying goodbye to a loved one at the end of their life is not easy. Many people aren't sure what to say and may not want to deal with the fact that their loved one is dying.

- Knowing when to say goodbye
- Being together at the end

Knowing when to say goodbye

It can be hard to know when to say goodbye and it can depend on:

- How long you have before the person's death. This can vary from months to hours.
- How aware the person is. Losing consciousness is part of dying for most people. When this will happen is hard to predict.
- Where the person is. Many people would like to be at home as they near death, but this may not be possible if they are too ill, don't have someone to care for them, or die quickly.

If able and if time allows, people often use this time to gather loved ones to say goodbye. But sometimes death happens quickly or a loved one is out of town or traveling. This can limit the time to say goodbye.

Being together at the end

If they can be together, family may take turns with the person who is dying, holding their hands, sharing good memories, or just sitting quietly. Some caregivers and family members may feel the need to stay busy by making meals or doing chores. This can also be a time for any religious or cultural rituals and other desired activities before death. It's a chance for many families and friends to express their love and support for each other. The key is to be reassuring and honest, and to speak from the heart.

Here are some hints that may help you in this difficult time.

- Try to plan ahead but know it's not possible to predict when the last minutes or hours of life may be.
- Understand that each person has their own needs and ways to express what they're feeling.
- Be open about knowing the end of life is coming.
- Try to avoid topics and memories that may cause hurt, stress, or pain.
- You don't have to be formal with goodbyes when taking a break from being together. Hospice experts suggest just expressing your love for your loved one.
- Think about using other types of communication for people who may be out of town

- or traveling, such as phone calls, video apps such as FaceTime or Skype, or other technology.
- Know that many experts believe people who are not awake or responding may still be able to hear what you're saying and know you are there.
- If you're having trouble dealing with your emotions, think about talking with your clergy or health care provider. They may be able to help or refer you to a counselor or mental health specialist.

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