



INFORMATION AND COMMON
SYMPTOMS EXPERIENCED AT

THE END OF LIFE

A guide to help you and your caregivers
understand the common symptoms
experienced at the end of life.

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THE END OF LIFE

As the end of life approaches, you and your family may wonder what lies ahead. No one can tell you exactly what will happen because every person is an individual and will have their own unique experience. The goal is to help you understand what can be done to reduce distress, as well as improve the support and care provided during the final days of life. We want to aid family and friends serving as caregivers and companions in learning how to be better prepared.

Some symptoms mentioned may or may not be observed because no two people will have the same experience during the end of life.

END OF LIFE SYMPTOMS

DECREASED APPETITE

It is natural for a person to lose interest in food and drink. The ability to swallow may become challenging. This is a normal part of the process and is not uncomfortable for him/her.

What You Can Do:

- Respect the persons' choice not to eat when offered food as it may be difficult or painful to swallow
- Offer sips of liquid; ice chips or soft foods if the person is awake and alert
- Gently wipe a moistened sponge applicator over and around the lips and mouth
- Apply lip ointment or lip balm

SOCIAL WITHDRAWAL

As the end of life approaches, he/she may become detached, and perhaps show little to no interest in things previously enjoyed. The person may sleep more, talk less, and become less active and engaged.

What You Can Do:

- Speak softly and gently
- Remember to identify yourself before speaking
- Ask permission to visit, sit by the person's bedside, hold the person's hand, or to speak on the telephone
- Provide reassurance that you are there to support your loved one
- Allow time for silence

SKIN TEMPERATURE AND CHANGES IN COLOR

As the human body slows down, blood begins to move from the extremities to the vital organs. The hands and feet may feel cold to the touch and turn a blotchy purple-blue color, while the abdomen remains warm. This change in color is called mottling and is expected. In addition, the person may experience abrupt changes in body temperature -- hot one minute, then cold the next. The person may take on a yellow hue or wax appearance. These are all expected changes in the dying process.

What You Can Do:

- Adjust the room temperature as needed
- Apply a cool, damp cloth to the forehead and back of neck if the person is feeling hot. Provide blankets (not electric), if the person is feeling chilled.
- Use a fan to circulate air and cool the person as needed

BOWEL AND BLADDER FUNCTION CHANGES

Changes in bowel and bladder function at the end of life is normal. The person may experience a decrease in activity of the bowel and bladder. He/she may become unable to control these functions. The person's urine may become more concentrated and give off a strong odor, decrease in volume, and turn a dark color. Constipation may occur due to decreased amount of food eaten and lack of movement.

What You Can Do:

- Keep affected areas clean and dry
- Watch for signs of bowel and bladder incontinence and utilize mattress pads, diapers, and/or liners in underwear
- Offer support and understanding

THE END OF LIFE SYMPTOMS

CONFUSION, RESTLESSNESS AND AGITATION

Restlessness and agitation are common at the end of life, which may be brought on by decreased oxygen, metabolic changes, dehydration, and medication. Although it may look distressing, these symptoms are not considered to be painful and can be controlled with medication as needed. The dying person may pick at their clothing, become fidgety/restless, or forcefully tug your hand.

What You Can Do:

- Do not startle the person by turning on lights, with loud sounds or by moving about abruptly
- Always identify yourself even if the person knows you well, as he or she may not recognize you at times
- Use a gentle reassuring voice; offer support
- Don't disagree with the person if they become confused. Instead, offer reassurance, "I am here for you and I am listening to you. You are safe."
- Consider light hand massage or soothing music
- Speak with the medical team about medications to help relieve agitation

VISIONS AND HALLUCINATIONS

Visions and hallucinations are commonly experienced during this process. Although they can be unsettling to caregivers, they rarely upset the person and are often reassuring and comforting.

What You Can Do:

- Do not judge or criticize
- Share who is present in the room
- Allow for silence, be supportive; talk softly and calmly
- Do not discount the experience
- Notify the medical team if the dying person appears distressed or frightened

CONGESTION IN LUNGS, THROAT AND BREATHING CHANGES

You may observe changes in breathing—shallow and fast or slow and labored. There may also be gurgling sounds due to pooling of secretions in the throat and the inability to clear them. These changes are to be expected and are not uncomfortable or painful.

What You Can Do:

- Remain calm. Do not panic, as this may create distress in the person
- Ask staff to reposition them
- Wipe their mouth with a soft, moist cloth to remove excess secretions
- Ask the medical team about medications specifically prescribed to reduce labored breathing or minimize secretions
- Speak softly and offer support

CARING FOR YOURSELF

Providing care to the person who is dying can be a physically and emotionally taxing process that often goes unrecognized. It is important to remember to care for yourself so that you may continue to be present as a caregiver and advocate.

- Take breaks at regular intervals and seek assistance with care that is physically or emotionally demanding
- Utilize WPH services including Pastoral Care, Holistic Nursing and Caregiver Support for emotional and spiritual support as you may experience a wide range of emotions such as anger, sadness, relief, moments of joy, etc.
- Eat and sleep at regular intervals
- Ask and accept support from family and friends
- Speak to the nursing staff with any questions or concerns that you may have, including those about visitation and funeral planning after death

WHEN DEATH OCCURS

This information may seem overwhelming; Hospital staff want you to know what to expect and are available to help. When death occurs, you may have strong feelings of helplessness and loss which are normal emotional responses.

The Signs of Death:

- No breathing
- No heartbeat

If death occurs in the hospital, the nurse will check for vitals and then notify the hospital provider to confirm that death has happened. This may take time. You are encouraged to do what is most comfortable for you. You may want to stay in the room or step out. There is no right or wrong way to be at this time. After the doctor has pronounced that death has occurred, the staff will ask about your preferences for funeral arrangements and encourage you to make contact with a funeral home. You may not have an identified funeral home or plan, which is okay as you may need time to speak with family/friends for planning.

You will be provided time to be in the room after death occurs. When you are ready to leave, let the staff know. The funeral home will receive the death certificate electronically from our hospital and provide family with the original copies that will be needed.

DEATH AT HOME

If death occurs at home and hospice is involved in the care, the first call is to hospice so that a nurse can come to the home to confirm that death has occurred. The nurse will then make calls to your doctor and the funeral home. Again, you will be allowed to spend the time you need prior to the arrival of the funeral home representative.

If death occurs at home and hospice is not involved, your first call should be to 911. Explain to the operator that your call is not an emergency; that the person was ill and his/her death was expected in the home. Request a police officer for assistance. Once the police arrive, provide the name and number of the doctor, as well as your request to have the funeral home pick up his/her body. The officer and your doctor will determine the next steps.

If you have questions that have not been answered here, please speak with your medical team.

*“You matter because you are you,
and you matter to the last moment of your life.”*

- Dame Cicely Saunders