In-Home Aides

Partners in Quality Care

HOME CARE ALLIANCE of MASSACHUSETTS
www.thinkhomecare.org

October 2025

Objectives:

- Define End of Life Care
- Review the dying process
- Review ways to help a dying person with comfort care

References:

https://www.nia.nih.gov/health/end-life
https://medlineplus.gov/endoflifeissues.html

NCDHHS/DHSR/HCPEC | Home Care Aide Curriculum | July 2021 Module 22 End of Life Care-

https://info.ncdhhs.gov/dhsr/hcpr/curriculum/pdf/115_Module%2022%20End%20of%20Life%20Script_FINAL.pdf

https://www.nia.nih.gov/health/end-life/providing-care-and-comfort-end-life

"How people die remains in the memories of those who live on."-

Cicely Saunders

End of Life Care

As an In-home aide, you may provide care for a person with a terminal illness which is a disease or condition that will eventually cause death. End-of-life care is the term used to describe the support and medical care given during the time surrounding death. Such care does not happen only in the moments before breathing ceases and the heart stops beating but rather it can be provided for days, weeks or months for a person living with a chronic or terminal condition. The dying process is unique for each person. There is no way to predict exactly what course a person's process will take. At the end of life, each story is different. Death comes suddenly, or a person lingers, gradually fading. For some the body weakens while the mind stays alert. Others remain physically strong, but cognitive (i.e., thinking, reasoning, remembering) losses take a huge toll. Although everyone eventually dies, each loss is personally felt by those close to the one who has died. End of life care is caring for the whole person (i.e., holistic care). Palliative care is patient and family care centered that optimizes *quality* of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing *physical, intellectual, emotional, social, and spiritual needs* and to facilitate a person's autonomy (self-sufficiency and right to decisions), access to information, and choice. The person may be receiving Hospice care as well. Hospice care is a concept or philosophy of care that focuses on a person's comfort and quality of life rather than curing the person's disease.

Important Components of Quality at End of Life Include:

- Pain management- Discomfort during the dying process can come from a variety of sources. Listen to what the person is saying about their pain and watch for clues, such as trouble sleeping, showing increased agitation, or crying. Report clients pain according to the plan of care, your observations can be helpful for the medical team to know if a client's pain is not controlled.
- Spiritual peace- People nearing the end of life may have spiritual needs as important as their physical concerns. Spiritual needs include finding meaning in one's life and ending disagreements with others, if possible. The dying person might find peace by resolving unsettled issues with friends or family. Visits from a social worker or a counselor may also help. Many people find solace in their faith; others may struggle with their faith or spiritual beliefs. Notify your supervisor if your client or client's family expresses a desire for assistance with arranging spiritual care, such as the desire to speak with a member of the clergy. A person receiving Hospice care will have pastoral or other counselor as part of their Hospice team.
- Receiving treatment the person chooses- If the person can still communicate, ask them what they need. Always talk to, not about, the person who is dying. When you come into the room, identify yourself to the person. Be culturally sensitive when caring for your client; know the client's social and religious practices and be aware that these factors may affect your client's needs and desires and follow the client's plan of care; this is especially helpful for older clients. Report any client preferences to your supervisor for any changes needed in the plan of care.

End of Life Care

Caring for someone who is dying can be hard. It is important to receive education from your agency on the dying process. The dying process is a unique experience for each person; however, there are often similarities to be aware of and how they may affect your client and client care.

- Physical weakness and lack of energy – a weakened system carries less oxygen to muscles, making movements and physical activities hard to accomplish. This can cause a client to withdraw from others as they feel burdensome since others now must perform tasks and activities of daily living (ADL's) for them. When providing personal care, move the client slowly at his/her own pace to minimize pain or discomfort. Do not rush the client.
- Increased sleeping – this can be due to exhaustion from visitors or activities, medications, or the disease process. Simply being present with the client can be helpful and show the client you care.
- Loss of appetite – as a person's disease progresses, the digestive system weakens. Likewise, some medications can change the taste of foods, making mealtime unpleasant. It is normal to have a change in eating habits during the dying process – the dying client's priorities are changing, and nourishing their bodies is not a priority anymore. If the client is not eating or drinking, mouth care is important as a comfort measure. Follow the plan of care for mouth care for your client.
- Difficulty swallowing – eating, drinking, and taking medications can be challenging when the swallowing reflex weakens. The client may require soft foods or liquids at this point and should not be forced into eating meals or solid food. Report any difficulty in your client swallowing to your supervisor and follow the plan of care for client intake of food or fluids.
- Confusion – this can be the result of factors including medications, disease, or decreased oxygen to the brain. Try and reassure your client gently and try to explain who you are and who others around you are. Report any increased confusion your client may experience to your supervisor.
- Restlessness – this can be a sign that the client is uncomfortable, in pain, or confused about something. It can also be a sign that the client will die soon. Be sure the client is safe and not doing harm to themselves and just be present and calm with the client. If the client has a religious belief, they may want someone of their faith to be there with them for an end-of-life ritual, prayer, or other ceremony unique to their beliefs.
- Bowel movements – incontinence is common at this point, as muscles weaken and mobility decreases. Be sure to keep the client's skin dry and clean and keep a record of bowel movements. More than two days without a bowel movement could be problematic for the client.
- Body temperature – as the heart weakens and body systems start to fail; circulation and body temperature will be affected. If the client can, let them tell you how they feel and whether they want blankets or coverings to stay comfortable. Watch for clues from someone who cannot tell you how they feel (they are trying to pull covers off or are shivering or pulling cover up).
- Breathing – a signal of the active dying process is when a client starts to exhale for longer than they inhale. This can happen for days or weeks before passing. Breathing then becomes irregular and can speed up. The death rattle breathing noise is created by excess saliva at the back of a client's throat and is too far down to be suctioned.
- Increased energy – a client may become alert or have a spurt of increased energy a few days or hours before they die. This phase does not usually last long.

End of life care also includes helping the dying person manage mental and emotional distress. Someone who is alert near the end of life might understandably feel depressed or anxious. 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. Offer a listening ear and do not offer advice. *Listening and being present can make a difference. Showing <u>empathy</u> and <u>patience</u> are qualities needed to provide end of life care.*

End of Life Care

There are ways to make a person who is dying more comfortable. Discomfort can come from a variety of problems. For each, there are things you or a healthcare provider can do, depending on the cause. For example, a dying person can be uncomfortable because of:

- Pain- A person at the end of life may be on pain medication to alleviate pain and/or relieve a sense of breathlessness. Other ways to alleviate pain such as repositioning, relaxation techniques, and distraction may also be used. Follow the client's plan of care for assisting a client in pain. Notify your supervisor if a client states they are having pain that is not controlled or appears to be in pain. Medicines or pain techniques can be increased or changed by the healthcare provider. People who are dying may not be able to tell you that they are in pain so watch for clues such as grimacing or moaning.
- Breathing problems- Shortness of breath (dyspnea) or the feeling that breathing is difficult is a common experience at the end of life. Follow the client's plan of care for assisting a client with shortness of breath (examples- raising the head of the bed, opening a window, using a humidifier, or having a fan circulating air in the room). Follow the plan of care and notify your supervisor for changes in the client's breathing.
- Skin irritation- Skin problems can be very uncomfortable. With age, skin naturally becomes drier and more fragile, so it is important to take extra care with an older person's skin. Skin care is important with clients as they become bedridden. Follow the client's plan of care for applying lotion. Dryness on parts of the face, such as the lips and eyes, can be a common cause of discomfort near death. Follow the client's plan of care to assist with dry or irritated skin (examples- applying a lip balm, however, if a client is on oxygen, do not use petroleum-based products such as Vaseline on the face, lips or skin as it poses a fire risk); a damp cloth placed over closed eyes might relieve dryness. If the inside of the mouth seems dry, giving ice chips (*if the person is conscious and can swallow*) or wiping the inside of the mouth with a damp cloth, cotton ball, or swab. Follow the plan of care for your client. Sitting or lying in one position puts constant pressure on sensitive skin, which can lead to painful bed sores (i.e., pressure ulcers). When a bed sore first forms, the skin gets discolored or darker. Watch carefully for these discolored spots, especially on the heels, hips, lower back, and back of the head. Report skin changes such as redness, discoloration, or sores to your supervisor. Follow the plan of care for providing skin care and prevention of bed sores (examples- turning the person from side to back and to the other side every few hours as assigned on the plan of care may help prevent bed sores). Try putting a foam pad under an area like a heel or elbow to raise it off the bed and reduce pressure. Ask if a special mattress or chair cushion might also help. Keeping the skin clean and moisturized is always important. Keep the bed linen clean, dry, and wrinkle free.
- Digestive problems- Nausea, vomiting, constipation, and loss of appetite are common issues at the end of life. The causes and treatments for these symptoms are varied, talk to your supervisor and report these client symptoms right away. There are medicines that can control nausea or vomiting or relieve constipation which is a common side effect of certain pain medications. If someone near death wants to eat but is too tired or weak, you can assist with feeding per the client's plan of care. To address loss of appetite, try gently offering favorite foods in small amounts. Or try serving frequent, smaller meals rather than three big meals, follow the client's plan of care with how to assist with eating. Losing one's appetite is a common and normal part of dying. Swallowing may also be a problem, especially for people with dementia. A conscious decision to give up food can be part of a person's acceptance that death is near. Talk to your supervisor if a client is refusing food and/or has difficulty swallowing.
- Fatigue- It is common for people nearing the end of life to feel tired and have little or no energy. Keep activities simple. Follow the client's plan of care for ways to assist with fatigue (example, a bedside commode can be used instead of walking to the bathroom, a shower stool can save a person's energy, as can switching to a sponge bath).