

Comfort Care in the ICU

What to expect at the end of your loved one's life

This handout explains what family and friends can expect when it is nearing the end of their loved one's life.

You have learned so much during your loved one's illness. Your support and love for them has ensured that they received excellent care. Now it is time to learn what your loved one may experience as they face the final stage of their life.



Removing the Ventilator

The *ventilator* is the machine that moves air in and out of your loved one's lungs. At the time you and your care team decide it is time to remove the ventilator:

- Your care team will talk with you about any concerns you might have and answer any questions.
 - You can ask anything you need to ask. Please feel free to raise any concerns or wishes you have. Be sure to ask your team about anything you do not understand.
- The nurse and respiratory therapist will work together to remove the breathing tube. You might see them looking at each other inside the room. This is to ensure they coordinate care with each other.
 - You are part of the care team. Please ask the nurse or respiratory therapist any questions you have, even while they are removing the breathing tube.
- Some people stop breathing in just a few minutes. Other people may live hours or days after the ventilator is removed.
 - You can be with your loved one, talking softly or holding their hand.
- The nurse will talk with you about turning off the monitors in the room, and may also remove other monitoring devices.
 - This allows everyone to focus on your loved one. You can share stories and memories or just sit quietly with them. Tell the nurse if you would like to play music, have the door opened or closed, or if you would like the lights dimmed.

- The respiratory therapist will slowly adjust the ventilator settings while the nurse closely watches your loved one to ensure they receive medicine to keep them comfortable.
 - You can talk gently with your loved one or hold their hand, letting them know they are loved and safe.
- The nurse will watch closely for any signs of pain or discomfort. The goal is not to make death come more quickly, but to make your loved one's transition through the end of life as comfortable as possible.
 - You know your loved one best. Please tell the nurse if you see any signs of discomfort in your loved one.
 - Once your loved one is comfortable, the respiratory therapist will prepare to remove the breathing tube. You are welcome to stay in the room for this procedure. This process can cause secretions and changes in the breathing pattern. These are all normal and expected. Some people make a coughing sound as the tube is being removed, but we do not believe they are in pain if that happens.
 - For some patients, it is not possible to remove the breathing tube. If this is true for your loved one, the respiratory therapist will suction your loved one's mouth. If you wish, the securement device on your loved one's mouth can be removed.

Physical Signs

There are physical signs that usually mean death is near. These signs may or may not be present in your loved one:

- **Coolness:** Your loved one's hands and feet may be cool or cold to the touch. Their skin may even change color.
 - You can keep your loved one warm with blankets or gentle massage or warm washcloths. You can hold their hands or feet to help warm them.
- **Congestion:** Your loved one may have gurgling sounds coming from their chest or throat. This occurs because they cannot cough up normal secretions such as saliva. The sound may be loud and might cause you to worry – but it is not dangerous or uncomfortable for your loved one. Sometimes suctioning causes more discomfort.
 - You can gently turn your loved one's head to the side. Doing this usually lessens the sound. You can also use a moist washcloth or swab to wipe their mouth.
 - You can help keep your loved one's lips soft and not chapped by using lip balm. Ask your nurse for a tube of lip balm.



- **Sleeping:** Your loved one may be sleeping and seem to be unresponsive. Their eyesight may also change – it might be blurred or they might have tunnel vision.
 - You can sit with your loved one and gently hold their hand. Tell your loved one your name rather than expecting them to know who you are.
 - You do not need to speak loudly. You can softly talk with them even though they may not respond. Never assume your loved one cannot hear you. Hearing is one of the last senses to be lost at the end of life.
- **Incontinence:** Your loved one may lose control of bowel and bladder function as the muscles in that area begin to relax.
- **Breathing pattern changes:** Your loved one's breathing pattern may change and become irregular. They might take shallow, quick breaths. There can also be periods of no breathing for 5 to 30 seconds, or even up to a full minute.
 - Please make sure you are taking your own deep breaths. Be sure to drink water and get rest.

Letting Go

- **Giving permission:** Your loved one might try to hold on in order to be sure that those they love are going to be all right.
 - You can let your loved one know that you will take care of yourself and that they will always be remembered.
- **Saying goodbye:** Saying goodbye is your final gift to your loved one.
 - You can sit beside your loved one or lie in bed with them. Say everything you need to say. This can be simply saying, "I love you." Or it might include favorite memories or stories of places or activities you shared. It may include saying, "I'm sorry for whatever ways I contributed to tension or difficulties in our relationship." It may also include saying, "Thank you for...."
 - For some people, tears are a common part of saying good-bye, while others might cry later or not at all. Please be gentle with yourself and others. We all grieve differently.
 - Spiritual care and social work staff can help. Please let your nurse know if you would like to meet with them.

Leaving a Legacy

Being in the Intensive Care Unit brings struggles and worries, but it can also provide some gifts. As family and friends gather, you often end up sharing stories of better times with your loved one.

Do you have a story about...

Did your loved one have strongly held beliefs? Did any of their beliefs change throughout their life?

Where did your loved one find inspiration? What or who motivated him or her?

What struggles did he or she face?

What did he or she desire most in life?

How did your loved one choose his or her profession? Did your loved one have favorite hobbies?

Did he or she ever talk about memories from childhood?

Are there life lessons your loved one taught you?

How do you think your loved one would like to be remembered after he or she dies?

Your own story...

Is there something you would like to say to your loved one that you have not said already?

Is there something so important that you would like to take the time to say it again?

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

- UW Medical Center:
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Care Unit: 206.597.3600

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Intensive Care Unit:
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- Harborview Medical
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