

What to expect in the last days and hours of life in the Intensive Care Unit (ICU)



Information for patients and caregivers



Patient Education

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Sometimes, even after all of the ICU team’s efforts and hopes, treatments cannot cure or even help a very ill patient. There are times when we believe the best treatment is to focus only on comfort.

We will talk to you about not increasing or even removing life support to keep your loved one from suffering. We will be open and honest when talking to you about any changes to the treatment plan.

Dying, like living, is a different experience for everyone. Knowing that your loved one is close to dying is very difficult. Knowing what you can expect to see, feel and do can give you some comfort.

This booklet will share:

- what happens when the ICU team removes life support
- the changes you can expect to see in your loved one
- what you can do to help your loved one
- what to do if you need help

You can read this booklet all at once or just read the parts that you need. Remember, you might not see all of the changes listed in this booklet.

Please speak to your ICU team if you have any questions or concerns. We are here to support and help you.



“What we once enjoyed and deeply loved we can never lose, for all that we love deeply becomes a part of us.”

Helen Keller

What happens when the ICU team removes life support?

We remove life support in slow steps so your loved one does not feel any pain or discomfort.

- We stop any life support machines that are helping with blood pressure and heartbeat. We continue to give medicines that help your loved one with pain or other discomfort.
- We stop the ventilator (breathing machine) in a few steps. At each step, we make sure your loved one is comfortable and not short of breath. Your loved one will breathe room air once the breathing machine is stopped.
- If your loved one is on dialysis, we stop the dialysis machine.
- If your loved one has a feeding tube, we may remove it.
- We no longer do any bloodwork testing.
- We turn off the monitor in the room, but we have the monitor on outside the room so we can continue to check on your loved one.

What can I do during this time?

You and your loved one's family and friends may stay in the room as life support is being stopped. If you feel you have to leave the room, we understand. Your comfort is also important to us.

If you would like prayers, flameless candles, music, pictures and other messages of love in the room, please ask our ICU team to help you.

Bring familiar things from home for comfort. For example, you can bring blankets, photos and music.

We would be honoured to help in the celebration of your loved one's life.

What changes can I expect to see in my loved one?

Pain or discomfort

We remove life support slowly to make sure your loved one does not feel any pain or discomfort. But, we still look for any signs of pain. These can include frowning, moving around, or changes in blood pressure heart rate or breathing. We treat any signs of pain with medicine to make sure your loved one is comfortable.

What can I do to help?

- Ask our team about heat/cold massage or relaxation therapy to help reduce pain.
- If you think your loved one is in pain or uncomfortable, explain what you see to the ICU team. We will do our best to relieve discomfort.
- Ask questions if you are not sure what is happening or how we are giving your loved one medicine.

Changes to breathing

Your loved one will breathe differently after we remove the ventilator. We may also remove the breathing tube in certain cases.

Their breathing may become faster than normal or slower than normal. Their breathing may also stop for short amounts of time. These pauses may get longer as your loved one nears death. We give your loved one medicine to make sure they are comfortable at all times.

Your loved one may start to sound like they are snoring. This may happen because as the muscles in their tongue and jaw relax, some saliva collects in the back of their throat. We give your loved one medicine to help dry the saliva. We also turn them to help drain any extra saliva and keep them comfortable.

Changes to hunger and thirst

Most patients do not feel hungry or thirsty during this time. If your loved one is awake, alert and able to swallow, you can offer them ice chips, mouth swabs and/or other foods. Please speak with a member of the ICU team before you do. Providing fluids through a tube in their vein or feeding them through a tube in their nose may help provide comfort.

What can I do to help?

- Raise the head of the bed before you feed your loved one ice chips. Stop right away if you hear them coughing.
- Do not feed or give fluids to your loved one if they are drowsy or sleepy. It may go into their lungs and cause them to cough and choke.
- Speak with your ICU team to find out what is best for your loved one.

Changes to skin and temperature

As your loved one dies, the colour and temperature of their skin may change. Your loved one may look paler, their skin may look bluish (especially lips and fingers) and feel colder. These changes are normal.

What can I do to help?

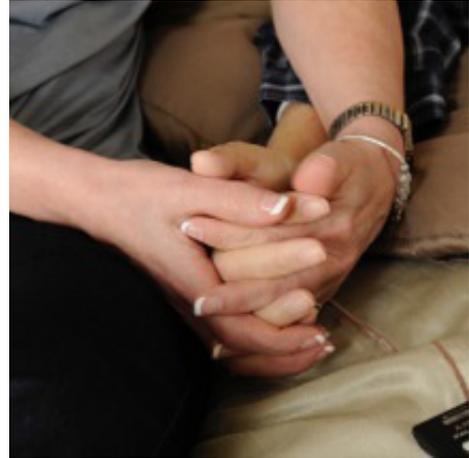
Add or remove blankets to make your loved one feel more comfortable.

Changes to behavior

Your loved one may seem restless or confused during this time. This is common. We can give your loved one medicine to help calm them if needed.

What can I do to help?

- Sit with your loved one and hold their hand.
- Always speak to them as if they can hear you. They may look like they are sleeping, but they may still be able to hear you and listen to you.
- Speak softly, clearly and in short sentences. You may have to repeat yourself. Share news, plans, stories, feelings and memories.
- Reduce loud noises. You may want to softly play some of their favourite music. You may bring some from home. We also have some music available in the unit.
- If they are confused, gently remind your loved one what your name is and who you are. Don't argue with them if it takes some time for them to understand.
- If they see something that is not there, reassure and comfort them if they are upset. You can try to gently change the topic.



What if I need help?

It is normal to feel many different things as your loved one nears death. You may feel afraid, sad, angry, worried, guilty, embarrassed, and loss. You may want to be with people, or you may want to be alone. We can let you know about some quiet spaces in the hospital if you would like to be alone.

Share your feelings with each other. Share stories and memories. If you find it hard to talk to your family, you can talk to a health care provider or spiritual care provider.

If you feel like you need more help with your feelings, please talk to us. We can tell you about hospital and community supports available to you.

Please know you can ask the ICU team for help.

Call us any time. We are here to support you and guide you during this time.

