# WLSM family information

###### What does it mean to withdraw life-sustaining measures or life support?

Your care team is there to help you and your loved one. However, when a patient is very ill, the care team cannot always help them get better despite their best treatments, efforts and hopes. In these situations, the aim is to keep your loved one comfortable while allowing them to die with dignity and respect.

Withdrawal of life-sustaining measures involves several steps, throughout which respect, dignity and your loved one’s comfort is the care team’s main priority. When the decision is made to withdraw life support and allow death to occur, you can expect the following to take place:

* Medications that control blood pressure or heart rate will be stopped
* The ventilator (breathing machine) will be turned off and the breathing tube is usually removed
* If your loved one is on dialysis, it will be discontinued
* The vital signs monitor may be turned off; staff will watch your loved one for comfort rather than checking his or her vital signs
* Routine tests like blood work and X-rays will no longer be ordered
* Intravenous fluids will be decreased or stopped
* Tube feeding will be stopped and the feeding tube may be removed
* Any treatments or medications that are not aimed at treating symptoms, increasing comfort, maintaining dignity or supporting cultural-social well-being will also be stopped

Adjustments may occur to meet the needs of your family and your loved one. Your care team will discuss these steps with you in more detail.

###### What can I expect after life support is withdrawn?

It is difficult to predict when death will occur. In some cases, it comes quickly. In other circumstances, it may occur several hours or even days after life support is withdrawn. Regardless of the amount of time before death, your loved one will continue to receive care.

###### What symptoms could my loved one experience and how will these be treated?

Your loved one will be closely watched for signs of pain or distress. If you notice any change that concerns you, tell a member of your care team.

***Pain and shortness of breath:***

* Pain may cause changes in facial expression, agitation, or other signs of discomfort. Pain will be treated with medications like morphine which can be quickly adjusted to ensure comfort.
* Shortness of breath may occur, particularly as the breathing machine is turned off and the breathing tube removed. Medications are given to ensure that your loved one is comfortable.
* When pain and shortness of breath are treated with medication, the dose given will be based on the amount of comfort medication your loved one is already receiving. Studies have shown that giving medication for comfort does not shorten life. There is no reason to over treat or undertreat pain or shortness of breath.

***Changes in breathing pattern:***

* You may notice pauses in breathing, snoring, or rapid shallow breathing. This is a normal part of the dying process and not necessarily a sign of discomfort. It generally does not need to be treated.
* Changes in swallowing may cause saliva to pool at the back of the mouth and cause a rattling or gurgling noise when your loved one breathes. This is likely not uncomfortable for your loved one. However, medications and treatments may be given if it causes discomfort.

***Anxiety and agitation:***

* Signs of agitation can include restlessness, frequent movements, or pulling at blankets and tubes. Your loved one will be watched closely for these symptoms and provided sedative medications as needed.

***Hunger and thirst:***

* At end-of-life, most people do not feel hungry or thirsty. As the body’s systems begin to shut down it can become difficult for people to tolerate food and fluids. For this reason, stopping fluids and tube feeding during this time is recommended. Some people experience discomfort from dry lips or a dry tongue. This is best treated with moist swabs or an artificial saliva spray rather than giving fluids intravenously.

###### How can I support my loved one during this time?

You are welcome to be in the room as life support is stopped. This is a very personal decision. Some families and family members prefer to be present and others do not. Your health care team will support any decision you make. Simply sitting with your loved one, speaking quietly with them, and holding their hand can help to provide comfort.

If you would like to bring in items like photos, music, and letters from friends and family to celebrate the life of your loved one, you may do so. If there are cultural or religious rituals that are important to your loved one, you may bring in your own spiritual leader or ask your care team to help arrange this.

###### What if I need support?

During this time, you may have many different feelings such as sadness, anger, fear, guilt, or even relief. It can be helpful to talk with the friends and family members about your feelings and fears. All members of your health care team, including the doctors, nurses, respiratory therapists, social workers and spiritual care providers are there to support you during this very difficult time. If you would like some time alone, there are spaces in the hospital for quiet reflection or prayer.

Community resources are available to support your family during and after the end-of-life process. Your care team can provide more information on what support is available.

###### If I have questions, who can I ask?

If you are concerned about your loved one’s comfort at any time or have questions about their symptoms and how they are being treated, please let a member of your care team know. Sometimes it helps to write down questions or concerns.

There are many members of the team caring for your loved one. With around-the-clock care, you may meet doctors, nurses, and respiratory therapists who will become new members of your care team. Feel free to ask questions and introduce yourself. Your care team is there to support you and your family throughout end-of-life care.

###### What if our loved one wanted to be an organ or tissue donor?

Organ and tissue donation may be an option following death. Experts in organ and tissue donation are available to answer questions and support you and your family through the donation process. Your care team may raise the issue of donation with your family. Please feel free to talk to your team about organ and tissue donation.

If your loved one wishes to donate his or her organs and or tissues, the timing for withdrawal of life support will be discussed. The organ and tissue donation teams and the physicians from the intensive care unit will be a part of the discussion with you and your family. All teams and team members will ensure your loved one is comfortable. The medications they receive for comfort will not change.

Additional medications and tests may be required. If so, the organ donation coordinator will discuss this with you.

You will be able to be with your loved one when life support is removed. Vital sign monitors will remain in place. When your loved one dies, two physicians will confirm that death has occurred. Your loved one will then be moved to the operating room for donation. If you wish to be with your loved one after organ donation has taken place that can be arranged.

Even if your loved one wished to be an organ donor, donation may not always be possible. The dying process is unpredictable and may take longer than expected. In some cases, your loved one’s organs may not have received enough oxygen to work well for someone else. It is important to remember the gift of life is in the decision to donate. We recognize the potential disappointment when organ donation is not possible and will do all we can to support you through this.

The timeline for tissue donation is different from organ donation and may occur within 24 hours of death.

Staff from the intensive care unit and the organ and tissue donation teams will be available to answer any questions you may have. If you wish to discuss organ donation or your decision to do so, please ask to speak to a member of your care team at any time.

###### Questions?

You may still have questions about what happens at end-of-life. Sometimes it helps to write down your questions. Please don’t hesitate to ask questions and raise any concerns you may have with any member of your care team. Your care team is there to support you, your loved one and your family through this difficult time.