A ventilator is a type of breathing machine. It does the work of breathing when you are too sick to breathe well on your own. It can be a difficult decision for parents and the medical team to decide when or if a ventilator is right for a child who is very ill.

Learning about the issues involved with a ventilator before a medical crisis occurs can be very helpful. Here are answers to some questions about ventilators that other parents have asked.

What is it like to be on a ventilator?

- A breathing tube is placed through the child’s mouth, down the throat, and into the windpipe (trachea). The breathing tube is then connected to the ventilator.
- Medicine is given to lessen the discomfort. This medicine usually makes a child sleepy. The child must be relaxed to allow the machine to work well.
- The ventilator forces air through the tube and into the lungs.
- The child is not able to talk, eat or get out of bed.
- Since the child is often not awake, it can be hard to interact with him or her.
- In order to keep the breathing tube clear of mucus, a child will need to have a thin, long hose placed inside the larger tube that is in their windpipe to suction the mucus.
  - This can be painful and can cause the child to cough or gag.
  - The medical condition of the child will determine how often the mucous will need to be suctioned out.
- Many children on ventilators are cared for in the hospital ICU.
What medical problems could happen from using a ventilator?

- The breathing tube can irritate the vocal cords and make it hard to talk after the tube is taken out.
- The breathing tube can irritate the throat and make it hard to swallow after the tube is taken out.
- Lung damage can happen from air being forced into the lungs by the ventilator.
- There is a greater chance of getting lung infections that are hard to treat.
- The act of placing a breathing tube can lead to life-threatening complications or death.
- If a very sick child is put on a ventilator, the child’s lungs may become weaker and dependent on the machine. The child may not be able to breathe again without help from the ventilator.

Ask your doctor for more information about the risks of using a ventilator.

Are there other treatment options besides a ventilator?

- Sometimes a child’s breathing can be helped for a short time by using a special machine that forces air and oxygen into the lungs through a tube attached to a nose or full-face mask. This breathing treatment is called BiPAP.
- BiPAP is most often used for children at night, when they need extra help breathing while they sleep. BiPAP can be used at home.
- BiPAP is not as strong as a ventilator and is not an option for every patient.
- BiPAP can be very uncomfortable. It may also limit interactions with family members.

How long is a ventilator needed?

It may be hard for the healthcare team to know. The length of time varies depending on a child’s condition. The goal is to try to get a child off a ventilator as soon as it is safe to do so. A child must be able to breathe on his or her own.

For a very small number of children who need to be on a ventilator for a long period of time, the medical team may talk about the possibility of surgery. This surgery is called a tracheostomy.
Why would someone decide not to put a child on a ventilator?
When a child is very sick and not expected to get better, the healthcare team and family may not want to use a ventilator. They may feel that the ventilator doesn’t make the child’s quality of life better. And, being on a ventilator may cause more suffering.

The healthcare team and family may choose to keep the child as comfortable as possible without a ventilator.

Does a ventilator always help?
A ventilator does not cure the disease or the medical problems that are causing the child to be very sick. It only helps a child to breathe while the doctors can see if the other treatments are working to help the child get better.

Why would someone take a very sick child off of a ventilator?
Many children who are close to dying never improve enough to breathe on their own. For these children, the healthcare team will talk with the family to help decide what is best for the child. Doctors may suggest removing the breathing tube to allow the child to die peacefully.

Once the breathing tube is removed, some children may live for minutes. Other children may live longer—hours, days, or even weeks.

The healthcare team will continue to care for the child and support the family. The medical team will continue to give all of the treatments that are helping. They will keep the child as comfortable as possible for the rest of the child’s life.

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Where do we go from here?

Healthcare teams are here to help guide and support families to make the right decisions for their child.

Talk with your child’s doctor and others on the healthcare team about your questions and wishes and their suggestions for your child’s care. It’s helpful for your medical team to learn about your personal, cultural and religious values.

You may also want to talk with others who understand and support your values, such as a spiritual leader or family members.

After a decision is made, the doctor can fill out forms to let the treatment teams know what is decided. No matter what decision is made, it can always be changed or modified at any time.

The healthcare team recognizes that these decisions are very difficult, but with their support, combined with the love parents have for their child, the right decision will be made.