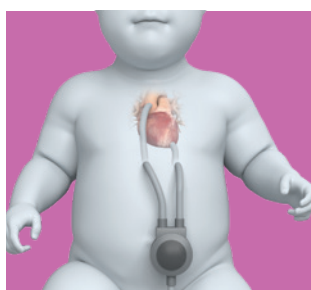


A decision aid for a

Ventricular Assist Device (VAD)

A device for **children** and **adolescents** with advanced heart failure



Exploring Options

Your child is being considered for a VAD. This booklet should help you understand what a VAD is and help you and your family think about what is best for your child. Your and your child's values and goals are the most important factors in making a decision.



What are your and your child's current feelings?

- What are your and your child's hopes and fears?
- What are your and your child's biggest questions?

Now that you've thought about your and your child's feelings, let's talk about the details of this **DECISION**.

Your child has severe heart failure.

Heart failure is when the heart is too weak to pump enough blood for the body. Your child may feel tired, short of breath, swollen, have a stomach ache, or may not want to eat. If your child cannot describe how he or she feels, he or she may just appear irritable or fussy. For most people, heart failure gets worse over time and can lead to the need to have a heart transplant or death.



You did not want this to happen.

Your child is very sick and needs major surgery to live. Your doctors may be considering a heart transplant for your child. Even if your child can get a heart transplant, he or she will likely have to wait a long time. If medicines are unable to control your child's heart failure while he or she waits for a heart transplant or if your child is too sick for a transplant, your doctor may consider a VAD.

This may make you feel scared, confused, or angry. You may not be sure what is best for your child and feel pressured to make a decision quickly. These emotions are normal.



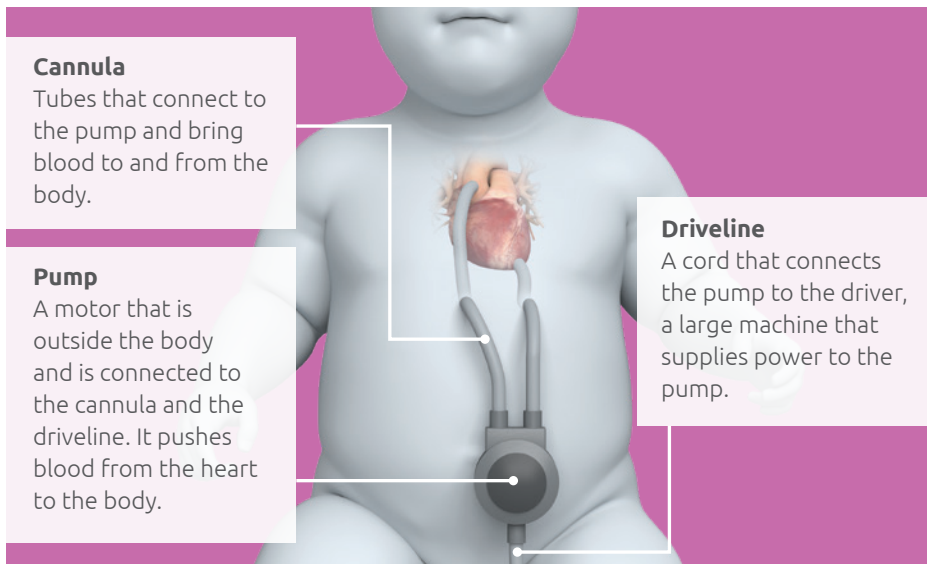
This is a major decision.

If the doctors feel your child is eligible for a VAD, you are facing a major decision. While no one can predict the future, understanding what could happen may help you feel better about your decision and more prepared for what happens after. While this may be hard to think about, people in your position have wanted to know this information.

Some people choose for their child to get a VAD. Other people decide for their child not to get a VAD. There is no right choice, only what you want for your child and family. The right choice depends on how you wish for your child to live the rest of his or her life.

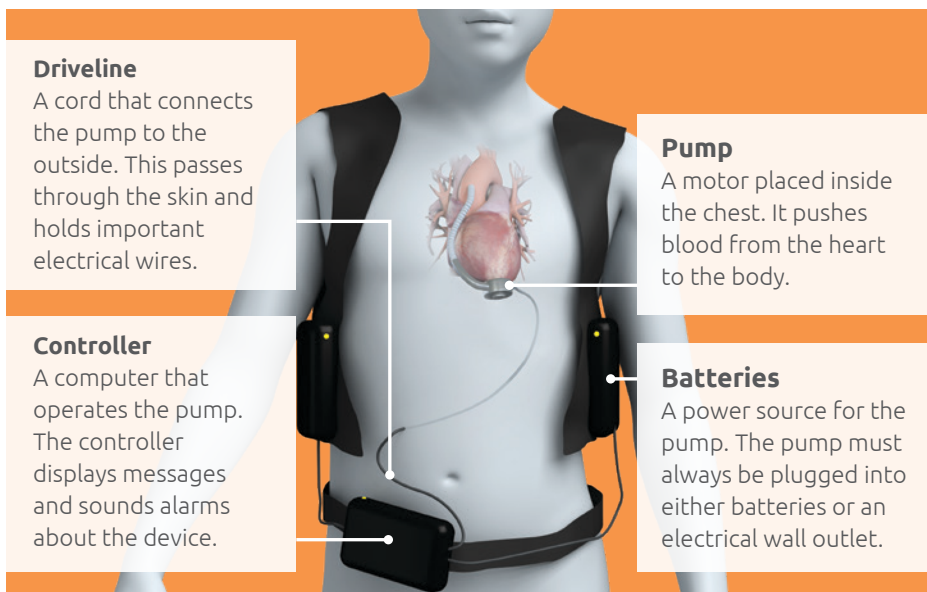
What is a **VAD** (Ventricular Assist Device)?

A VAD is a mechanical device that helps your heart pump blood. There are two different device types, depending on your child's size and heart defect.



Berlin Heart

The Berlin Heart is usually used for smaller children. The pump is on the outside of the body and is connected to the heart by tubes called cannula. Children on the Berlin Heart must stay in the hospital until they get a heart transplant or the Berlin Heart is removed.



HeartMate 3

The HeartMate 3 is usually used for larger children. The pump is on the inside of the body. A small cord exits the body and connects the VAD to batteries or wall power. Children on this type of pump often can go home on the VAD to wait for transplant.

Your medical team will choose the device that is best for your child. The right device depends on your child's size and heart defect. In general, smaller children will get the Berlin Heart and older children will get the HeartMate 3. In some cases, your medical team may choose a different device for your child.

VADs are used for **DIFFERENT** reasons

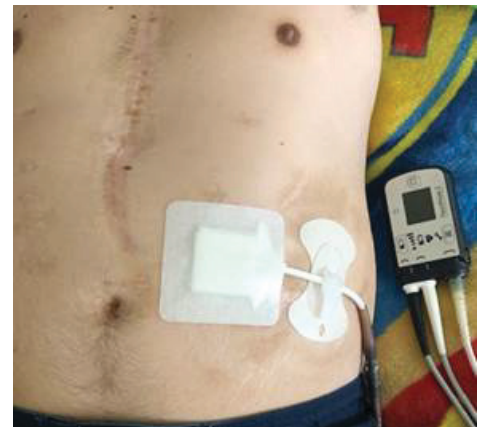


A Berlin Heart cannula in an infant.

- Usually a VAD helps support children until they can get a heart transplant. This is called “bridge to transplant” (or BTT).
- Sometimes it is not clear if the child can have a heart transplant, but a VAD is needed to keep him or her alive while a decision is made. This is called “bridge to decision” (or BTD).
- Sometimes VADs are used to treat children with heart failure who cannot get a heart transplant. This is called “destination therapy” (or DT). These children will remain on the pump for the rest of their lives, and is only possible if your child gets the kind of device that allows them to leave the hospital.

What is the process of getting a VAD?

- Getting a VAD requires open-heart surgery.
- The surgery can be dangerous, and recovery can be long and hard.
- Depending on the type of VAD used, children may stay in the hospital a few weeks or until they can get a heart transplant, which can take several months. Most older children and adolescents can leave the hospital. Most infants and young children cannot go home on a VAD.
- If the child can go home with the VAD, the medical team will teach the child and family how to use the equipment and stay safe at home.
- If the child needs to stay in the hospital with the VAD, the goal is for him or her to be awake, comfortable, and participating in normal activities.
- Children with a VAD do not necessarily have to be in the ICU or have an IV.



A HeartMate 3 driveline site in an adolescent.

What will my child's life be like with each **OPTION?**

The numbers below are from recent medical studies. However, no one can know what will happen to any one person.

Life with a VAD

Will my child survive to get a heart transplant?

About 88% who get a VAD as a bridge to transplant will survive to transplant.¹



How will my child feel?

- Most children with heart failure feel better with a VAD. Most children will have more energy, gain weight, and be able to attend school and play.
- Many children require a temporary feeding tube while on VAD.
- Being on a VAD can cause depression and anxiety. VAD patients may see a psychologist for counseling.

What complications might occur?

Serious complications can happen on any VAD, though each VAD is different. See next page for details on complications.

Life without a VAD

How long will my child live?

Children usually do not live as long without a VAD or transplant. It is hard to predict how long a child may live—it may be days, weeks, or months.

What might happen if my child doesn't get a VAD?

- Nearly all children without a VAD or transplant will continue to have severe heart failure symptoms, which include shortness of breath, stomach pain, and swelling.
- Families may choose to continue medicines that help the heart and reduce swelling. Families may also choose to stop these medicines and give only medicines that treat pain and anxiety directly.
- In some cases, children may be able to leave the hospital to spend their remaining time at home.
- Palliative care and hospice services will be able to help you make these choices. They can also help keep your child comfortable until he or she passes away, whether in the hospital or at home (*see description on page 7*).

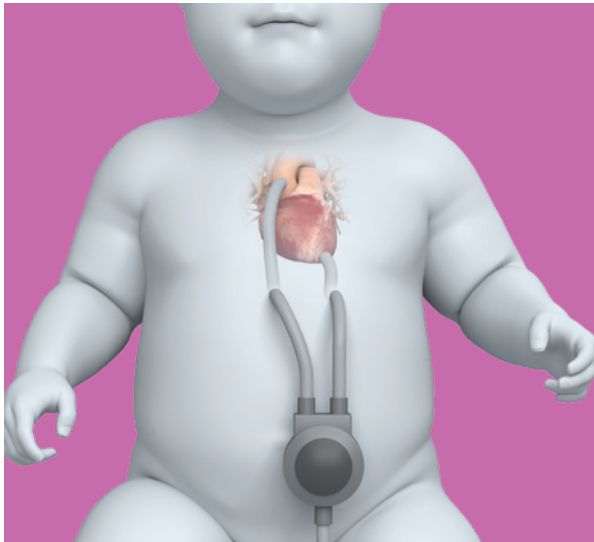
¹ The Action Network, 2020

Does my child have a say?

- Yes. Your medical team is interested in both your and your child's wishes.
- If your child is under the age of 18, you will have to give permission for your medical team to place the VAD. This is called consent.
- If there are two legal guardians, both will have to agree to get the VAD.
- If your child is between the ages of 12–18 and is able to understand the decision, they will also have to agree to get the VAD. This is called assent.
- If you and your child disagree on what is best for him or her, your medical team will work with your family to help you come to a decision together.
- If your child is too young to talk or is too sick to speak, or is unable to understand the decision, you as the legal guardian(s) will make the decision on his or her behalf.

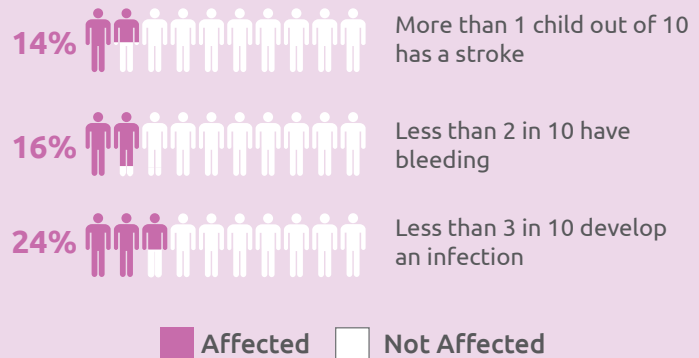
What **COMPLICATIONS** might occur with a VAD?

Complications are different for each VAD. The risk of stroke, bleeding, and infection will vary depending on your child's age and type of heart disease.



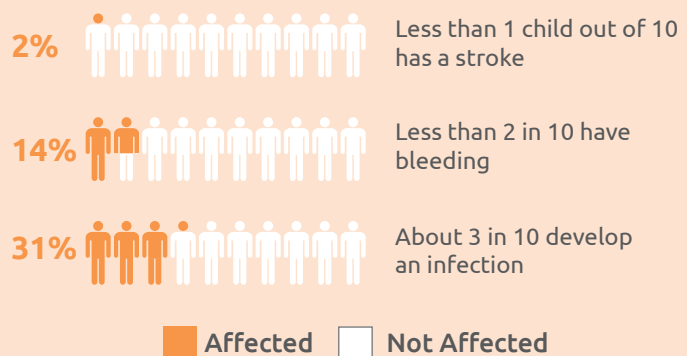
With a Berlin Heart Pump¹

The average length of time a child has a Berlin Heart is 2–4 months.



With a HeartMate 3 Pump¹

The average length of time a child has a HeartMate 3 is 3–12 months.



¹ The Action Network, 2020

What happens if my child has a severe complication?

Your child may have a severe complication that makes heart transplant not possible or changes his or her quality of life to the point where you no longer feel transplant or further VAD support is the right choice. At this time, you and your doctors may choose to have the VAD turned off to let your child pass away. This is called **compassionate deactivation**. When compassionate deactivation is performed, your medical team will make sure your child feels no pain or anxiety at the end of life.

With or without a VAD, resources are here to make your child feel **COMFORTABLE** and to help make hard decisions.

What is palliative care?

Palliative care is a medical care for children with serious illnesses. Palliative care doctors and nurses focus on reducing symptoms, pain, stress and anxiety, and work to make sure families' emotional, spiritual, and cultural needs are met. The goal of palliative care is to improve a child's quality of life while waiting for transplant or before he or she passes away.

Palliative care does not replace the medical care children receive. They work with your medical team when your child's future is uncertain. Children can still be on the transplant list and receive palliative care services. The palliative care team works with the cardiology team.

Children do not have to be dying to receive palliative care services.

What is hospice?

Hospice care is for children near the end of their lives. This care includes medical, emotional, spiritual, and cultural support, and helps to provide comfort and peace at the end of life. Hospice care may be provided at home or in the hospital.

Children receiving hospice care may choose to continue taking medicines for their heart, but usually choose not to have surgeries to keep them alive. The hospice care team works with the cardiology team and the families to make these decisions.

Most children receiving hospice care are no longer on the transplant list.

Family Perspectives

"I was grateful to hear that a VAD could support my child who needed a transplant, and I felt that whatever choice we made, the medical team would respect that choice."

"For us [the VAD] was the right choice to go through with it to give her a chance."

"I asked the doctor: what if I said 'no more?', and he said that was always an option."



If my child gets a VAD, how will their life **CHANGE?**

There are many life-changing aspects of life on a VAD. **Some details only apply to those who are able to go home with a VAD.**



Power Source: Your child must be plugged into a power source at all times – loss of electrical power to the pump can result in death. When sleeping, your child will plug into an electrical outlet. During the day, he or she can switch over to batteries, which last up to 17 hours.



Carrying Equipment: For children able to go home, equipment can be carried in a vest, backpack, or on a belt. Along with batteries, the child will have to carry the controller. Battery packs and equipment weigh about 3 to 7 pounds. Carrying extra battery packs and an extra controller is also important, in case they need to be changed.



Medicine: With a VAD, your child will have to take blood thinners until the VAD is removed. He or she may need to continue some medicine to help with his or her heart, but most children take less medicine after getting a VAD. Your child also will have to go to the doctor's office for check-ups.



Driveline Care: The driveline site (where the electrical cord exits the skin) must be cared for carefully. Bandages must be changed and the site should be cleaned several times a week. Lack of care could cause a deadly infection.



Water Precautions: Due to the equipment and driveline site, your child cannot go into water. This means your child can't swim or take a bath. For children able to go home, the medical team will teach you how to use a special "shower bag" to safely shower with the device.



Cost: Depending on your insurance coverage, you may have extra costs with the device. Many families have to pay for the driveline bandages. You may also have co-payments for your child's medical care.



Emotions: The VAD may cause emotional effects for both children and families. Some people are very grateful for the VAD and get used to these lifestyle changes. Others worry often about the equipment failing or feel overwhelmed with taking care of the device. This stress can lead to depression and anxiety. Many doctors strongly recommend all patients considering VAD to receive mental health support.



A VAD is a major decision for the **ENTIRE FAMILY.**

Being a caregiver for a child with heart disease affects the entire family. This includes parents, siblings, and other relatives who live in the home or help care for the child. When a child gets a VAD or a transplant, the family's lifestyle can change even more.

Most caregivers feel happy that they can support and care for their child. However, some caregivers also feel stressed with responsibilities, finances, and caring for other family members. Siblings may feel they are not getting enough attention. Everyone in the family may feel worried for the child's health and outcomes.

Caregiver Tasks and Considerations

If your child is able to go home:

At least two caregivers will be trained to learn how to operate the VAD and care for the child. This includes:

- Driveline site bandage changes and checking for infection
- Battery Care
- Equipment Care
- Managing medicines
- Bringing your child to appointments

If your child needs to stay in the hospital on the VAD:

In most cases, caregivers cannot be at the bedside all the time, especially if they have work or other family members to take care of. However, a caregiver needs to spend time at the hospital with your child to bond and provide comfort and support. This includes:

- Bathing
- Dressing
- Playing
- Other normal age-appropriate things (talking, singing, affection)



Family Perspectives

"I don't know any parents who have gone through what I have gone through and everybody is different."

"I would tell other families to consider their child's feelings towards the VAD."

"She was suffering at that point. She was not progressing. You could see she was tired. So we decided to give her rest."

Take some time to **CONSIDER** what you have learned and think about what is best for your child and family.

How do you want your child to live the rest of his or her life (check one box)?

Do everything we can to keep him or her alive, even if that means having major surgery and being dependent on a machine until transplant

Let my child live the rest of his or her life without going through major surgery or being dependent on a machine

Reflection	With a VAD...	Without a VAD...
What are your and your child's biggest hopes?		
What are your and your child's biggest fears?		

What are your biggest questions ...

... for your doctor, surgeon, or cardiologist?

... for your child?

... for your family?

... for patients who currently have a VAD?

If your child is unable to communicate their own wishes, what do you think they would want for themselves and their lives?

If possible, would you like for you and your child to meet another child who was on a VAD?
☐ Yes ☐ No

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

for him or her. **This pamphlet and the associated video (at <https://patientdecisionaid.org>) are FREE FOR DISTRIBUTION.** This work is licensed under a Creative Commons Attribution, Non-Commercial, No-Derivatives 4.0 International License.