This booklet is to help you understand the different kinds of mechanical circulatory support (MCS) devices used to treat heart failure. You can learn more at www.seattlechildrens.org/VAD. We urge you to ask questions and share your concerns at any time.
Mechanical Circulatory Support
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What is mechanical circulatory support?

Mechanical circulatory support (MCS) is a treatment for heart failure when other treatments, like medicine and surgery, are not enough to fully support your child's heart. MCS uses a pump to help your child’s heart move blood through their body. This allows your child’s heart to rest and recover.

There are different kinds of MCS and they have different kinds of parts. In general, there are 3 main parts of all MCS devices:

- **Pump** (placed inside or outside of the body)
- **System controller** (monitors the pump and gives warnings and alarms)
- **Power source**

Some MCS devices pump blood like the heart does, with a pumping action. Others keep up a continuous flow of blood. With a continuous flow device, your child might not have a normal pulse, but their body will still be getting the blood it needs. Some MCS devices are called ventricular assist devices (VADs) because they support the ventricles (lower chambers) of the heart. Other MCS devices do the work of the entire heart (artificial heart).

What are the other treatments for heart failure?

- **Medical therapy**: Medicine and lifestyle changes can help symptoms of heart failure. Medicine and a healthy diet may help a sick heart work more easily. Although your child’s quality of life may improve, their heart failure may continue to get worse over time and need additional treatment, such as surgery.

- **Surgical therapy**: Surgical procedures may be performed by specially-trained surgeons (surgical cardiologists) on the blood vessels, heart muscle or heart valves. Although these procedures may relieve your child’s symptoms and improve how the heart works, they do not always stop the heart from getting worse.

- **Heart transplant**: When the heart fails to a point where it really impacts your child’s quality of life, your child may need a heart transplant. However, many factors affect how a donated heart will work in your child if they have advanced heart failure. As a result, not all people benefit from a transplant.

Why does my child need MCS?

Doctors will consider MCS for your child if their heart is too weak to pump blood effectively to the other organs in the body. This is only considered after doctors have tried all medicine and surgery treatments that are an option for your child.

Some conditions that may be treated with MCS are:

- Cardiomyopathy
- Duchenne Muscular Dystrophy
- Myocarditis
- Chemotherapy-induced heart failure
• Congenital heart disease
• Transplant rejection

The use of MCS depends on many factors. These factors also affect how long your child will need MCS.

**The 4 main uses of MCS**

• **Bridge to decision:** When MCS is used for a short period of time for a person who is very sick. It is called a “bridge to decision” because it allows time for doctors to do tests and families to make decisions about treatment.

• **Bridge to recovery:** When MCS is used for a short period of time until the heart recovers and becomes strong enough to pump on its own.

• **Bridge to transplant (BTT):** Short or long-term use of MCS to support a person's heart until a donated heart becomes available. The use of MCS before a transplant may improve how your child recovers after the transplant.

• **Destination therapy (DT):** Long-term use of MCS for people with advanced heart failure who are not able to receive a heart transplant. DT is considered only when all other treatment options (medicines, lifestyle changes, heart procedures) have been tried unsuccessfully. The goal of DT is to improve your child’s quality of life through the end of life.

**Who are the members of the MCS Care Team?**

**Your child’s care team (See glossary for definitions)**

• Pediatric cardiac surgeon
• Cardiologist
• Attending
• Fellow
• Senior resident
• Intern (first year resident)
• Nurse Practitioner (NP)
• CICU and surgical floor bedside nurses
• CICU and surgical clinical nurse specialists (CNS)
• Respiratory therapist
• Perfusionist
• Heart failure/transplant nurse coordinator
• Social worker
• Pediatric Advanced Care Team (PACT)
At your child’s bedside

A nurse will provide your child’s bedside care, checking their temperature, breathing, heart rate and blood pressure, giving medicines and providing daily care. All of your child’s care is supervised by doctors who are trained in MCS.

Rounds

We will come to your child’s bedside each day to talk about treatment goals and your child’s plan of care. These sessions are called “rounds.” We encourage you to take part in rounds by sharing your thoughts, questions and concerns. We expect you to have questions and want to hear them.

After your child moves from the Cardiac Intensive Care Unit (CICU) to the surgical unit, we will continue to have rounds every day with the cardiology and surgical unit teams.

What are the different types of MCS?

HeartMate

This type of MCS is surgically implanted next to your child’s heart. It helps the left side of the heart (left ventricle) pump blood to the body. A system controller outside of the body tells the heart how fast to pump the blood. The system controller and pump are connected by wires (driveline) that sends electronic data to the device. This type of MCS must be connected to an energy source or battery at all times.

The HeartMate is a good choice for older children. It is designed to work for months, or even years, if your child were to need it. Children with this type of MCS can go home from the hospital after fully recovering from surgery. It is portable enough for your child to remain active.

HeartWare

Similar to the HeartMate, this type of MCS helps the heart pump blood to the body, but it can help the right or left side of the heart. Children with a HeartWare VAD can also go home from the hospital after fully recovering from surgery.

Syncardia Total Artificial Heart (TAH)

This type of MCS is surgically implanted in the body. It replaces the entire heart after surgeons remove the diseased heart muscle. A pump on the outside of your child’s body sends air to the device. Chambers within the device push blood out to the body like a normally beating heart does.

A Syncardia TAH is larger in size than the HeartMate and HeartWare, limiting its use to older children and adults. Portable TAH system drivers can be
used to allow your child to go home from the hospital after fully recovering from surgery. This type of MCS is usually used as a bridge to transplant after complete heart failure. However, it can also be used as destination therapy.

**CentriMag and Pedimag**

The Centrimag is a type of MCS that sits outside of your child’s body. It connects to your child’s heart through tubes. It can be used for either left- or right-side heart support. It is a short-term solution used in the CICU to support circulation while longer-term options are considered.

The Pedimag is a smaller version of the Centrimag for younger children.

**Berlin Heart**

The Berlin Heart is an MCS device that can support the left or right ventricle, or both in a child of any age. It has sizes just for children, including newborn babies. A small pump located outside of the body is connected to the heart with tubes.

Your child will need to stay in the CICU until fully recovered from surgery and then may be transferred to the surgical unit once stable.

**Other kinds of MCS**

In addition to the devices listed above, medical companies are constantly working to develop, refine and research new MCS devices. All of the MCS
devices currently on the market are for use in adults. When they are used in children, it is called “off-label.” Companies are currently working to develop MCS devices for children and young adults to provide support for short or long-term use.

**What is surgery like?**

Once we know what kind of MCS is best for your child, your child will have surgery to put in the device. The device is put in by a surgeon and surgical team specially trained in MCS.

Before the surgery, we give your child medicine through a thin plastic tube (IV) to prevent any pain. We also give your child medicines to stay asleep during surgery.

Your surgeon will review the procedure they plan to perform with you. The procedure depends on the kind of MCS your child will have and their specific medical needs.

The surgery can last several hours. Your child will stay on a breathing machine throughout the surgery.

**After surgery**

After the surgery, your child is taken to the CICU. Your child will have an X-ray when they get there. Your child will have a lot of equipment and tubes after surgery. It can be overwhelming. Read our handout “Equipment To Expect After Heart Surgery In The Cardiac Intensive Care Unit (CICU)” [www.seattlechildrens.org/pdf/PE1476.pdf](http://www.seattlechildrens.org/pdf/PE1476.pdf).

Over the next few days, we will remove some of the equipment and tubes as your child recovers. We will slowly lower some of the medicines that your child needed before surgery. Your child may need to stay on some of the medicines they were on before surgery.

Sometimes, your child may need additional surgical procedures to help the MCS device work properly or to fix complications if they arise.

**Will my child have pain after surgery?**

We will give your child pain medicine to help them during the healing process. After surgery, your child will likely have pain in their chest area. We partner with you and your child to prevent and relieve pain as completely as possible.

You know your child best. No matter the level of your child's pain, believe they are hurting and respond right away. In addition to medicine prescribed for pain, you can also help your child cope by distracting them with music, games, TV or videos.

Child Life specialists are members of the healthcare team who work directly with your child and family to help reduce anxiety and adjust to the hospital experience. Read our handout “Child Life Department: Helping children cope with a hospital stay” [www.seattlechildrens.org/pdf/PE339.pdf](http://www.seattlechildrens.org/pdf/PE339.pdf).
What are some of the risks of MCS?
Some of the risks involved with MCS include:

• Bleeding
• Right heart failure
• Infection
• Device failure
• Blood clots
• Difficulty adjusting to life with a MCS device, including care responsibilities and body image

Before surgery, we will talk with you about the benefits and risks of the device. We encourage you to share your concerns and ask questions.

What types of medicine will my child need?
Your child will need medicine after surgery to minimize the risk of complications and help control pain. They will also have medicines to reduce blood pressure, improve circulation, prevent blood clots, reduce swelling and give them nutrients important for heart function.

Every person takes a different combination of medicines. Your child’s care team will prescribe the medications that are most appropriate for your child’s needs. Making sure your child takes these medicines regularly and exactly as directed by your care team keeps them as healthy as possible during recovery or waiting for transplant.

Can my child have visitors?

Parents and caregivers
Parents and caregivers may be with their child anytime. The only exception to this rule is when special procedures are being done in the CICU, and you are asked to wait nearby.

Siblings, other relatives and friends
Siblings, other relatives and friends can visit between 8 a.m. and 8 p.m. The number of family and others who can be at the bedside at one time in the CICU is limited to 3 people. This may vary based on individual needs of your child, the space available in their room and their condition.

Your nurse will work with you to meet your family’s needs while assuring the best and safest care. At first, all sibling visits need to be planned with your nurse and child life because seeing your child on MCS can be confusing and frightening. Child life specialists are also available to help siblings adjust to seeing their brother or sister on MCS. Children under the age of 12 who are not siblings may not visit children in the CICU.
Family members or visitors who have illnesses that could be passed along to others, such as the cold or flu virus, should not come to visit your child at the hospital. Doing so can place your child at great risk, especially once your child has an MCS device supporting their heart.

**Can my child go home?**
If your child has a HeartWare or HeartMate device, it may be possible to go home from the hospital after recovering from the surgery (about 2 to 4 weeks). Children with other kinds of MCS devices must stay in the hospital.

**How will I know how to care for my child at home?**
If your child is able to go home, we will teach you and your child how to care for the device while your child is recovering from surgery. This includes:

- Driveline dressing care
- Troubleshooting monitor alarms
- Recording information and reporting any issues to your care team
- What to expect during follow-up clinic visits
- How to reach your child's care team when you are home

A member of the MCS care team will always be available to answer questions or address any concerns you may have, day or night.

**Glossary**

**Anticoagulants:** Medicines that prevent blood clots. Also known as blood thinners.

**Attending doctor:** Directs your child's care and supervises the residents and fellows caring for your child. This doctor works closely with your child's surgeon and cardiologist.

**Battery:** Part of the MCS that supplies power when not plugged into to a power source. Batteries are an option for powering only some MCS devices (HeartMate and HeartWare). Batteries allow you to move around or leave the house with the device.

**Biventricular assist device (BiVAD):** A type of MCS used if both ventricles are too weak to meet the body's needs. HeartWare, Centrimag and Pedimag pumps can all be used as BiVADs. Another treatment option for this condition is a total artificial heart (TAH).

**Cardiac Intensive Care Unit (CICU):** Distinct unit, staffed by a distinct team of providers, where babies, children, teens and young adults who are critically ill with heart problems are cared for by a medical team with special training and expertise.
**Cardiac Intensive Care Unit (CICU) nurse:** Intensive care nurse who provides and coordinates most of your daily care and education while in the CICU. The bedside nurse will be your main contact with other members of the healthcare team while in the CICU.

**Cardiologist:** Doctor who specializes in treating heart conditions.

**Cardiomyopathy:** Means “disease of the heart muscle.” In people with cardiomyopathy, the heart is enlarged, thickened or stiff. It makes it harder for the heart to pump and deliver blood to the rest of the body, which can lead to heart failure.

**Chambers:** The parts of the heart that hold and pump blood. There are 4 chambers: right atrium, left atrium, right ventricle, left ventricle. (see ventricles)

**Chest tube:** A tube placed into the space between the lung and chest wall that removes air or fluid. Chest tubes remove fluid from around your child’s heart and lungs after surgery.

**Child life specialist:** Focuses on your child’s emotional and developmental needs. They help reduce the stress of a hospital stay. They also provide information about play, child development and adjustment to illness.

**Clinical nurse specialist (CNS):** Registered nurse with advanced education and training. They oversee quality, safety and staff education. They are a clinical expert and consult on patients with complex care needs.

**Congenital heart disease:** A problem with the heart’s structure or function present at birth.

**Diuretics:** Medicine to help the body get rid of salt and water. Diuretics are used to treat high blood pressure and swelling. Also known as “water pills.”

**Driveline:** Connects the pump to the system controller and contains power and electronic cables. It exits through your child’s skin, on the right or left side of their belly (abdomen).

**Duchenne Muscular Dystrophy:** A genetic disease that affects the muscles of the body.

**Exit site:** Location where the driveline passes through the skin.

**Fellow:** Licensed doctor who has completed their training in general pediatrics and is going through further training in pediatric cardiology. During rounds, they help supervise the residents and lead the development of your child’s daily plan of care. The fellow works closely with your attending doctor.
Flow: The amount of blood that goes from the pump to the rest of the body. Measured in liters per minute (L/min).

Heart failure/transplant nurse coordinator: Bridge between your child’s hospital stay and care at home. Provide education about care and will remain available to you once you are home.

Inotropes: Medicines that help the heart contract, allowing the heart to pump more effectively. Inotropes also help lower high blood pressure in the arteries of the lungs (pulmonary hypertension), which can cause the right side of the heart to have to work harder.

Left ventricular assist device (LVAD): The most common type of heart pump. It helps the left ventricle pump blood to the main artery that carries oxygen-rich blood from the heart to the body (aorta). HeartWare, HeartMate, Centrimag and Pedimag pumps can all be used as LVADs.

Mechanical circulatory support (MCS): The use of any kind of mechanical pump to support heart function and blood flow in people who have weakened hearts. This is the broad term that includes VADs (support the lower chambers of the heart) and artificial hearts (support the whole heart).

Myocarditis: Inflammation of the middle layer of the heart wall. Myocarditis is usually caused by a viral infection. If myocarditis becomes severe, the pumping action of the heart weakens and the heart is no longer able to supply the body with enough blood.

Nurse practitioner (NP): Registered nurse with advanced education and training. They practice independently and work closely with doctors. They diagnose, treat and teach patients and families about serious and chronic conditions. They also make referrals.

Pediatric Advanced Care Team (PACT): Specialty care team, including doctors, nurse practitioners, nurses and social workers, that offers consultation about the care of children with what may be a life-threatening illness. They work with your child’s healthcare team to help you make treatment choices that are right for you and your child. They can provide your family with extra support during a difficult time and make sure the goals of your child and family remain at the center of all discussions with your child’s healthcare providers.

Pediatric cardiac surgeon: Doctors who have been trained in pediatric heart surgery. Immediately following surgery, the pediatric surgical team and the intensive care doctors will care for your child.
**Perfusionist:** Technologists specializing in the circulation of blood outside of the body (extracorporeal circulation). They have special training to operate the heart-lung bypass machine and MCS devices.

**Power cable:** A cable containing electrical wires that transfer electrical power to the system controller from a power source (batteries or AC electrical power).

**Pump:** Part of the MCS device that is attached to the heart. It helps the heart send blood to the body.

**Resident:** Licensed doctor who is in training in a pediatric specialty. They will have the most contact with you and your child. They give daily orders for care and update the attending doctor about your child’s progress. An intern is a resident who is in their first year of training. Senior residents are in their second or third year of training.

**Respiratory therapist:** Evaluates your child’s breathing. They may treat breathing problems with oxygen, medications, techniques to clear the airway, or a ventilator (breathing machine).

**Right ventricular assist device (RVAD):** A type of MCS that is usually used only for short-term support of the right ventricle after heart surgery. An RVAD helps the right ventricle pump blood to the lungs.

**Social worker:** Skilled counselor who works with families to provide emotional support and get the resources they need.

**Speed:** The number of times the pump spins in a minute (revolutions per minute or RPM).

**Supplements:** Iron, potassium and magnesium are common mineral supplements for people with MCS devices.

**Surgical clinical nurse specialist (CNS):** Nurse who provides and coordinates staff education in the inpatient surgical unit. The CNS is specially trained to serve as an educated resource for patients and staff.

**Surgical floor bedside nurse:** Nurse who provides and coordinates most of your child’s daily care and education on the surgical unit. This nurse is your main contact with your child’s other healthcare team members.

**Surgical unit:** A distinct unit, staffed by a healthcare team with special training and expertise to care for babies, children, teens and young adults who are recovering from surgery.
**System controller:** The control unit is the 'brain' of the pump. It operates the pump and has lights, messages and alarms that indicate when the batteries need to be changed. It alerts you if there are any problems with the system.

**Total artificial heart (TAH):** A type of MCS device that replaces both ventricles and all 4 heart valves. This device takes over the entire function of the heart.

**Ventricles:** The lower chambers of the heart that pump blood to the lungs (right) and body (left). The upper chambers (right and left atrium) collect blood from the lungs and body.

**Ventricular assist device (VAD):** A type of MCS device that helps pump blood from the lower chambers of the heart to the rest of the body.

**Ventricular assist system (VAS):** A system includes an implanted pump, an external controller, a power source (batteries, AC adapter) and accessories.

**Watts:** How the amount of electricity used to run the pump is measured.

### Notes
To Learn More

- Heart Center 206-987-2015
- Ask your child’s healthcare provider
- www.seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your child’s nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.

Seattle Children’s offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children’s will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201.

This handbook has been reviewed by clinical staff at Seattle Children’s. However, your child’s needs are unique. Before you act or rely upon this information, please talk with your child’s healthcare provider.

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