



# WELCOME to the MACC Fund Center for Cancer and Blood Disorders



The MACC Fund Center at Children's Wisconsin provides care to children, adolescents and young adults with cancer and blood disorders. Children's Wisconsin is a teaching hospital known throughout the United States for its excellence.

Our team of doctors, nurses, social workers and other care team members focus on what matters most to you and your child. As your care team, we strive to provide family-centered care in a kid-friendly and safe space. We work to communicate openly and honestly and include you and your child in the decisions that impact your family.

We believe in the value of consistent care and a team approach. Your child may receive care in our **outpatient clinic** or **day hospital**.

Each of these areas is described on the next page.

Sincerely,

## The MACC Fund Center Team

Carrie Orlebeke, BSN, RN, MBA, BMTCN  
MACC Fund Center Ambulatory Director



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## **MACC Fund Center Clinic** 5th floor – elevators “R” & “S”

A clinic visit may include:

- **Vital signs:** Checking temperature, heart rate, breathing, blood pressure, height and weight
- **Blood tests:** Most patients who are seen in the clinic will have blood taken. Your child may get their blood taken in the clinic lab room. They may need to go to an outpatient lab.
- **Medicine review:** Our staff will review all of your home medicines with you. It is easy to forget the names of all these medicines. Please bring your child’s medicines so we can look through them with you. Bring vitamins or supplements, too.
- **Visit by team members:**
  - When you arrive in clinic, our front desk staff will check you in. It’s important to bring your insurance card with you to your appointment.
  - A complex care coordinator will get your child’s height and weight and vital signs.
  - You will then be seen by a nurse clinician, nurse practitioner or doctor. You will discuss how cares have been going at home, how your child has been feeling and the plan for your child.

## **Northwestern Mutual Day Hospital** 5th floor – elevators “R” & “S”

Day hospital visits are scheduled for:

- **Blood products**
- **IV medicines**

Transfusion visits will take place in the day hospital. We offer a large community play area with:

- A craft table
- A big screen TV
- Video game consoles for patients and families
- Child life specialists who know how to talk with patients of different ages. They have ways to help prepare your child for any upcoming procedures, distraction and coping ideas, and offer plenty of fun things to do to stay busy.
- A recreational therapist can offer activities to support body, mind, social and emotional needs. They also offer fun ways to stay busy.

Day hospital visits will also include getting vital signs, placing an IV and getting blood samples. We will watch your child throughout their transfusion to make sure it is going well.



## Thalassemia team

**These are the members of the team  
that will be helping to care for your child.**

### **Hematologist**

This is the doctor that takes care of problems with the blood cells. They will be your child's main doctor.

### **Endocrinologist**

This is the doctor that looks at growth, development, hormones and the effects of too much iron in the body.

### **Hematology advanced practice provider**

This provider works closely with the hematologist. They watch over your child in the day hospital.

### **Hematology nurse**

The nurse will help organize the care you get in the clinic and in the day hospital (if needed). They:

- Will be the person you call with questions
- Help with FMLA paperwork
- Teach you how to take care of your child

### **Cardiology advanced practice provider**

This provider looks at the heart. They check for complications that can happen to patients with thalassemia. They will help treat any problems with the heart.

### **Psychology**

This doctor counsels patients and families. They help you with what to do if your young child needs help with their behavior. They also do mental health screening for older children.

### **Neuropsychometrist**

This provider tests how a child thinks. They talk with families about school services. They also work with school programs. This gives children the help they need in school.

### **Social work**

The social worker helps families find what they need to take care of their child. They can help with insurance, transportation and finding a primary doctor.

### **Dietitian**

The dietitian helps you make sure your child is eating right. This helps you to make sure your child gets all the vitamins and minerals they need.

### **Genetic counselor**

The genetic counselor helps the family learn about genetic diseases like thalassemia. They will talk about your family history. They can order tests that your child needs.



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## Transfusion-dependent thalassemia

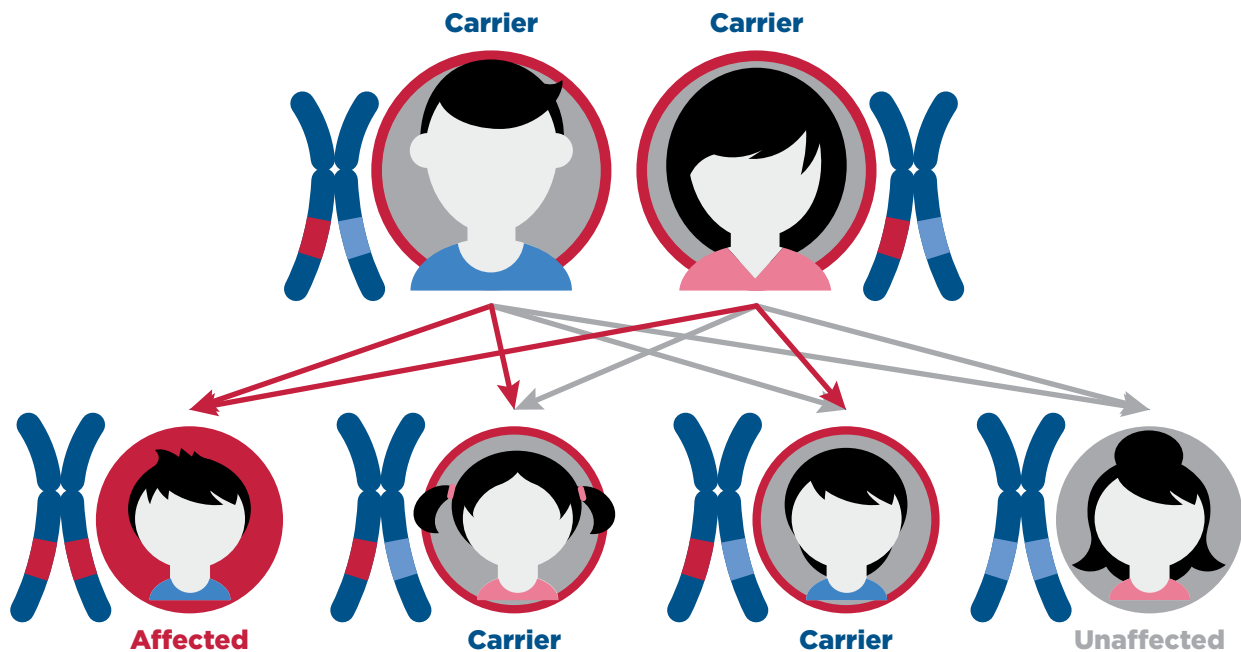
Transfusion-dependent thalassemia (TDT) is a blood disorder. A child inherits TDT from their parents. TDT is a lifelong disorder. TDT is also called:

- Beta thalassemia major
- Cooley's anemia
- Hemoglobin E/Beta-thalassemia

### How did my child get TDT?

TDT is inherited through genes. Both parents must carry the gene for thalassemia. TDT occurs when a child gets a thalassemia gene from each parent.

A child might get only one thalassemia gene. This is called a carrier. Carriers do not have symptoms of TDT and they often don't know that they are carriers. Carriers may be told that they are slightly anemic and have small red blood cells.



## **How does TDT affect my child?**

Everyone has red blood cells in their blood. Red blood cells have hemoglobin. Hemoglobin carries oxygen to all parts of the body.

TDT causes the body to not make enough red blood cells and hemoglobin. This causes anemia. It means your child's body will not get all the oxygen it needs.

Blood transfusions are needed to treat anemia. This will provide enough hemoglobin so your child's body can continue to grow and develop.

Most people with TDT live long and healthy lives.

Your child may have some problems due to the thalassemia and blood transfusions. Some of the most common problems will be covered in the next few sections of this binder.

Your child's care team will help you learn how to best care for your child. You will be taught everything you need to know about this chronic illness and how it is treated.



## When to call the clinic

### Call the Hematology Clinic at (414) 266-2420, option #2.

After hours, urgent calls will be transferred to the Children's Wisconsin operator and you will ask for the hematologist on call to be paged.



### **ALERT: Call 911 or emergency services right away if:**

- Your child is not breathing.
- You cannot feel your child's heart beating.
- Your child's skin and lips look blue.
- Your child is having a seizure.
- You cannot wake your child (loss of consciousness).

### What are the symptoms of low hemoglobin (red cells or RBCs)?

Call the doctor right away if your child has any of the following symptoms. A red cell transfusion may be needed.

- Weak, very sleepy
- Dizzy or lightheaded
- Headache
- Fast pulse (heartbeats)
- More yellow eyes or skin
- Pale skin

### What are signs of gallbladder disease (cholecystitis)?

Call the doctor right away if your child has these signs of gallbladder disease:

- Severe abdominal pain on the right side
- Nausea and/or vomiting
- Yellow eyes and/or skin

### What are the signs of a severe infection?

Call the doctor right away if your child has any of the following symptoms of infection:

- Temperature of 101.5°F (38.5°C) or higher for three days or more
- Shaking and chills (rigors, cold). These may go with fever and can be a sign of serious infection. Your child's doctor will want to see your child right away, or your child may need to be seen in the emergency room.

### What are the signs of heart disease?

- Chest pain
- Shortness of breath during rest or when exercising
- Feeling lightheaded or dizzy
- Fast heartbeat
- Irregular heartbeat



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## What are the signs of a neurological problem?

- Seizure
- Severe headache
- Not being able to pass urine
- Having stooling accidents
- Not being able to use arms or legs as usual

## What are the signs of a blood clot?

- Swelling, redness or pain of an arm or leg
- Severe headache
- Chest pain or shortness of breath



### **ALERT: Call your health care team if you have any questions or concerns or if your child:**

- Has a temperature of 101.5°F (38.5°C) or higher for three days or more, or concerns about an infection
- Is exposed to chicken pox or measles. Review the handout on chicken pox exposure.
- Is not able to drink fluids or keep them in the stomach (throwing up) for 24 hours. If your infant has not been able to drink fluid or keep fluid in the stomach for 12 hours, take your infant to see a doctor.
- Is not passing urine in a normal amount or as often
- Has liquid stools that continue for 24 hours
- Does not have a bowel movement in three days
- Is unable to take medicines
- Has pain or discomfort
- Has tried what the doctor told your child to do and it is not working
- Has noticed any changes, even something like just feeling different than normal. It is important to tell the doctor about these changes.
- Has special health care needs that were not covered by this information

This sheet was created to help you care for your child or family member. It does not take the place of medical care. Talk with your health care provider for diagnosis, treatment and follow-up.





## Blood transfusions

Some patients with thalassemia need to get blood transfusions to help keep them healthy. Blood transfusions are usually safe and are done often. They do two things:

- Increase the number of red blood cells, which carry oxygen
- Increase the amount of normal hemoglobin in the body

This can help a person feel better quickly.

At Children's Wisconsin, blood transfusions are given in the MACC Fund Center Day Hospital. The day hospital is staffed by nurses, care partners and an advanced practice provider that know about thalassemia. First, your child will have an IV (intravenous) line placed. Then, some blood will be taken. The blood will be used to check their red blood cells. It also allows the blood bank staff to test your child's blood with the blood that will be given during the transfusion.

The blood that will be given to your child has been tested carefully. This helps to reduce the risk of exposing your child to any diseases that could be transmitted to them.

The amount of blood that your child will receive at each visit depends on what their hemoglobin is each time. It also depends on your child's weight. The amount will change as your child grows. The blood is given slowly over a number of hours to make sure your child handles it well. The amount of time it takes depends on how much blood they get.

There can be some problems that happen with the blood transfusions. We watch closely for these problems your child might have, such as:

- Changes in blood pressure
- Skin rash
- Cough
- Having a hard time breathing
- Throwing up
- Headache
- Pain in the stomach, side or back

These problems are called transfusion reactions. The reaction often happens during the transfusion but could happen in the next 24 hours. In rare cases, your child could have a delayed transfusion reaction, which happens about one week after the transfusion was given.

The staff will check your child's heart rate, temperature, breathing and blood pressure often while they are in the day hospital. You should tell a nurse or other staff member if your child has any of the symptoms of a reaction.

If your child does have a transfusion reaction, they will probably get medicines before any other blood transfusion they get in the future.

Another problem of blood transfusions can be iron overload. Please see **section #6** on "[Iron overload in thalassemia](#)" for more information.





# Iron overload in thalassemia

## What is iron overload?

Iron overload is when there is more iron than the body can handle. Extra iron gets “stuck” in parts of the body. Patients who need blood for thalassemia can end up keeping too much iron in their body. This is because:

- Blood has a lot of iron and it is hard for the body to get rid of it.
- People with thalassemia absorb more iron from food than most people. This brings even more iron into the body.
- Iron stays in the heart, liver and other organs most often, and extra iron can cause damage.

## How is my child protected from iron overload?

- We will check your child’s blood tests for iron levels on a regular basis.
- Your child will need a test called Magnetic Resonance Imaging (MRI) to look at their organs for iron overload. We will do this MRI every one to two years.
- Your child might need to take a medicine to help get rid of the extra iron in the body.

## What do I need to know about the MRI test for iron overload?

The MRI to check for iron in the body can only be done at certain hospitals, one of which is Children’s Wisconsin. An MRI is a very strong magnet, so extra care is needed:

- Nothing with metal can be worn in the MRI area. Your child should not wear:
  - Jewelry
  - Hair clips
  - Clothing with zippers or metal snaps
- Let us know if your child has any metal in their body like a metal plate or pin.
- You should talk with the MRI staff about it. Most times the type of metal used in their body will not be pulled on by the magnet and your child will still be able to get the test.
- The MRI machine looks like a narrow tube. Your child will lay on a table that slides in and out of the tube. Some people don’t like being in the small space and find it helpful to listen to music or have a movie playing while they get their MRI.
- Your child will need to hold very still so we can take clear pictures.



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## What do I need to know about the medicines for iron overload?

Most patients will need to take a daily medicine that will help the body to get rid of the extra iron. This is called chelation. Your child's doctor or nurse practitioner will keep a close eye on their blood tests and will change the dose of the medicine if needed. The medicine that is usually used first is called **deferasirox**. It is taken either as a pill or as sprinkles that can be mixed with a soft food like yogurt or applesauce.

Sometimes your child might be able to take a short break from taking their iron overload medicine. Your child's doctor or nurse practitioner will let you know when you can stop giving it and when you will need to start it again.

If the deferasirox isn't working well enough, then they might need to start a different medicine called **deferiprone**. It is a pill or a liquid taken two times every day. If your child is taking deferiprone, they will need to get their labs checked more often because it can cause your child's blood counts to be lower than normal. We will also check for problems with the liver or kidneys.

Another medicine for iron overload is called **deferoxamine**. It is given every night as an injection under the skin that goes in slowly over 8 to 12 hours. Sometimes it is given in the veins in a hospital. Your doctor will let you know if your child needs this medicine.



# Thalassemia and the heart

## What should I know about heart problems?

Patients with thalassemia have a high risk of heart problems. This can be from thalassemia and from the treatment for it. Heart problems are the most common cause of death for people with thalassemia. It is very important to get checked for heart problems and treated if needed.

## What are symptoms of heart problems?

Symptoms of heart problems may include:

- Problems breathing, even when they are resting
- Fast heartbeats
- Fainting
- Chest pain
- Feeling very tired
- Swelling around the ankles

## How do I know if my child has heart problems?

There are some tests that can be done to check your child's heart:

- **Electrocardiogram (ECG or EKG)** to look at the heart rhythm
- **Echocardiogram (Echo)** to look at the heart function and size
- **Cardiac MRI** to check for iron overload

Some of these tests will be done every year. Some tests might only be done if they are having symptoms. A cardiologist may suggest more tests.

## What causes heart problems?

- The heart may beat too fast. Anemia can cause this to happen. The heart beats faster because it is trying to pump extra oxygen out into the body. This can make the heart become larger.
- Iron overload can cause heart problems. It causes extra iron in the body to be left in the heart and other organs. Please see **section #6** on *“Iron overload in thalassemia”* for more information.

## How can I help to prevent these problems?

- Medicines are the best way to help the body get rid of the extra iron. If your child gets medicines for iron overload, it is very important that they take them as scheduled.
- It is important that your child is physically active to keep their heart healthy. Your doctor can help you decide what types of activity would be good for them.
- It is important that people with thalassemia eat well, don't smoke and don't drink too much alcohol.





# Thalassemia and the **liver**

## Why is the liver important?

The liver is an important part of the body and has many jobs. One job is to filter the blood to take any toxic materials out of the body. It can also take out germs to help prevent infections. The liver also makes bile, which is something that helps the body to break down food.

## What causes liver problems?

One of the major causes of liver problems in thalassemia is iron overload. This is extra iron in the body that gets put into some organs like the liver. Please see **section #6** on [“Iron overload in thalassemia”](#) for more information.

Another possible liver problem is an infection from one of the hepatitis viruses. There are A, B and C types of hepatitis. Hepatitis B and C can cause damage to the liver. One way that a person can get hepatitis is from blood transfusions, if the person giving blood has the virus. The risk, however, is very small because there is a lot of testing and screening done for people who donate blood.

## What could happen to my child?

If the body is not able to get rid of extra iron, then some of it can stay in the liver. If too much iron stays in the liver, it can fill up the liver and cause scars. This is called fibrosis, and it can keep the liver from working right. Too many scars can cause something called cirrhosis, which can be very serious. Hepatitis B and C can also cause fibrosis and cirrhosis. In some cases, cirrhosis can lead to liver failure or liver cancer.

## How do I know if my child has liver problems?

We will do tests every year at your child’s clinic visit. Most of these are blood tests:

- Liver enzymes (AST, ALT)
- Hepatitis A serology
- Hepatitis B serology
- Hepatitis C serology
- HIV test
- MRI Liver Iron (LIC)

## How can I help to avoid liver problems?

If your child is given medicines for iron overload, it is very important that they take these medicines as directed. This is the best way to help because it will help the body to get rid of the extra iron. It is also important for your child to drink lots of water and eat well.







# Thalassemia and the **spleen**

## **Why is the spleen important?**

The spleen is a small organ in the abdomen, near the stomach. Some of the jobs of the spleen are to filter the blood and to make lymphocytes. Lymphocytes are small white blood cells that help the body fight disease. The spleen helps fight infections. When it filters blood, it will break down red blood cells that are no longer used by the body. When it breaks them down, it takes out the globin and iron from those cells so the body can use them again.

## **What causes spleen problems?**

For people with thalassemia, when the spleen breaks down the red blood cells, the iron can stay in the spleen instead of getting reused. Also, red blood cells in people with thalassemia are smaller and a different shape. This means they can get stuck in the spleen instead of getting filtered out. These reasons can make the spleen larger. This is called splenomegaly or hypersplenism. When the spleen is larger, it starts working faster and will start killing more red blood cells. This can lower hemoglobin levels. Also, when the spleen is big, it can push on the stomach and make it harder to eat full meals. This can sometimes make a person with thalassemia not gain weight or grow as they should be. This can make them need to get blood transfusions more often. Transfusions can help by making the body stop making extra red blood cells.

## **How is a large spleen treated?**

If the spleen doesn't get smaller with blood transfusions and is causing problems with weight gain and growth, then the spleen may need to be taken out. This surgery is called a splenectomy. There are always some risks with having surgery and getting anesthesia. Taking out the spleen can also make someone a higher risk for infections for the rest of their lives. They will need to take steps to lower their risk of infection. This means getting certain vaccines both before and after removing the spleen. It also means taking medicine after the spleen is removed and maybe for the rest of the person's life.





# Thalassemia and the **gallbladder**

## **What should I know about the gallbladder?**

Patients with thalassemia have a risk of getting gallstones. Gallstones can cause problems if they get stuck going out of the opening of the gallbladder.

## **What is the cause of the gallstones?**

Gallstones are usually caused by extra bilirubin. Patients with thalassemia have extra bilirubin.

- Bilirubin is from the breakdown of red blood cells.
- The breakdown of red blood cells happens faster for patients with thalassemia.

## **What happens if my child has gallstones?**

Often, the gallstones don't cause any problems for patients with thalassemia.

Gallstones can sometimes cause:

- Pain in the belly
- Pain below the right shoulder blade
- Pain in the back
- Upset stomach or throwing up

Pain can get worse after eating fatty foods.

## **What is the treatment for gallstones?**

Surgery to remove the gallbladder might be needed. Once the gallbladder is removed, they will not get any more gallstones. Then they will not have painful symptoms.





# Thalassemia and **infectious diseases**

## What is an infectious disease?

It is an illness caused by germs. These germs cause infections. Patients with thalassemia can have a higher risk for infections. There are many reasons for this.

## What are the risks of getting an infection?

- If your child gets blood transfusions, there is a very small risk that they could get an infectious disease. The infections we are most concerned with are:
  - HIV
  - Hepatitis viruses (A, B, C)
- If your child had their spleen taken out, they have a greater risk for getting very sick from infections. They must go to an emergency department right away if they get a fever.

## How can I help my child stay safe?

- Your doctor will check labs yearly to make sure your child did not get certain diseases.
- Children with thalassemia should be seen by a doctor if they have a fever that lasts three days. Your child may get sick more quickly than other children.
- If your child gets blood transfusions, the blood that is given to them will be tested very carefully for many different diseases. The blood center takes many steps to make sure the blood is as safe as possible.

## What can I do to help prevent infections?

- Your child should have all standard vaccines. Vaccines help prevent infections.
- If your child has a fever of 101.5° F or higher for three or more days, they need to see a doctor.
  - Call your hematology nurse or doctor if you think your child needs to be seen. They can help you decide where to bring your child.
  - Your child needs a full exam and some lab tests. Be sure the provider knows that your child has thalassemia so they get the right care.
- **If your child had their spleen removed:**
  - They may have to take antibiotics forever to prevent infections.
  - It is important for your child to get certain vaccines before and after their spleen is removed.
  - Children who have had their spleen removed must go to an emergency department right away if they have a fever of 101.5° F or higher. They should not stay at home to see if it goes away.





# Thalassemia and **diabetes**

## **What does diabetes have to do with thalassemia?**

Patients with thalassemia are at high risk for getting diabetes. Diabetes is an endocrine problem where blood sugar is high. This can be very serious and can cause damage to the eyes, nerves, kidneys and heart.

## **What causes diabetes?**

The main cause of diabetes in people with thalassemia is iron overload. Iron overload can damage the cells that make insulin. Insulin is the hormone in the body that helps the body absorb sugar, also called glucose, from food. The sugar goes into our cells to create energy. When there is not enough insulin, blood sugar does not go into all cells but into the blood. Blood sugars can rise very high and be quite dangerous.

## **What are the symptoms of diabetes?**

Your child may become more thirsty, use the bathroom more and/or have urinary accidents. Diabetes causes many children to lose weight without trying. They can also feel very tired and not have energy to keep up with normal activities.

## **How will I know if my child has diabetes?**

We can check with yearly tests or test if your child develops symptoms of diabetes. These tests include:

- Fasting blood sugar or a blood sugar two hours after eating.
- Oral glucose tolerance test. Your child will drink a very sugary drink. Then blood sugars are checked over the next two hours.
- A blood test called “fructosamine.” This test tells us if the blood sugar has been high over a period of time.
- Urine tests to look for sugar in the urine.

## **How can I prevent these problems?**

- If your child is taking medicines for iron overload, it is very important to take them as your doctor prescribes them. This is the very best way to prevent iron buildup from damaging the cells that make insulin.
- It is also important to eat healthy foods and get plenty of exercise.
- Work closely with a dietitian and doctor to help your child stay healthy.

## **How is diabetes treated?**

If your child is diagnosed with diabetes, you will need to check blood sugars at home with a glucose meter. Sometimes patients need insulin injections to bring blood sugars into a healthy range. Many patients will keep track of how much sugar they are eating and choose foods that will not raise blood sugars as much.







# Thalassemia and **endocrine disease**

## **What should I know about endocrine disease?**

Endocrine means glands that release hormones. Many children with thalassemia will have concerns with their hormones. This is because organs that make hormones are sensitive to iron overload. These organs include glands, like the thyroid gland, testicles, ovaries and pancreas.

## **How can endocrine disease affect my child?**

Children with endocrine disease often do not grow very well. They might be shorter than their peers. They can grow slowly or might not have puberty changes. They may get diabetes or have problems with blood sugars. They can have weakened bones or get broken bones. They may have problems with calcium levels in the blood.

## **How do I know if my child has endocrine disease?**

Your pediatrician and thalassemia team will do blood tests and X-rays to look for any hormone concerns. At every visit, they will check your child's growth. They will watch to be sure that your child is having puberty changes at the right time.

## **How can I prevent these problems?**

If your child is using medicines for iron overload, it is very important to take these medicines as your doctor prescribes them. This is the very best way to prevent iron buildup from damaging the cells that make insulin. It is also important for your child to eat a healthy diet, get plenty of exercise and work closely with a dietitian and doctor to be sure they are staying healthy.

## **How are endocrine concerns treated?**

If we find a hormone concern, we can treat it with replacement hormone. That may include taking thyroid medicine pills, growth hormone shots under the skin or puberty hormones. Bone health can be helped by giving calcium and vitamin D to your child each day.





# Thalassemia and **growth**

## Does thalassemia affect growth?

Many children with thalassemia have slowed growth. Growth is very important in childhood because many girls complete their growth by the time they are 14 years old. Many boys are at their full height by the time they are 17 years old. Nutrition is very important to reach their best height.

Your child may notice that they are not growing the same as their peers, which can be distressing. Children can end up very short if this growth concern is not addressed early.

## How does this happen?

Growth may be affected by chronic anemia, iron overload and hormone changes.

## How will I know if my child has growth concerns?

Your pediatrician and your thalassemia team will measure your child at every visit and mark that height on a growth curve. They will show you this curve at each visit so you can see your child's growth. They will let you know if your child's growth is steady. There are some other tests that can be done to monitor growth. These tests will be done on a schedule or if there are new concerns about growth:

- **Thyroid hormone, growth hormone, puberty hormones**
- **Bone age X-ray** of left hand and wrist
- **Growth hormone test** This is done in the infusion center.

## How can I prevent these problems?

If your child is taking medicines for iron overload, it is very important to take them as your doctor prescribes them. This is the very best way to prevent iron buildup from damaging the cells that make insulin. It is also important to have a healthy diet, get plenty of exercise and work closely with a dietitian and doctor to help your child stay healthy.

## How are growth concerns treated?

Once we find a cause for your child's growth slowing, we will replace the hormone that is missing. That may include taking thyroid medicine pills, growth hormone shots under the skin or puberty hormones.





# Cures for transfusion-dependent thalassemia

If your child has transfusion-dependent thalassemia, there are some treatments that might help them. They include a bone marrow transplant or gene therapy.

## What is a bone marrow transplant (BMT)?

Bone marrow transplant replaces unhealthy blood-forming cells with healthy ones from a donor. These new cells create normal hemoglobin and help address your child's anemia.

### Transplant steps:

1. The doctor searches for a donor with healthy blood-forming cells. The donor may be a family member, an unrelated person or umbilical cord blood.
2. Then, your child is given medicines called chemotherapy. This is to get rid of their unhealthy blood-forming cells.
3. On the day of the transplant, the donated cells are given to your child through an IV. The way it is given looks a lot like a blood transfusion. The new cells travel to the inside of the bones. This is where they will start to grow and make the new healthy blood cells.
4. It takes months for these new cells to grow and rebuild your child's blood cells and immune system. Your child will need to spend some time in the hospital for the team to watch and treat any side effects or other problems. After the hospital stay, your child will need to be seen often in the clinic. If you live far away, you and your child will need to stay close to the hospital.

## What is gene therapy?

Gene therapy is a newer treatment. The patient's blood-forming cells are changed to fix their anemia. The change might be done so they start making healthier hemoglobin. The change might also be so the body makes more fetal hemoglobin. Fetal hemoglobin is the type of hemoglobin newborn babies make. Either of these changes can help fix the anemia.

### Gene therapy steps:

1. The first step is to take some of the blood-forming cells out of the body. This is called harvesting or collecting. Before this can be done, your child



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will get medicine to help increase the number of cells in the body. The blood-forming cells are taken out so they can be changed. This part looks kind of like donating blood.

- 2.** The harvested cells are sent to a lab where they are changed. The change is to teach them to start making the healthier hemoglobin or to increase the production of fetal hemoglobin.
- 3.** Once the change of the cells is done, the cells are returned to the hospital. It can take months for the cells to be ready.
- 4.** Your child will stay overnight in the hospital. They will receive medicines called chemotherapy to kill the blood-forming cells in their body. This will let the new changed cells grow.
- 5.** On infusion day, the new cells are given to your child through an IV. The new cells travel to the inside of the bones. There they will start making the new healthy blood cells.
- 6.** It takes months for these new cells to grow and rebuild your child's blood cells and immune system. Your child will need to spend some time in the hospital for the team to monitor and treat any side effects and any problems.

If you want to look into these options, your child's hematology team will discuss their case with the BMT and gene therapy team. They will review and decide if your child could be helped with one of these therapies. Then they will meet with you to talk about these options.



## Nutrition for patients with thalassemia

Good nutrition is important for all children. Making meals with a wide range of foods from each food group helps make a balanced diet. A balanced diet supports your body's health and well-being. A balanced diet helps you get all the vitamins and minerals you need.

A child with thalassemia needs some nutrients in larger amounts.

- Their body uses some nutrients more.
- Some may have slow growth, poor immune systems and lower bone health.
- Vitamins and minerals needed for the immune system and bone health are vitamin D, calcium and zinc.
- To grow right, your child needs food that meets their energy needs.

Your doctor may check your child's blood levels to see if these vitamins are in need.

There are nutrition guidelines if your child needs blood transfusions.

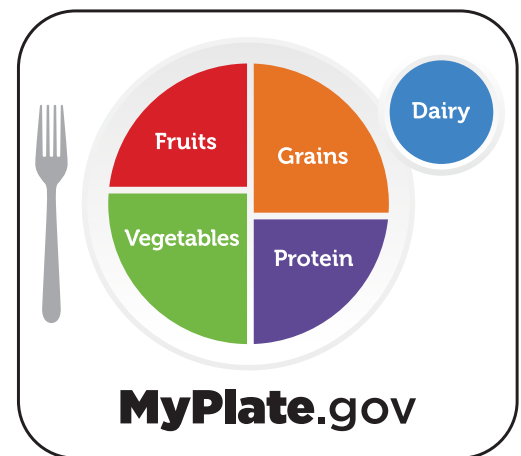
- **Non-transfused thalassemia:** follow a low-iron diet. Try not to eat iron-fortified cereals or other iron-fortified foods (enriched bread, enriched pasta) or large amounts of red meat.
- **Transfused patients on chelation therapy:** a low-iron diet is not needed.

### Nutrition tips

- Aim to eat at least three times each day. If you feel hungry in-between those, have a snack.
- Eat different foods each day. This helps the body get more vitamins and minerals.

### Making balanced meals using MyPlate

- Use **MyPlate** to create balanced meals.
- Try to eat at least three different food groups for your meal.
- The most balanced meals have all five food groups.
- Think about foods that you like in each of the food groups to plan balanced meals.
- To eat balanced snacks, try to have two different food groups from **MyPlate**.



## Practice making meals using MyPlate

FOOD GROUP	EXAMPLES OF FOODS IN THAT GROUP
<b>Fruits</b>	Apples, bananas, grapes, pineapple, mango, kiwi, pears, peaches, dragon fruit, durian, strawberries, blueberries, blackberries
<b>Vegetables</b>	Cabbage, bok choy, green beans, spinach, kale, collard greens, mustard greens, chard, broccoli, cauliflower, bell peppers, okra, lettuce, tomatoes, carrots
<b>Grains</b>	Bread, rice, pasta, potatoes, corn, quinoa, kamut, teff, tortillas, barley, millet, oats, oatmeal
<b>Protein</b>	Fish, chicken, tofu, tempeh, turkey, ham, eggs, peanut butter, nuts, seeds, lentils, beans
<b>Dairy</b>	Milk, plant-based milks, yogurt, cheese

### Balanced meals examples:

- Eggs + raspberries  
+ whole wheat toast with butter
- Noodles with chicken  
and vegetables
- Lentil soup + whole grain roll  
+ salad

### YOUR balanced meal ideas:

1. \_\_\_\_\_  
\_\_\_\_\_
2. \_\_\_\_\_  
\_\_\_\_\_
3. \_\_\_\_\_  
\_\_\_\_\_

### Balanced snacks examples:

- Apple + peanut butter
- Hummus + carrots
- Tzatziki with pita

### YOUR balanced snack ideas:

1. \_\_\_\_\_  
\_\_\_\_\_
2. \_\_\_\_\_  
\_\_\_\_\_
3. \_\_\_\_\_  
\_\_\_\_\_





## Dental care with thalassemia

### Why is dental care so important?

Children with thalassemia can have more problems with their teeth than others. This includes:

- A higher risk for dental decay (cavities)
- Delayed teeth growth
- Changes in the size and shape of the teeth
- Problems with buildup on the teeth (plaque)
- Swelling and painful gums (periodontitis)

Extra iron in the body can also cause dry mouth and painful swelling of the glands that produce saliva (parotids).

### What should I do to help with this problem?

It is very important for your child to see a dentist every six months. They need to have regular dental exams and cleanings. They also need to take good care of their teeth at home. This includes brushing and flossing at least two times per day.

### What does my child's dentist need to know?

Your child's dentist should talk with your child's hematology team before any dental work is done, other than cleanings and exams. We may need to make special plans if your child needs to be sedated (put to sleep).

If your child had their spleen taken out, they will need to take an antibiotic before they see the dentist. Contact your child's hematology team before seeing the dentist. They will make sure you get the antibiotic if it is needed.





# Thalassemia and **mental health**

## How can thalassemia affect mental health?

When children or teens have a lasting illness, it can impact their mental health. You may see changes in:

- Activity
- Mood
- Relationships
- School

Your child may struggle with their mental health because of the disease and from the impact of treatments. If they also have concerns like ADHD, depression or anxiety, this can make coping with thalassemia even harder.

## What are some mental health concerns?

- **Education:** Some kids have low energy and struggle to focus. They also may have to miss school for transfusions. Problems with school can affect mood and self-esteem.
- **Activities:** Sometimes, kids are less active and spend less time outside. This can lead to problems with mood and physical health.
- **Body image:** Slower growth and delays in puberty can cause kids to feel sad or concerned about how they look.
- **Family:** Teens with long-term illness can have more conflict with parents as they cope with their disease. This can also add to parents' stress. They worry about their child's health. They also have to work hard to manage their child's illness.
- **Social life:** Patients worry about talking about their illness with friends. They may fear being picked on by others.
- **Health anxiety:** Some children worry about their future health and their long-term well-being.

## What can I do if I am concerned about my child's mental health?

Talk to your child's doctor if you have concerns about these or other mental health topics. Many children can get help by talking to a therapist. The therapist can help find ways to deal with mental health concerns.

The Children's Wisconsin Mental and Behavioral Health (MBH) navigator team (414-266-3339) can help you find a therapist in your area. A pediatric psychologist can see your child at annual full clinic visits to assess mental health and help guide services, if needed.



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## Outpatient and inpatient psychosocial services

**These services are offered for patients in the hospital or in clinic. Talk to your care team to get started.**

SERVICE	HOW THEY HELP
<b>Child life</b>	Child life specialists teach skills that help to manage illness. They help patients and families understand illness and prepare for procedures. They also help the siblings or children of young adult patients. They give support during painful or stressful events. This includes help with taking medicine.
<b>Creative arts therapies</b>	Creative arts therapies help the mental health needs of patients. They use art or music for therapy while in the hospital.
<b>Hospital-based school</b>	Hospital-based teachers work with patients in their room. They can work with grade school students through high school. They work with your child's school teacher to keep them on track.
<b>Psychology</b>	Psychologists provide therapy and teach ways to cope with illness. They also test areas that might be affected. This includes learning, emotions and behaviors.
<b>Recreational therapy</b>	Recreational therapists use activities to focus on body, mind, social and emotional needs. They may meet one-on-one or in group sessions and teach new hobbies and resources. This can help during and after treatment.
<b>Social work</b>	Social workers meet with all patients and families to understand how they can help with social, emotional and financial needs. They will review concerns about work, school, sibling, insurance, transportation, guardianship and custody needs to offer help.
<b>Spiritual care</b>	Chaplains provide spiritual and emotional support for patients and families during a hospital stay. They help families of all faiths or beliefs.
<b>Volunteer therapy dog</b>	Trained, certified therapy dogs offer comfort in the hospital or clinic. They can help lower stress and change focus when struggling.

