

School Toolkit for People with Transfusion-Dependent Thalassemia

A GUIDE TO HELP YOU COMMUNICATE
WITH SCHOOL PERSONNEL
ABOUT THALASSEMIA



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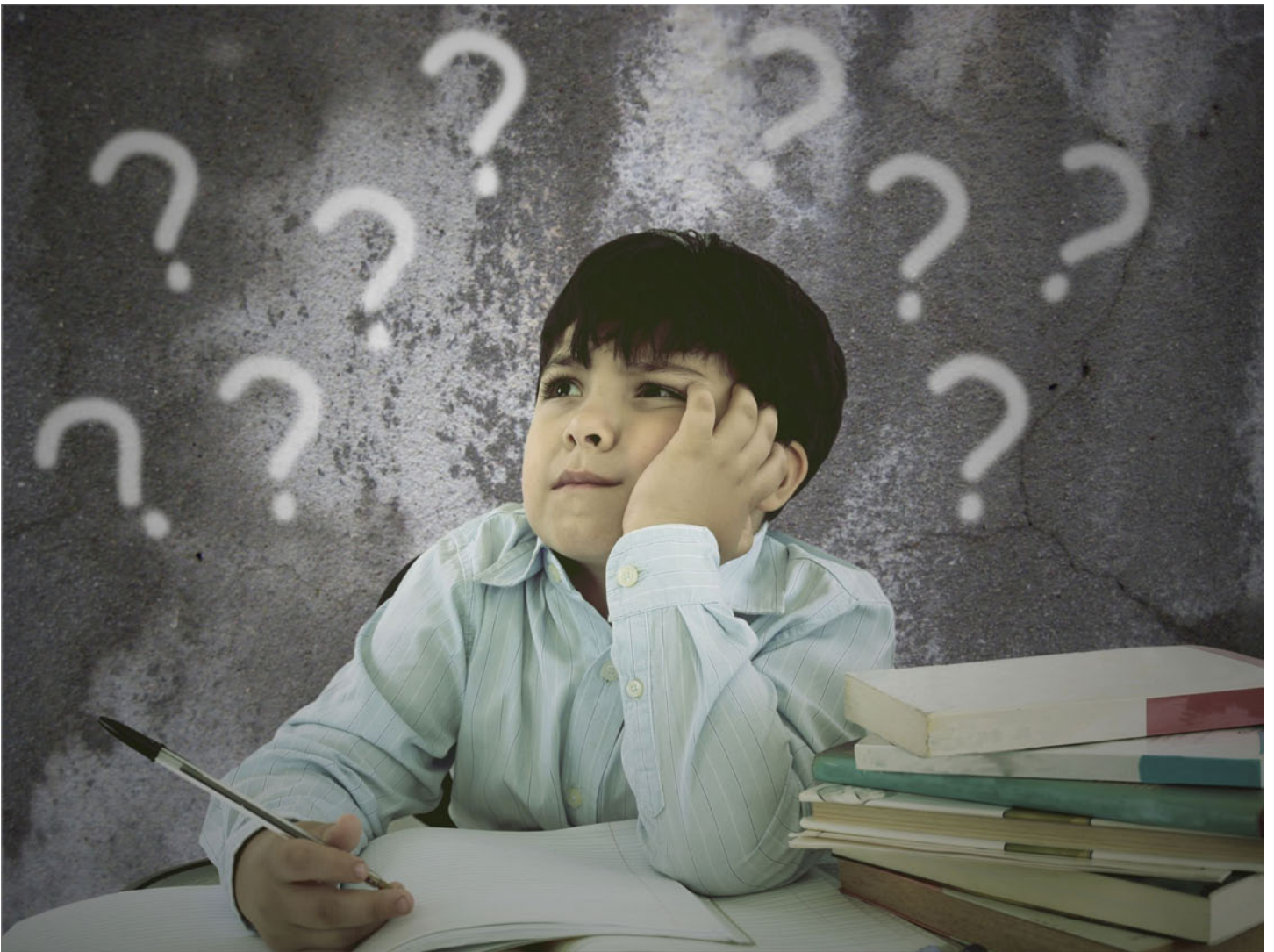
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Section A



Overview

Dear Parent,

Welcome to your School Toolkit for People with Transfusion-Dependent Thalassemia! This Toolkit will be an informative and helpful tool to use during your child's educational years.

Why is this Toolkit necessary? Over the years, the Cooley's Anemia Foundation has heard from patients and parents who have encountered difficulties with school officials when their child has had to miss classes to get transfusions or has had schoolwork otherwise impacted by issues related to thalassemia.

This was reinforced when the Foundation, as part of a cooperative agreement with the Centers for Disease Control and Prevention (CDC), conducted a series of focus groups. One objective of these groups was to determine the barriers that prevent a person with thalassemia from adhering to treatment. Participants indicated that having to take time off from school for transfusions and having to catch up on missed school work were among those barriers.

We've prepared this Toolkit to give you ample **information to help with issues that may arise in connection with your child's school participation**. This Toolkit can provide valuable guidance in communicating with teachers, school nurses and other school personnel about the challenges that thalassemia presents.

This Toolkit will help you to:

- Learn **when to communicate** with your child's teacher and/or school nurse.
- Determine **what information** to share with school personnel.
- **Set up a strategy** so that your child's education and health care needs are both adequately addressed.
- Explore whether a **Section 504** designation or other option is appropriate for your child (if your child is in a public school).

Of course, every person with thalassemia has different challenges and is in a different situation. Some people find that most school-related issues that arise due to thalassemia can be

solved with a brief phone call; others require in-depth meetings and a detailed plan created by both you and school personnel. **This Toolkit is customizable**, so you may remove items that do not pertain to your child or add specific information that relates more directly to your child.

For example, nowadays many thalassemia patients participate in school physical education activities with no problems; if your child does not need any accommodation for gym activities, modify the information in this toolkit to reflect that.

If you have questions that this Toolkit does not answer, if you feel that you need more assistance, or if you have comments about how the Toolkit can be improved, please **contact the Cooley's Anemia Foundation (info@thalassemia.org, 212-279-8090)** and we will be happy to offer whatever assistance we can, including **putting you in touch with other families that have experience communicating their needs to school personnel**. The Foundation is also happy to provide teachers with additional information about thalassemia if they would like to teach students more about thalassemia.

Our goal is to ease a potentially stressful situation and make the student-educator experience more productive and beneficial for all concerned.

Cooley's Anemia Foundation

“This Toolkit is customizable, so you may remove items that do not pertain to your child or add specific information that relates more directly to your child.”



Why Is Communicating with School Personnel Important?

Education is all about communication. The teacher communicates information to a child through lessons and assignments, and the child communicates his/her understanding of it back through tests, homework and class participation.

Parents are also involved in the communication process with educators, although not on an everyday basis. As the parent of a child with thalassemia, you will need to become more involved in this process because it is likely that your child's teachers, school nurses, and other personnel are not familiar with thalassemia. You and your child will be in the position to educate them about something new.



Some parents (and patients) may feel a little uncomfortable about discussing their experiences with thalassemia. **Each individual has a different comfort level** in terms of how much he or she wants to reveal about his or her child's experience with thalassemia; some are very open about it, while others prefer to limit the number of people who are aware that their child has thalassemia.

There is no "right" way to feel about this; however, even if you prefer to keep this information as private as possible, it is important that the appropriate individuals in your child's school know that your child has a disorder that may require special consideration.

Please be aware that school districts have rules which govern what information about a child may be shared and with whom it may be shared, especially information related to a child's health. (These rules apply to school personnel; it does not prevent a parent from sharing information about his or her child.) If you have any concerns about this, please let the school personnel you will be speaking with know that you wish this information kept confidential. And make sure that both you and the school personnel are clear on who should be told about any confidential information and how that information should be conveyed.

In general, the schools should not challenge you about your child's need to miss school due to a medical condition; however, due to budget cuts and overworked staff, it is possible that you may encounter school personnel who do not want to give extra assistance to your child. If

this happens, there are disability acts that apply to federally funded school programs. These acts, usually referred to as “Section 504,” are a tool that can be used by qualifying students to officially plan missed days and ways to make up work. This will be discussed later in this document (see “Do You Need to Consider a Section 504 Plan,” page 18).

Remember: you can contact the Cooley’s Anemia Foundation if you would like to be put in touch with parents who can share their own experiences speaking with school personnel.

To summarize:

- School personnel may not be familiar with thalassemia and may need to be educated about how it may affect your child’s school experience.
- School districts have rules that determine what student information a teacher or school personnel can share with other school personnel. This does not affect what information a parent or student may wish to share and is in place to protect the student’s privacy.
- Express any concerns about confidentiality to the appropriate school personnel.



Should I Involve My Child in This Process?

You will be communicating information about your child to people outside of your family, so your child will need to be involved in the process. Every child is different and what your child wants to do in terms of disclosure will depend on a number of factors, including your child's age, your child having an understanding of why there's a need to tell people and how open your family is about discussing thalassemia.

Why Are We Telling People at School about Thalassemia?

Start by explaining to your child why you need to let people at the school know about your child's experience with thalassemia. You might tell your child:

1. You are going to be missing school for your transfusions and will need to make up missed work and exams. We need to let the school know about this so we can make plans.
2. They also need to know that you might be really tired some days or might be fighting an infection, so they can know what to do. *(A child might be comforted by having an authority figure "in the know" about his/her thalassemia, especially if s/he is very anemic; the child may feel better if the teacher knows the child is fatigued rather than lazy or careless.)*
3. They need to know what we want them to tell anyone who notices that you miss school a lot and asks them about it.
4. Not all the teachers will know about this. We can let the school know who we think should know and also tell them if there is anyone we think should NOT be told. And you can help us decide who gets told and what they get told.



How Does Your Family Feel About Discussing Thalassemia with Others?

Families develop different ways to manage the information about their child's thalassemia. Some do not tell anyone and do not talk about it very much at home. Some families talk openly about it and feel very comfortable sharing this information with most people in their lives.

You will need to evaluate your family's level of privacy about thalassemia before you talk to school personnel. It may be very hard to go into your child's school to talk about thalassemia if you do not talk about it freely at home or to others in your life.

On the other hand, if you are very open and discuss thalassemia freely, you may want to consider how much you need to discuss with the school. The rule of thumb is to share only the information that is in the best interest of your child.

Can My Child Communicate His or Her Needs About Disclosure to Me?

Most school age children are able to talk about who they want to tell about their experiences with thalassemia. The more you include your child in the process of discussion, the more he or she will feel a part of it and will state what he or she prefers.

To summarize:

- Your child should be involved in this process in a manner that is comfortable to him or to her.
- Explain to your child why telling people at the school about his or her experience with thalassemia will help.
- Figure out how much information should be shared.

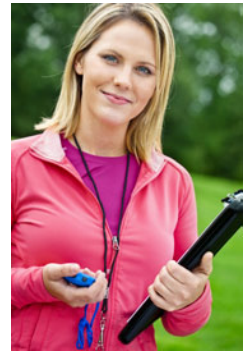
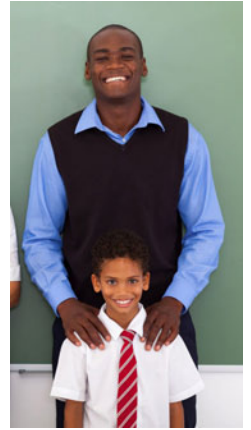
Who at the School Should You Communicate With?

Every school is different, but in general it is a good idea to discuss your child's experience with thalassemia with those who will have the most direct contact with him/her. In elementary school, or another school setting in which your child spends most of the day in one classroom, it is important to speak with your child's main teacher and with the school nurse.

However, depending upon the structure of the school, there may be other individuals who you may need to speak with. These might include other teachers who work with your child on a regular basis (e.g., physical educator teacher, art teacher), your child's guidance counselor, and the principal or vice principal.

Your child's classroom teacher and/or the school nurse can advise you as to whether you should speak directly with other teachers and other staff.

In higher grades, when a student typically has many different teachers during the course of the day, there may be many people who need to be aware that your child will be absent frequently. In this instance, it may be best to contact the school nurse, the guidance counselor or the principal's office; explain that your child has a condition that will impact attendance and that you want teachers to know about it; and ask what is the best way of going about communicating this information. Your child's school may already have in place a system for sharing this kind of information.



To summarize:

- You should discuss your child's experience with thalassemia with those school personnel who will have the most direct contact with him/her.
- In higher grades, there may be more teachers who need to know about your child's experience with thalassemia. The school may have a system for sharing information of this sort.

When Should You Get In Touch with the School?

The earlier you can talk with the school personnel, the better. Try to set up a time before the school year begins; if that is not possible, set one up as soon as possible after the school year begins.

Different schools set teacher-student assignments at different times. In many schools, students do not find out who their new teacher will be until July or August and it may be difficult to contact the teachers and school nurses during these summer months. Still, **find out from the school when and how (email or phone) you can contact the teacher and the nurse**, then let the teacher and nurse know that you would like to set up a time to meet with them (together, if possible).

Remember: Every teacher in every school in every school system is different – and the needs of your child may be different than the needs of another child. While this Toolkit focuses on what to do in a face-to-face meeting, **in many cases, a simple phone call or two may be all that is needed** to adequately communicate with your child’s teacher and/or school nurse.

For example, a sample email for your child’s teacher might read:

My name is _____ and my child (Name) will be in your class this year. I would like to set up a time when I could meet with you and the school nurse to talk about a medical condition for which my child receives treatment and which requires some missed class time or affects class participation. Please let me know when you have some times available that we might meet; if possible, I would like to meet before the school year begins. I will also send a separate email to the school nurse to find out his/her availability. If you think there are any other school personnel who should be involved in this meeting, please let me know. Thank you, and I look forward to hearing from you.

If your child will be attending high school or another school in which s/he changes classrooms and teachers throughout the day, contact the school nurse and explain that you have a child with a medical condition that will result in some missed class time. Ask the nurse who else should be involved in the meeting – the guidance counselor, the principal, etc. Some schools may be divided into teaching “teams,” and **there may be a team leader that would be the appropriate person** to include for this meeting.



To summarize:

- Try to set up a meeting as early as possible.
- In some cases, a meeting may not be necessary: a phone call can accomplish everything that needs to be taken care of.



What Should You Say at the Meeting?

Following is an outline of how a typical meeting might go. **You may need to change this so that it reflects your own child's situation.** For example, if s/he has complications, whether thalassemia-related (such as low bone mass or diabetes) or non-thalassemia-related (such as asthma) that might impact total participation, you should talk about those during this meeting as well. Or if you feel that your child is lively and active and generally does not get too tired in the days leading up to a transfusion, you may want to omit the sections that deal with special considerations during those days.

Also, remember that **in all likelihood, the people you are speaking with have no knowledge of thalassemia.** While thalassemia can be a very serious disorder, proper management of thalassemia means that **your child can have a very successful school experience,** and the school personnel need to get an accurate picture of what thalassemia means for your child.

- Thank the teacher and nurse (and anyone else who is attending the meeting) for taking the time to meet with you. Take a moment to discuss any concerns you might have about confidentiality before the meeting starts.
- Tell them that your child has a genetic blood disorder known as thalassemia. You are here because you want to talk about any potential challenges and jointly set up a plan for a successful school year.
- Provide resources (for example, from Section B) and tell them a little bit about thalassemia and how it affects your child. **Depending on what form of thalassemia your child has and how severe it is, you might tell them:**

Should your child be present at this meeting?

There is no right or wrong answer to this question. Every child is different, and many children may feel uncomfortable taking an active role in such a meeting; however, **if your child is interested and wishes to be involved, it is a good idea to include him/her.**

This can be beneficial both for your child and for the school personnel at the meeting: Your child can gain valuable experience in advocating for him- or herself. The school personnel can hear information directly from the student's perspective that might have a significant impact.

- Thalassemia is a genetic disorder; it is not a condition which is contagious or which can be “caught” by other children or adults
- People with thalassemia have defective hemoglobin which decreases the amount of oxygen that is carried around the body. **As a result, your child needs frequent blood transfusions, usually every ___ weeks.** If your child does not get these transfusions, a very severe anemia will develop, along with other serious complications.
- As long as your child receives treatment, **s/he can fully participate in a traditional school experience; however, s/he may need some special considerations.** For example, often the biggest challenge for patients with thalassemia is dealing with feeling tired or fatigued during the day or two prior to a transfusion. On these days, they may have trouble concentrating, have head or back aches, or be irritable.
- Some students might need to take a break from class and get a drink of water or a small snack when they feel increasingly tired, or they may need acetaminophen or ibuprofen to combat headaches and back aches. You will need to discuss with the school nurse what kind of medicine is appropriate for your child’s aches.
- There may also be days near transfusions when the child might sometimes need to refrain from engaging in physical education activities. **(This is something that you should discuss with your doctor in advance of the meeting.** Many thalassemia patients are capable of engaging in physical education activities and playing sports to the full extent.) Or there may be days near transfusions when your child is more than normally tired after coming from gym class.



- Tell them that in addition to transfusions, your child takes a daily medication that is related to thalassemia; however, this is taken at home so it should not be an issue in school. (If your child is prescribed deferiprone and is required to take a dose during school hours, let the nurse know this. In addition, your child may be taking medicine for other thalassemia-related complications or for conditions that are unrelated to thalassemia; if s/he needs to take doses of these medicines during the school day, this information

should also be provided. You may want to make arrangements for your child to take the medicine in the nurse's office.)

- Explain more about your child's transfusions.
- Tell them that in general, your child needs a transfusion every ____ weeks (if your child is fairly regular), but that there may be times when that changes. **If your transfusion date is always (or usually) on the same day of the week, let them know which day it is.**
- Let them know how much time the entire transfusion process takes; **if your child will be gone for an entire day, or if s/he will need to leave school at a specific time, make it clear that this is the case.** (You may need to explain what is involved with your transfusion visits.)

- If your child is able to do homework or other school work while being transfused, let the teacher know this; if the amount that s/he can do while being transfused is limited, make the teacher aware of this as well. **Let the teacher know that you will be working with your child to come up with a strategy to complete missed homework and assignments on time.**



- Let the teacher know that you will try to inform him/her about transfusions as far in advance as possible. Come up with a time frame for notice of missed classes that works for both of you.
- If there is flexibility in scheduling transfusions, **ask the teacher to set up a system so that you know in advance of tests or other important dates** so that you can make an effort to schedule around them.
- Let the teacher know that it is possible that on occasion your child may need to miss school for thalassemia-related medical reasons that go beyond scheduled transfusions and cannot be anticipated. For example, it's possible that your child may develop a transfusion reaction, an infection or another complication that may require that he or she spend time in the hospital.

- **Work with the teacher to develop a system for dealing with missed classes.** Should the teacher email homework and missed class assignments to your child? Should

you try to make arrangements with a particular friend of your child's who will bring home materials handed out in your child's absence? What should be the policy for making up missed tests and examinations? What suggestions does s/he have for getting notes on information given out in class?

- Use the "Transfusion Schedule Help Sheet" provided in this packet. Go over it with the teacher and see if there are changes that should be made to it.
- Ask the teacher if there is anything else that you need to do to make sure your child's educational experience is as full as it should be.
- If your child has any other issues, whether thalassemia-related (such as diabetes or low bone mass, for example) or non-thalassemia-related (such as asthma) that may require treatment during school hours or require special considerations, make sure to discuss these as well.
- **Work with the teacher and the school nurse so that you are in agreement about how to answer questions about your child's absences.** Decide how open or private you wish to be about your child's experience with thalassemia; however, realize that even if you are very open about your child's medical needs, the school may have a policy that prevents the nurse and teacher from being as open.
- If your child uses Desferal® and has scars on his or her body from the needle insertion, he or she may not be comfortable undressing for gym in front of others or he or she may be sensitive if someone asks about the scars. In addition, if your child has a port-a-cath, he or she may feel similarly self-conscious about its visibility. The teacher should be aware that these situations may create social or behavioral issues if your child feels uncomfortable or defensive.
- Give the teacher and nurse the "For More Information" list from Section B in case they need more information, as well as the Parent/Family Resource list, both of which are found in Section B.
- If a letter from your child's doctor is needed, you might use the sample letter in Section B as a guide.



- **Make sure that there are no more questions that you need answered or that the teacher or nurse needs to ask.** If some issues cannot be resolved at this meeting, make sure that a process is in place to resolve them.

- **Thank them** for giving you the chance to meet with them and for working with you.

Note: When your child is attending high school or another school in which s/he changes classrooms and teachers, this meeting may not include your child's teachers. If, as the school year progresses, you see a problem developing, you may need to schedule separate meetings with individual teachers to make sure they understand the situation and to work with them to develop appropriate strategies. You may also want to adapt one of the sample letters in Section B to communicate with teachers who were not involved in your meeting with school personnel.

To summarize:

- Prepare for the meeting by knowing exactly what information you need to present.
- Remember that the school personnel may have no knowledge of thalassemia and you may need to make sure they understand how it affects your child.
- Develop a system for taking care of school work missed due to transfusions, how to obtain homework assignments, etc.
- If your child has non-thalassemia-related issues that can affect his/her school experience, be sure to include these in your conversation.
- Decide whether your child should be involved in this meeting.

What Things Should You Do with Your Child to Meet School Challenges?

- Make sure you are **both on the same page** in terms of what information s/he wants other children to have.
- Set **reasonable expectations**. Some children may not be able to complete homework while receiving transfusions, so set up a schedule with time set aside for making up these assignments.
- Identify friends of your child who might be able to **bring home materials** from class or who can provide information on homework assignments, etc.



Do You Need to Consider a Section 504 Plan?

If thalassemia is creating an especially difficult educational challenge for your child (for example, your child's teacher does not give appropriate time to make up exams missed due to transfusions), **you may want to see if a Section 504 Plan might be of benefit to your child.**

Section 504 plans apply to all public schools and in a much more limited way to private schools that receive federal funding. If your child is enrolled in a private school, you will need to explore what is the school's obligation or policy concerning 504 plans.

The U.S. Department of Education states that "to be protected under Section 504, a student must be determined to: (1) have a physical or mental impairment that substantially limits one or more major life activities; or (2) have a record of such an impairment; or (3) be regarded as having such an impairment."

Also, "to be appropriate, education programs for students with disabilities must be designed to meet their individual needs to the same extent that the needs of nondisabled students are met. An appropriate education may include regular or special education and related aids and services to accommodate the unique needs of individuals with disabilities."

Examples of modifications and accommodations your child is entitled to under Section 504 include:

- Unlimited access to the school nurse. (The school nurse is an important team member in the development of an Individualized Health Care Plan and Emergency Care Plan).

Sometimes it helps to talk to families who have been through the 504 process. Your school may have parents who have volunteered to do this; if not, contact the Cooley's Anemia Foundation (info@thalassemia.org; 212-279-8090) and we will try to find a family in the thalassemia community who can talk about their experiences.

What is meant by a "disability?"

Section 504 utilizes a very broad definition of disability; the definition includes the requirement that a person has an impairment that "substantially limits one or more major life activities." Among the major life activities indicated is "learning." If your child's experience with thalassemia impacts his or her ability to learn, it may meet the definition of disability under which Section 504 plans fall.

- Parental consent to administer physician-ordered medications during the school day.
- Rest breaks as needed.
- An **extra set of books** to keep at home. (This can be helpful if the student is absent so that he or she has access to the course work).
- **Time extensions** for testing.
- Alternative setting for testing.
- Shortened assignments (as needed) to the **critical concepts**. (“Critical concepts” would be the most important aspects of an assignment; they enable students to get a “big picture” idea of a subject so that they have a basic understanding of what is being discussed.)
- Association with the school social worker.
- **Absences excused** when parents notify the schools that the child is absent due to thalassemia and related complications.
- Parents and schools work together to set up a system to obtain missed assignments and homework.
- Information handouts about thalassemia for teachers and school personnel.
- Tutoring (if absences related to the disability affect academic performance).
- Modified grades and content if tutored.
- Modified gym class or the option for the child to rest, as needed.
- Selective seating in the classroom.
- Elevator pass (as needed).



If you believe that your child would benefit from a Section 504 Plan, here are the steps that you should take:

1. **Contact your school guidance counselor** and let him or her know that you wish to have your child evaluated to see if s/he qualifies under Section 504. Each school district is different, but the guidance counselor should be able to direct you to the appropriate contact person in your district.

2. **Find out what steps are required for your particular school district.** In most instances, a written request (or “referral”) for evaluation must be submitted. Your referral should include an explanation of why you believe a Section 504 plan is necessary for your child.

3. The individual in charge of Section 504 policy for your child’s school may then form **a committee to review the referral** and determine if an evaluation is warranted. That committee will include people who are knowledgeable about your child; your child’s school history; and your child’s individual needs.



4. The committee will determine if an evaluation is warranted. If the committee decides one is not warranted and that a Section 504 plan is not needed, you may request that the committee let you know of the district’s process for **appealing this decision.**

5. If the committee decides that an evaluation is warranted, they will determine what information and tests are needed to make a decision about your child. The committee will be evaluating the nature of the disability/challenge (in this case, your child’s thalassemia) and how it specifically impacts your child’s education. **You should make sure that your child’s doctor is willing to communicate with this committee;** let the committee know of the doctor’s willingness; and encourage them to communicate with the doctor in order to better understand what is involved in your child’s treatment.

6. After the evaluation has been completed, the committee will meet with you to discuss the results. These meetings often involve a “parent advocate,” who may offer suggestions or advice from the viewpoint of another parent. If you feel it would be beneficial, you may suggest that your child’s doctor or another member of their healthcare team be invited to this meeting.

7. At this or a future meeting, the committee will recommend a **plan for services** under Section 504. You will be invited to comment upon the plan and to suggest any changes that you believe are required.

8. Your child's progress will be reviewed on at least an annual basis; you will have an annual review meeting each year to determine whether services are still warranted or if any changes are needed to the existing plan.



Most individuals who are legitimately eligible for Section 504 should be determined to be eligible through the referral and evaluation process; however, if your child's eligibility is denied, you may appeal this decision. Similarly, if you do not agree with the plan devised by the committee reviewing your child's case and if the committee is unwilling to alter the plan in a way that you think is appropriate, **you have the right to appeal this decision** as well. Your school district is required to inform you of the appropriate appeals processes in these cases.

All of the above may seem a little scary. Please know that **in most cases, schools are sincerely interested in making sure that your child is able to receive an education that is appropriate** and that this education is delivered in a way that is most beneficial to your child.

For more information about Section 504 plans, go to

<http://www2.ed.gov/about/offices/list/ocr/504faq.html>

<http://www.understandingspecialeducation.com/section-504.html>

To summarize:

- Section 504 plans can provide accommodations for students with a disability to ensure a more appropriate educational experience for them.
- There are a wide range of accommodations available under a Section 504 plan.
- There are specific steps that will need to be taken to determine if your child qualifies for a Section 504 plan.

Summary of Section A

Remember, **every child's experience is different**; you may have little or no need of the information that you have just read. But if you do, you now have knowledge that can help you smooth any bumps that may appear as your child with thalassemia goes through the educational process.

Also, remember that most **school personnel want their students to have a positive experience** and most school systems are anxious for the same thing. It's ultimately in the best interest of all concerned – students, parents, teachers and administrators – to create the best possible educational experience.

Good communication is key to achieving that goal. By educating school personnel about thalassemia; explaining what is involved in your child's treatment and what specific impact that can have on his/her educational routine; and determining the best way to overcome any obstacles or challenges to your child's education that thalassemia may present, you are ensuring a more smoothly-running, effective and efficient experience for both your child and the teacher.

One final point: The Cooley's Anemia Foundation (info@thalassemia.org; 212-279-8090) is here to **help answer any questions you may have about the information contained in this Toolkit and to offer help and guidance in dealing with issues that may arise**. The Foundation can also help you **connect with other families** who can share their own experiences in speaking with school personnel about thalassemia.

The school years are among the most exciting of a person's life. **May your child enjoy this time and find it a nurturing and rewarding experience.**



Section B



What is Thalassemia?

- Thalassemia is the name of a group of genetic blood disorders the impact of which ranges from mild to severe. The more severe forms have the potential to have a profound impact on a patient's life. About one thousand people in the United States are thought to have one of the more severe forms of thalassemia.
- In the more severe forms of thalassemia, the hemoglobin in red blood cells has too little protein to adequately transport oxygen throughout the body. In the most severe forms, such as beta thalassemia major, patients require regular blood transfusions to stay alive; these transfusions may be required as often as every two weeks.
- Some patients with somewhat less severe forms of thalassemia, such as beta thalassemia intermedia, e beta thalassemia or hemoglobin H disease, may not need to receive blood transfusions on a regular basis. These patients that are not transfused regularly can experience symptoms of anemia, including exhaustion, irritability, and weakness. Some of these patients may also have problems with growth and bone deformities.
- Patients that receive regular blood transfusions are at risk for a condition called "iron overload." Frequent blood transfusions add extra iron to the body; while iron in blood is a necessary component, too much iron can damage or destroy major organs such as the heart and liver. Patients with severe iron overload are also at risk for impaired growth, diabetes, low bone mass and other complications.
- Although patients with less severe forms such as beta thalassemia intermedia may not receive frequent transfusions, they may still develop iron overload due to their bodies' overproduction of red blood cells and other issues.
- In order to rid the body of excess iron, a patient needs to take a drug that acts as an "iron chelator." Such drugs work to take iron out of the body, and in some cases out of the organs. Currently there are three approved iron chelators on the market. Patients can be prescribed one chelator or a combination of two.
- Deferoxamine (often known by its brand name, Desferal®) is an iron chelator that has been around for over 40 years. It effectively removes iron from the body and for almost four decades was the only iron chelator approved in the United States. Desferal is delivered

subcutaneously by a small infusion pump that is worn for 8 to 10 hours daily (usually overnight). The major barrier to using Desferal is that it requires a daily needle stick in order to attach the infusion pump to the body. Social issues related to adherence with this medication are very common in adolescent and adult patients. Side effects can include infusion site reactions and possible hearing and vision loss.

- Deferasirox (often known by its brand name, Exjade®) is another iron chelator. The Exjade tablet is dissolved in a liquid (or in some cases mixed with food) and drunk daily. This medication is commonly used in children due to its relative ease of administration when compared with Desferal. Due to its oral route, side effects can include gastrointestinal issues.

- Deferiprone (often known by its brand name, Ferriprox®) is the newest approved iron chelator in the United States. Ferriprox has been approved internationally for close to 20 years. It is available in pill (tablet) form. Multiple Ferriprox tablets are taken three times daily in order to provide adequate iron chelation. Due to its oral route, side effects can include gastrointestinal issues. Patients on Ferriprox will also need to have their blood counts monitored closely for potential risk of effect to the patients' white blood cells.

- Patients that take their iron chelators regularly are able to remove enough iron to live long and active lives. Unfortunately, compliance to these iron chelators is often the biggest struggle for patients, as some of the medications are unpleasant to use and can cause side effects.



For More Information

The following resources can provide more information about thalassemia:

The Cooley's Anemia Foundation

www.thalassemia.org

Centers for Disease Control and Prevention

www.cdc.gov/ncbddd/thalassemia/index.html

Northern California Comprehensive Thalassemia Center

www.thalassemia.com

National Heart, Lung and Blood Institute: Thalassemias

www.nhlbi.nih.gov/health/health-topics/topics/thalassemia

This resource can provide further information on Section 504:

U.S. Department of Education

www2.ed.gov/about/offices/list/ocr/504faq.html

Sample Letter from Doctor

You may find it necessary to provide your child's school with a letter from your child's doctor. Below is a sample letter that you may want to give your child's doctor, which s/he may use as a guide and modify as is appropriate.

Dear :

I am the hematologist for *(your child's name)* and have been treating *(your child's name)* for beta thalassemia major for *(number)* years.

Thalassemia is a lifelong and serious blood disorder which requires regular treatment to keep the patient healthy and prevent potentially dangerous complications. This treatment includes regular blood transfusions, which in *(your child's name)*'s case are generally required every *(number)* weeks; however, the frequency of these transfusions can vary somewhat in the short term or may alter in a more permanent manner over the long term.

These transfusions manage the anemia that is caused by thalassemia and are essential to enabling *(your child's name)* to attend school and participate in his/her educational experience to the fullest. Please be aware that *(your child's name)* may be somewhat fatigued or tire more easily as the time for transfusions draws near; however, in most instances, this will require few adjustments to his/her school routine.

(If your child has other complications related to thalassemia which your hematologist feels may impact school performance, these can be noted here.)

A more significant issue is the amount of school time that *(your child's name)* will miss as a result of these regular transfusions. Please be aware that, while the actual transfusion process takes only a couple of hours, getting a transfusion typically will require *(your child's name)* to miss an entire day of school, due to the need to run tests, secure appropriately matched red blood cells, and monitor for any possible transfusion-related side effects.



Please contact me at *(phone number)* if you need to speak with me about thalassemia and how its treatment may require modification in *(your child's name)*'s school routine.

Thank you.

Sincerely,

Sample Letter for Classroom Teacher

In some instances, you may find it helpful to communicate with a classroom teacher who was not included in your initial meeting with school personnel. You may wish to adapt the following letter for that purpose.

Dear _____:

I am writing to let you know about some issues that may come up related to a medical condition that affects my child _____ (*child's name*).

My child was born with beta thalassemia major, a genetic blood disorder. Thalassemia is not contagious, but it is serious and must be properly treated. This treatment involves regular blood transfusions, which for my child generally occur every ____ weeks. While the actual transfusion process takes only a couple of hours, getting a transfusion typically will require (*child's name*) to miss an entire day of school, due to the need to run tests, secure appropriately matched red blood cells, and monitor for any possible transfusion-related side effects.

I have already met with school personnel to make them aware of this situation but wanted to reach out to you to explain why my child is frequently absent. In addition, I wanted to make you aware that on some days, especially those leading up to a transfusion, _____ (*child's name*) may feel fatigued and have low energy.

I am working with _____ (*child's name*) to make sure he can keep up with his school assignments. I would like to talk with you if there are any special arrangements we need to make to ensure his success in your class. Please contact me at _____ if you would like to arrange a time to talk.

Thank you.

Sincerely,

Sample Letter for Physical Education Teacher

In some instances, you may find it helpful to communicate with a physical education teacher who was not included in your initial meeting with school personnel. You may wish to adapt the following letter for that purpose.

Dear _____:

I am writing to let you know about some issues that may come up related to a medical condition that affects my child _____ (*child's name*).

My child was born with beta thalassemia major, a genetic blood disorder. Thalassemia is not contagious, but it is serious and must be properly treated. This treatment involves regular blood transfusions, which for my child generally occur every ____ weeks. While the actual transfusion process takes only a couple of hours, getting a transfusion typically will require (*child's name*) to miss an entire day of school, due to the need to run tests, secure appropriately matched red blood cells, and monitor for any possible transfusion-related side effects.

I have already met with school personnel to make them aware of this situation but wanted to reach out to you to explain why my child is frequently absent. In addition, I wanted to make you aware that on some days, especially those leading up to a transfusion, _____ (*child's name*) may feel fatigued and have low energy. This may affect his ability to participate fully in his physical education sessions.

I would like to talk with you if there are any special arrangements we need to make to ensure his success in your class. Please contact me at _____ if you would like to arrange a time to talk.

Thank you.

Sincerely,

Transfusion Help Sheet

If you need help with communicating your child’s transfusion schedule with school personnel, this Transfusion Help Sheet can help clarify when your child will be out of school for transfusions and help ensure that your child is able to complete missed assignments in a timely fashion. Your Sheet might be modeled on the sample below. For each month of the school year, provide a calendar. Circle or otherwise mark the dates when your child will be away from school for transfusions.

Beneath the calendar, there is room to provide information on transfusion dates, school work to be missed, name of the “home work buddy” who will bring home materials for your child and the homework buddy’s phone number or other contact information.

September						
S	M	T	W	TH	F	S
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30					

Transfusion Dates	
School Work to be Missed	
Homework Buddy	
Homework Buddy’s Contact Information	

Patient and Family Resource List

Important Telephone Numbers	
School	
Teacher	
School Nurse	
Treatment Center	
Hematologist	
Pediatrician	
Cooley's Anemia Foundation	(212) 279-8090; (800) 522-7222
Additional Resources	

Reminder:

The information above is helpful for you and your family. Your child's school also needs important contact information for you. If your school does not already have the necessary contact information, make sure you give it to them.

About This Publication

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For more information about thalassemia:

Cooley's Anemia Foundation

www.thalassemia.org

800-522-7222

info@thalassemia.org

Centers for Disease Control and Prevention

www.cdc.gov/ncbddd/thalassemia

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