

*Supporting Students
with*
***Bone Marrow
Failure Diseases***

*A Guide for
Parents & School
Personnel*

 **Aplastic Anemia & MDS**
INTERNATIONAL FOUNDATION



This publication is funded through a grant
from the Drew Carmichael Foundation

We are here to help!



The Aplastic Anemia & MDS International Foundation is an independent nonprofit organization. Our mission is to support patients, families, and caregivers coping with:

- Aplastic anemia
- Myelodysplastic syndromes (MDS)
- Paroxysmal nocturnal hemoglobinuria (PNH)
- Related bone marrow failure diseases

This publication provides basic information about bone marrow failure diseases and their symptoms, along with tips about how to best support the student with a bone marrow failure disease in the school environment. Although the Aplastic Anemia & MDS International Foundation strives to provide the most accurate and up-to-date information, and this information has been thoroughly reviewed by experts, it does not warrant or guarantee this information. Patients should always seek medical advice from a qualified physician and discuss these materials, individual questions, and concerns with their physician. For more information, call us at (800) 747-2820, or visit us online at www.AAMDS.org.



Table of Contents

Introduction	4
About Bone Marrow Failure Diseases	5
What is a bone marrow failure disease?	5
What is blood made of?	5
What are the three basic types of blood cells?	5
How are blood cells formed?	6
What are the symptoms of low blood counts?	6
How are bone marrow failure diseases diagnosed?	6
What are common symptoms of bone marrow failure diseases?	7
What is aplastic anemia?	7
What is paroxysmal nocturnal hemoglobinuria (PNH)?	9
What are myelodysplastic syndromes (MDS)?	10
 Understanding the Physical and Emotional Impact on a Student	 11
What are the physical problems the student may face?	11
What are the emotional issues the student may face?	12
Elementary age	12
Teens	12
How school attendance may be affected?	12
 Parents and Schools Working Together: Tips for Successful School Re-Entry	 13
Tips for parents and families	13
Tips for school nurses	13
Tips for school administrators	15
Tips for classroom teachers	15
What are other ways teachers can help?	16
How can the school help when a student is terminally ill?	17
Conclusion	18
 Recommended Resources	 19
Books for children	19
Books for teens	20
Online resources	21
More ways to get help	23

Introduction



School personnel, including school nurses, teachers, and school administrators, can have a significant impact on the well-being of students with chronic and serious illnesses, including those with bone marrow failure diseases. By working together with parents and healthcare providers, they can create a positive, safe, and supportive atmosphere for the student. This type of coordinated care facilitates understanding and enhances awareness and sensitivity by everyone in the school setting, including other students. By reinforcing the need for compassion, patience, and understanding for chronic and serious illnesses, school personnel will create a positive learning environment.

The first step for creating a safe and supportive school environment is the creation of a coordinated care plan. This typically involves bringing everyone involved with the student into a meeting to discuss the student's medical, emotional, and learning needs. At this meeting, it is also critical to clarify the roles and responsibilities of each person. Appropriate expectations and possible limitations the student may face should also be discussed. The benefits of developing this type of coordinated care plan for the student include:

- Better school attendance
- Fewer symptoms, including better alertness
- Fewer restrictions on participation in physical activities
- Fewer emergencies

This guide provides you with the information you need to know to create a positive school environment for the student with a bone marrow failure disease. The first section includes basic disease and treatment information about the three main types of acquired bone marrow failures diseases: aplastic anemia, paroxysmal nocturnal hemoglobinuria (**PNH**), and myelodysplastic syndromes (**MDS**). This is followed by an overview of the physical, emotional, and learning challenges a student may face. The third section provides tips and guidance for supporting positive re-entry into school. A resource section is provided at the end, with recommended reading and trustworthy websites where you can find additional information about bone marrow failure diseases, as well as tips and advice for creating a positive school environment.

About Bone Marrow Failure Diseases



What is a bone marrow failure disease?

In simple terms, a bone marrow failure disease is when something stops a person's bone marrow from creating the right amount of healthy blood cells. There can be many reasons for this. Sometimes one of the blood forming stem cells in the bone marrow becomes defective and creates defective blood cells. Sometimes a person's body attacks and kills blood forming stem cells so they can't make blood cells. For the most part, doctors don't know what causes bone marrow failure diseases.

In order to understand bone marrow failure diseases better, it's important to first know certain facts about blood.

What is blood made of?

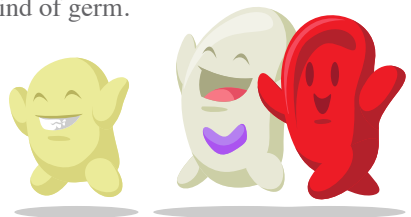
Blood is made of blood cells floating in plasma. The plasma is mostly made of water with chemicals in it. These chemicals include proteins, hormones, minerals, and vitamins.

What are the three basic types of blood cells?

1. Red blood cells are also called erythrocytes (i-RITH-ruh-sites). They make up almost half of blood. Red blood cells are filled with hemoglobin (HEE-muh-gloe-bun). That's a protein that picks up oxygen in the lungs and brings it to cells all around the body.

2. White blood cells are also called leukocytes (LEW-kuh-sites). They fight disease and infection by attacking and killing germs that get into the body. There are several kinds of white blood cells, each of which fights a different kind of germ.

3. Platelets are also called thrombocytes (THROM-buh-sites). They are small pieces of cells that help blood clot and stop bleeding.



How are blood cells formed?

The process of making blood cells is called hematopoiesis (hi-mat-uh-poy-EE-suss). Blood cells are made in the bone marrow. That's a spongy tissue located inside some bones. It contains young parent cells called stem cells.

These blood-forming stem cells can grow into all three types of blood cells. They make copies of themselves (clones), and they also produce mature blood cells.

When blood cells are fully mature and functional, they leave the bone marrow and enter the blood. Healthy people have enough stem cells to keep making all the blood cells they need every day.

What are the symptoms of low blood counts?

Most of the symptoms experienced by people with bone marrow failure diseases are caused by low blood counts. Specific symptoms depend on the type of blood cell affected.

A person with a low red blood cell count may:

- Feel a little tired or very tired
- Feel less alert or have trouble concentrating
- Have a loss of appetite or lose weight
- Have paler-than-normal skin
- Have trouble breathing
- Have rapid heartbeat
- Have reduced ability to exercise or climb stairs

A person with a low white blood cell count may:

- Have repeated fevers and infections
- Get bladder infections that may make it painful to pass urine, or make you urinate more often
- Get lung infections that cause coughing and difficulty breathing
- Get mouth sores
- Get sinus infections and a stuffy nose
- Get skin infections

A person with a low platelet count may:

- Bruise or bleed more easily – even from minor scrapes and bumps
- Get heavy menstrual periods
- Get tiny, flat red spots under your skin, which are caused by bleeding; these spots are called petechiae (puh-TEE-kee-ie)
- Have bleeding gums, especially after dental work or from brushing your teeth
- Get nose bleeds

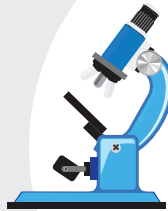
How are bone marrow failure diseases diagnosed?

Diagnosis is made through blood tests and a bone marrow biopsy. Once diagnosed, treatment and evaluation is given under the care of a hematologist.

What are common symptoms of bone marrow failure diseases?

School personnel or fellow students may be among the first to notice a student's symptoms. These can include complaining of fatigue, experiencing nosebleeds, or having excessive bruising on various body parts. The most common symptoms are:

- Bleeding from a cut or other wound that does not stop
- Small red or purplish spots like a skin rash (these are called “petechiae” and result from very small hemorrhages)
- Shortness of breath
- Chronic fatigue
- Decreased alertness
- Decreased attention span
- Lethargy
- Pale skin
- Ringing or buzzing in the ears
- Frequent colds, sore throats, or other infections



It is important to note that these symptoms can also signal many other illnesses. Only a doctor can make diagnosis of a bone marrow failure disease. A diagnosis can only be made after examining the student's blood and bone marrow.



What is aplastic anemia?

Aplastic anemia is a non-contagious, rare disease that causes the bone marrow to stop making all the blood cells the body needs. It is newly diagnosed in 600 to 900 people every year in the United States. It can strike people of any age, race, and gender, but it is more common among children, teenagers, and young adults.

There are two types of aplastic anemia: acquired and hereditary. Acquired aplastic anemia is much more common than hereditary aplastic anemia. In patients with acquired aplastic anemia, researchers believe that a patient's own immune system attacks their bone marrow stem cells. Hereditary aplastic anemia is usually diagnosed in childhood and is less common than acquired aplastic anemia. People who develop hereditary aplastic anemia usually have other genetic or developmental abnormalities.

In about 75 out of 100 of cases of acquired aplastic anemia, there is no known cause. For the remainder of patients, it can be linked to one of several causes, including:

- Medications, such as anti-inflammatory drugs, anti-seizure medications, and treatments for lupus and rheumatoid arthritis
- Exposure to certain toxins such as pesticides, arsenic, or benzene
- Radiation and chemotherapy used to treat cancer



The symptoms of aplastic anemia are caused by low blood counts. They can include fatigue, increased bleeding, bruising, and susceptibility to infections, among others. (See “What are the symptoms of low blood counts” on page 6 for more information)

There are a number of treatments for aplastic anemia:

- Blood transfusions may be given when blood counts are low. This temporarily replaces the cells the bone marrow has stopped producing.
- Immunosuppressive drug therapy can suppress the immune system’s attack against the bone marrow, permitting it to recover and begin producing cells again. About 70 out of 100 patients can be successfully treated with this therapy, but it can take several months to respond. The most common immunosuppressive drugs used to treat aplastic anemia are ATG (antithymocyte globulin) and cyclosporine. For patients with severe aplastic anemia (SAA), who have had an insufficient response to immunosuppressive therapy and who are not candidates for stem cell transplant, Promacta® (Eltrombopag) is approved for use.
- Growth factors are naturally occurring chemicals (proteins) in the body that cause bone marrow to make more blood cells. Man-made growth factors can be used to increase blood cell production and may be prescribed at any point during treatment.
- Bone marrow/stem cell transplant is considered the only cure for aplastic anemia. Transplants are most successful in younger patients with a related donor whose tissue type matches their own.

Aplastic anemia is a serious illness that requires immediate medical attention. Once considered a fatal illness, with standard treatments such as bone marrow transplants and immunosuppressive drug therapy, 70 to 90 out of 100 patients can now be treated successfully.

For more information on aplastic anemia, contact the Aplastic Anemia & MDS International Foundation, and order a free booklet titled **Your Guide to Understanding Aplastic Anemia**. Also visit www.AAMDS.org.



What is paroxysmal nocturnal hemoglobinuria (PNH)?

PNH is an ultra-rare and serious blood disease that causes red blood cells to break apart. Doctors call this breaking apart hemolysis (hi-MOL-uh-suss). It happens because blood cells are missing a protein that protects them from the body's immune system.

Fewer than 500 people are diagnosed with PNH in the United States each year. PNH can also occur with aplastic anemia or MDS. It is rare to see PNH in very young children, but it has been seen in teenagers.

When red blood cells break apart, the hemoglobin (HEE-muh-glo-bun) inside the blood cells is released. Hemoglobin is the red part of red blood cells. Its job is to carry oxygen around your body. So patients with PNH will often have anemia and will experience fatigue and decreased alertness. The release of hemoglobin causes other symptoms of PNH. These include back pain, abdominal discomfort, trouble swallowing, and blood clots.

The name “paroxysmal nocturnal hemoglobinuria” comes from:

- Paroxysmal means sudden and irregular
- Nocturnal means at night
- Hemoglobinuria means hemoglobin in urine.

Hemoglobin is the red part of red blood cells; it makes urine look dark

So the name “paroxysmal nocturnal hemoglobinuria” means sudden, irregular episodes of passing dark colored urine, especially at night or in the early morning. It is important to note, however, that many people with PNH do not have this symptom.

Treatment of PNH depends on the severity of the disease. It may include blood transfusions, growth factors, blood thinners, immunosuppressive drug therapy, or bone marrow/stem cell transplantation. A drug named eculizumab (Soliris ®) is also approved by the FDA to treat PNH.

For more information on PNH, contact the Aplastic Anemia & MDS International Foundation and order a free booklet titled **Your Guide to Understanding PNH**. Also visit www.AAMDS.org.



What are myelodysplastic syndromes (MDS)?

MDS is a group of disorders in which a person's bone marrow does not work well, and the bone marrow cells fail to make enough healthy blood cells. People with MDS can lack the right amount of red blood cells, white blood cells, and platelets. Children rarely get this disease.

The disease happens because the bone marrow cells do not develop into mature blood cells. Instead, these blood cells stay within the bone marrow in an immature state. The symptoms and the course of MDS may vary greatly from person to person. These differences depend on which blood cells are affected.

All people with MDS have two things in common:

- They have a low blood cell count for at least one blood cell type; this is called **cytopenia** (sie-toe-PEE-nee-uh)
- Their bone marrow and blood contain blood cells with an abnormal shape, size, or look.

Between 10,000 and 15,000 people are newly diagnosed with MDS each year. MDS occurs mostly in people over the age of 60.

MDS is classified into separate subtypes according to how the disease manifests itself in a patient's blood and bone marrow.

Treatment for MDS depends on the type of MDS, the severity of the disease, and on any specific genetic abnormalities found in the blood cells. Treatments include blood transfusions, growth factors, immunosuppressive drug therapy, and bone marrow/stem cell transplantation. In addition, there are three drugs currently approved by the FDA to treat MDS. These drugs include lenalidimide (Revlimid®), azacitidine (Vidaza®), and decitabine (Dacogen®). A bone marrow/stem cell transplant is the only cure for MDS.

For more information on MDS, contact the Aplastic Anemia & MDS International Foundation and order a free booklet titled **Your Guide to Understanding MDS**. Also visit www.AAMDS.org.

Understanding the Physical and Emotional Impact on a Student



What are the physical problems the student may face?

There are many physical problems that can affect a student with a bone marrow failure disease. School personnel, especially school nurses, should always be kept informed of the student's condition.

Physical problems can result from the disease itself or from the treatments:

- A low red blood cell count can cause the student to feel very tired and lack energy for normal activities. They may have limited ability to participate in physical activities because of fatigue or muscle weakness. Consider reducing requirements for participation in physical activities such as gym and sports and providing a place for the student to rest during the day.
- A low white blood cell count puts the student at risk for infection and certain precautions must be taken. If the counts are very low, the student may need to be kept home to avoid colds, flu, and other infections. In some cases, a special diet called a neutropenic diet may be required. This diet reduces exposure to food-borne illnesses and bacteria. It involves avoiding raw foods, including unwashed fruits and vegetables, salad bars, sushi, aged cheeses, and certain other foods.
- A low platelet count means the student may bruise or bleed easily. At school, reducing physical activity can help protect the student. Avoid contact sports or activities that may lead to getting banged or cut. Among younger students, playground activities may need to be restricted to avoid injuries.

Students may also experience changes in their physical appearance as a result of their disease and/or treatment. These might include weight gain or weight loss, puffy face, hair loss or excessive hair growth, pale skin, or large bruises.

These physical changes can also have an emotional impact on the student. School personnel should be alert to teasing or bullying that may result from the student looking different.

What are the emotional issues the student may face?



Learning to live with a chronic illness can be extremely difficult, even for the most well-adjusted child and his/her family. The lives of family members are likely to change because dealing with a bone marrow failure disease requires schedules to be adjusted for frequent doctor visits and planned or unexpected hospital stays. Parents must be vigilant about cleanliness in order to protect their child. Diets may have to change.

Any underlying mental health issues may become more apparent or worsen during the stress of dealing with these diseases. Parents and school personnel should watch for behavioral changes in the student, including increased anxiety, depression, aggression, or social isolation. Different behavioral reactions may occur with different age groups.

Elementary age

Early elementary-aged children are beginning to understand that they are part of a larger environment, but they still use their imagination for answers to overwhelming questions. They may believe their illness is “their fault.” They need to have a clear and simple understanding of their illness and what to expect. Older elementary-aged children may have a better understanding of their condition, but will be more aware that they are different from their peers. They may worry about being left out when they miss school or if their activities are restricted. Young children with chronic illnesses may also be subject to teasing or bullying.

Teens

Adolescents are developing their own identities, gaining independence, and taking on greater responsibilities. They may be much more involved in decisions regarding their treatments. However, compliance can be an issue with some teens. Some may neglect to take their medications consistently, thus endangering their health. Teens may also have body image issues related to the symptoms of their disease or the side effects of the medication. Things like hair loss, excessive body hair growth, weight gain, and the need to wear a mask to prevent infections may make a teen even more self-conscious. Counseling with a social worker or psychologist may be important for some teens.

How school attendance may be affected



The symptoms and treatment of bone marrow failure diseases can keep a student out of school for a long time. Frequent absences for blood transfusions and medical tests are common. In addition, the student may have frequent sick days. Low red blood cell counts can make it hard for a student to learn and concentrate. Low white blood cell counts can result in frequent infections.

Parents and Schools Working Together: Tips for Successful School Re-Entry

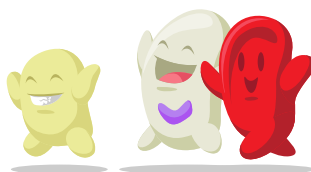


There are many things you can do to support a successful and positive re-entry into school for a student with a bone marrow failure disease. Families and school personnel, including classroom teachers, nurses, aides, and others who are in contact with the student each play an important role. This section provides tips for supporting a smooth transition.

Tips for parents and families

- Arrange a meeting with school administrators, teachers, nurses, and guidance counselors to discuss your student's diagnosis and special needs. Provide medical information about your child, including treatment schedules and doctors appointments. Be sure the school has written authorizations to administer medications and emergency treatment plans approved by your child's doctor.
- Authorize the appropriate exchange of information between the school and your child's doctor.
- Set up regular communications with the school to inform them of any changes in your child's condition or special needs.
- Familiarize yourself with federal laws (Section 504 of the Rehabilitation Act, Americans with Disabilities Act, and Individuals with Disabilities Educational Act) that provide protections for students with disabilities. Public schools are required to provide a written plan, called an Individualized Education Plan (IEP), on how to provide education to a student with a disability. Be sure to schedule regular review meetings with school personnel regarding the educational plan for your child.
- Every public school has a coordinator for special educational plans. And some hospitals have educational consultants who can help you coordinate your child's care at school.
- Help your child develop age-appropriate skills for taking care of himself.

- With the school's and your child's permission, talk to your child's friends and classmates about the diagnosis. Give them age-appropriate information. The school nurse and counselor may be able to help you talk to classmates. Older students may prefer to have these discussions with their peers without your participation.
- Ask your child about any concerns regarding returning to school and ways that you can help. Reassure your child that these concerns are normal and that he or she has your support and the support of everyone at the school.
- Consider acquiring a medical ID bracelet for your child to wear or providing identification and key medical information on a card that stays in the student's backpack. This safeguard could be important if your child needs medical attention when no knowledgeable staff is available.
- If you rely on school buses for transportation, be sure that your child's regular bus driver has basic emergency contact information for your student.
- Consider contacting your local 911 communications facility and asking them to make a note about your child's rare disease under your address and telephone number. In the event of an emergency, this information could help medical response teams.



Tips for school nurse

- Become informed about bone marrow failure diseases to help facilitate discussions between school personnel and families. Order and read **Your Guide to Understanding Aplastic Anemia, MDS, or PNH**.
- Visit the Aplastic Anemia & MDS International Foundation's website at www.AAMDS.org and the Online Learning Center at www.AAMDS.org/learn. There you can read the most up-to-date information on bone marrow failure diseases and view videos of experts talking about these diseases and their treatment.
- Make sure you have up-to-date information on the student's medical status, blood counts, and treatment.
- Know what medications the student is taking, when the medication is to be given, and the common side effects of each medication.
- Know what symptoms constitute a medical emergency and develop or review a plan with the student's doctor for handling such emergencies.
- Discuss with the parents any possible problems with infectious diseases that may come from other students, including chicken pox, flu, and other viruses.

Tips for school administrators

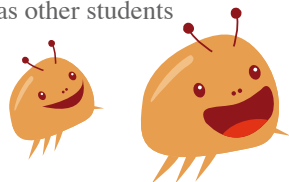
- Be aware of social, emotional, psychological, and health-related needs of the student who is dealing with bone marrow failure disease. Chronic illness does not need to stand in the way of education.
- Be aware that a student with a bone marrow failure disease often looks healthy, despite their illness.
- Be aware of scheduled treatments and any resulting absences from school.
- Share information about any behavioral changes you see in the student with the family and other school personnel. It is quite common for these students to express anxiety, depression, or—in younger students—regression in your classroom. Changes in memory, attention, and perception should also be shared with all parties concerned with the care of the student.
- Expect questions from other students and be prepared to provide appropriate information. Be aware of state and federal regulations which protect the student's privacy. You will find a suggested reading list to facilitate classroom discussion at the end of this publication.
- Help the student continue studies when away from the school by providing work that can be done outside the classroom.
- Maintain regular communication with the student and the family. Working collaboratively with the family, home tutor, or hospital school program will make the transition back to school much smoother for the student.



Anyone tasked with helping a student with a bone marrow failure disease, or other life threatening illness, may experience unexpected thoughts and feelings. These may include worries about the possible death of the student and its impact on other students. If this happens, it may be helpful to speak with a physician, social worker, or nurse about your thoughts and feelings.

Tips for classroom teachers

- Be sure that school staff who will be responsible for the student's care at school and school-related activities fully understand the student's health and learning needs and are properly trained to provide appropriate support.
- Conduct periodic review meetings with all parties to be sure the school has current and accurate information about the student's condition and needs and to keep the lines of communication open with parents and the student's health care providers.
- Encourage teachers and other school personnel to create an environment that views a student with a bone marrow failure disease the same as other students except for the need to respond to health issues.



What are other ways teachers can help?

IMPORTANT NOTE: The suggestions below should only be implemented after discussing them thoroughly with the student's parents and ensuring that they are in alignment with school policy.

To help support the young student who is returning to school, teachers can initiate discussion in the classroom about health-related topics like these:

- There is a need for everyone to see his or her doctor regularly.
- Immunizations, proper diet, adequate exercise, and rest contribute to good overall health.
- Physicians and nurses are people who help you stay well and take care of you when you are sick.
- Hospitals are places where people can go when they need special care.
- Most people will have some kind of illness in their life.
- No one is at fault when serious illness strikes and being sick does not mean you did something bad or that you're being punished.



Teachers might also have classmates imagine they are ill and ask themselves the following questions:

- How would I like people to treat me?
- How would I feel if I were treated differently because of my illness?
- How would I want my friends to help me when I am sick?

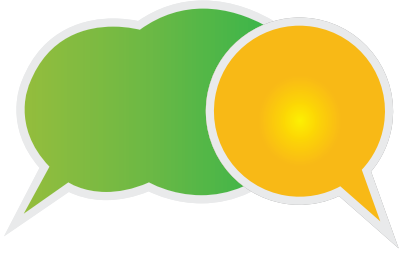


The student who returns to school can also explain their illness to their peers through the use of books, dramatic plays, or simple explanations with help from their parents or the school nurse.

Prolonged absences may make the student feel lonely and out of touch with their peers. Here are ways the teacher and the student's classmates can help:

- Keep in touch with the student and his/her family through cards, letters, and drawings.
- A video recording of the student's classmates is one of the best ways to help keep the student involved with the school. The video may include personal messages and group songs from both classmates and faculty.
- Have classmates call the student with homework assignments and information about school events.
- Let the student know their desk, cubbyhole, or locker is being saved for their return.
- Plan a special welcome for the student when he/she returns to school.





It may also help ensure a successful re-entry into school if the parents send a video message from their child back to the school. Classmates may be less surprised at any physical changes the student has undergone if they have the opportunity to see their friend in a video. A video from the student can also give the teacher an opportunity to initiate a classroom discussion about the student and his illness.



How can the school help when a student is terminally ill?



While the emphasis of this document is on life and living, some patients do die as a result of their bone marrow failure disease. Unfortunately, this topic is rarely discussed. In the case of terminal illness, it is important for both the school and the teacher to be notified. Even in the final weeks of life, school can remain a rewarding experience for the student. As death approaches, classmates may want to say goodbye through cards and letters.

After a student dies, classmates may express their grief in a variety of ways. Feelings of loss should be acknowledged, but no attempt should be made to force classmates to talk about the death or to deal with grief before they are ready. Organizing a class project, such as planting a tree or collecting money to donate to charity, may help with the healing process. As is true for adults, young people will deal with grief at their own pace and in their own way.

Conclusion

We trust, now that you have read this guide, you have the basic tools and information necessary to effectively support a student with a bone marrow failure disease in the school. The information helps your understanding of what you can do to create a safe and supportive learning environment and where you can go to get additional information and guidance. The next step is to put a clear plan in place and follow that plan.

If you haven't done so yet, set up a meeting including the student's parents, school nurse, teachers, and school administrators.

During this meeting, you should:

- Make sure each person has a copy of this guide and has read it before the meeting
- Review and discuss what you learned from this guide
- Identify any gaps in knowledge you may have
- Discuss and write down a plan for supporting the student on daily basis, if a crisis should occur, and during school re-entry, if appropriate

Know that you are not alone – the Aplastic Anemia & MDS International Foundation is always there to help. If you would like additional guidance, have questions about bone marrow failure diseases and their treatment, or would like to talk with another parent who has gone through this process of supporting a student in the school, we can help. We wish you all the best, and we know that if you follow the tips in this guide and your action plan, you will indeed create a positive, safe and supportive school environment for the student living with a bone marrow failure disease.



Recommended Resources



Books for children

Henry and the White Wolf, by Tim & Tyler Karu, 32pp, Workman Publishing Company, 2000. Henry, a very sick little hedgehog, receives treatment from the White Wolf that makes him feel even worse but eventually cures him, and through the ordeal, he holds a stone to help him stay strong and brave.

Stevie's New Blood, by Kathryn Ulberg-Lilleby, Oncology Nursing Society, 2000. Stevie, who is undergoing treatment for leukemia, receives a bone marrow transplant.

The Fall of Freddie the Leaf, by Leo Buscaglia, 30pp, Slack Inc, 1982. Story of Freddie the leaf as he lives through all of the seasons, ending with the realization that death is a part of life. For ages 4-8.

When Molly Was in the Hospital: A Book for Brothers and Sisters of Hospitalized Children, by Debbie Duncan, 32pp, Rayve Productions, 1994. For ages 3-12. Anna's little sister is very ill, and she learns to come to terms with it.

Why, Charlie Brown, Why?: A Story About What Happens When a Friend Is Very Ill, by Charles Schulz, 64pp, Ballantine Books, 2002. When a friend of the Peanuts gang is diagnosed with leukemia, they all have different reactions. The book follows her treatment and recovery.

Young People and Chronic Illness, by Kelly Huegel, 176pp, Free Spirit Pub, 1998. For ages 9-12. This book is divided into stories of children living with chronic illness and strategies for managing these conditions.

Books for siblings

There's a Little Bit of Me in Jamey, by D.M Anadeo, Morton Grove, IL, Albert Whitman and Company, 1992. Brian's brother Jamey has leukemia. This story addresses common sibling issues, but shows the remarkable way Brian helped his brother through a bone marrow transplant.

What About Me? When Brothers and Sisters Get Sick, by A. Peterkin, New York, Magination Press, 1992. A young girl attempts to cope with her brother's illness. This book also deals with the complicated feelings of a well child in such a situation.

When Molly Was in the Hospital: A Book for Brothers and Sisters of Hospitalized Children, by A. Peterkin. Rayve Productions, 1994. Anna tells the story of her sister Molly's hospitalization through her point of view.

Books for teens

Easy for You to Say: Q and As for Teens living with Chronic Illness or Disabilities, by Miriam Kaufman, 285 pp, Firefly Books, 2005. Practical and frank topics geared exclusively for teens with chronic illness or disabilities.

It's Not About the Bike: My Journey Back to Life, by Lance Armstrong, 304 pp, Berkley Trade, 2001. Inspirational story of famed champion overcoming cancer.

Books for parents, teachers, and nurses

Coping with Caregiving: A Beginner's Guide to Caring for Your Loved Ones Without Suffering from Caregiver Burnout by Annabelle Stevens and Carolyn Stone 2014. In this guide, the authors outline some of the best strategies for beginners who suddenly find themselves placed in the role of caregiver.

Healing Images for Children: Teaching Relaxation and guided Imagery to Children Facing Cancer and Other Serious Illnesses, by Nancy Klein, 280pp, Inner Coaching, 2001.

Parenting Children With Health Issues: Essential Tools, Tips, and Tactics for Raising Kids With Chronic Illness, Medical Conditions, and Special Healthcare Needs, by Foster W. Cline and Lisa Greene, Love and Logic Press, 2007.



Online resources

Aplastic Anemia & MDS International Foundation (AA&MDSIF)

www.AAMDS.org

AA&MDSIF provides information and support for patients and their family members. Call (800) 747-2820 for your free information packet on aplastic anemia, MDS, or PNH, or to talk to a patient educator. You can also visit our Online Learning Center at www.AAMDS.org/learn

American Academy of Pediatrics

www.aap.org

This site provides general information on promoting health and well being for children. You can also search for articles on specific bone marrow failure diseases.

National Library of Medicine (NLM)

www.nlm.gov

NLM is the world's largest medical library. Their website provides comprehensive information on various bone marrow failure diseases.

National Institutes of Health (NIH)

www.nih.gov

NIH is the nation's leading medical research agency. They provide important medical discoveries that improve people's health and save lives. NIH scientists investigate ways to prevent disease as well as the causes, treatments, and even cures for common and rare diseases. On this website you can search for aplastic anemia, MDS, or PNH and see the research they are doing now.

Girlshealth.gov

www.girlshealth.gov

This site is sponsored by the National Women's Health Information Center (NWHIC) of the U.S. Department of Health and Human Services. It is written by and for young women in their teens. A section under "Illness and Disability" addresses many questions and concerns expressed in this age group about hospital life, school, friends, family, and dating.

GotTransition

www.gottransition.org

(202) 223-1500

Got Transition/Center for Health Care Transition is a cooperative agreement between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health. Our aim is to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

Group Loop – Online Support for Teens

www.grouploop.org

Group Loop is a safe (and fun) online community where teens affected by cancer can meet and connect with each other to build social and emotional support, and to regain a sense of control over their lives.

Learning Disabilities Association of America (LDA)

www.ldaamerica.org

(412) 341-1515

The LDA provides support to people with learning disabilities, their parents, teachers, and other professionals. An online course is available for parents describing how to get the services your child needs under the Individuals with Disabilities Education Act (IDEA).

National Marrow Donor Program - Be the Match Foundation

www.marrow.org

(800) 627-7692 (General Information)

(888) 999-6743 (Office of Patient Advocacy)

Nonprofit organization dedicated to creating an opportunity for all patients to receive bone marrow or umbilical cord blood transplant needed.

Make a Wish Foundation

www.wish.org

(800) 722-WISH

Makes wishes come true for terminally ill children.



National Family Caregivers Association (NFCA)

www.caregiveraction.org

(800) 896-3650

(301) 942-6430

Grassroots membership organization for family caregivers. Supports family caregivers through education, information and referral services, and advocacy.

Supersibs!

www.supersibs.org

Support for siblings (ages 4-18) of cancer patients.

Scholarships available for high school seniors.

Stop Bullying

www.stopbullying.gov

StopBullying.gov provides information from various government agencies on what bullying is, what cyberbullying is, who is at risk, and how you can prevent and respond to bullying.

More Ways to Get Help

The Aplastic Anemia & MDS International Foundation (AA&MDSIF) is here to help. We provide the following services:

- Personalized support through patient educators
- Free educational materials on aplastic anemia, MDS and PNH
- Online Learning Center with presentations by medical experts
- Support Connection
- Communities of Hope support groups
- Patient and family conferences
- Print and electronic newsletters
- Clinical trials information

Contact us today. Here's how:

- Call us: (800)747-2820
- Email us: help@aamds.org
- Go to our website: www.AAMDS.org



Connect with AA&MDSIF on Social Media

***Why should you be a part of
our social media communities?***

Find out the latest research

- Our social media accounts publish the latest in bone marrow failure disease research and articles about treatments.
-

Connect with fellow patients and families

- Meet other people who are dealing with your issues, share ideas, and build friendships.
-

Get inspired

- Watch and read hopeful stories from other patients and volunteers about how they're working to fight back against disease.
-

Learn about upcoming events

- Get updates on upcoming walks, webinars, conferences, webcasts, and more!
- Participate in events that you can't attend in person.
- Our social media accounts will connect you with what's happening at our conferences, walks, and webcasts so even if you can't make it in person, you can still participate and stay up-to-date.

Join the conversation!



www.facebook.com/aamds



www.twitter.com/aamdsif



www.youtube.com/aamds




You already get the electronic newsletter – why should you sign up for social media?

Each social media account contains different content. You will find that not all of our posts are the same on Facebook, Twitter, and YouTube and that a lot of it is different from the electronic newsletter, too. Follow all of our accounts to make sure you're up-to-date on the latest news.

Aplastic Anemia & MDS International Foundation

100 Park Avenue, Suite 108 • Rockville, Maryland 20850
(800) 747-2820
(301) 279-7202
(301) 279-7205 fax

help@aamds.org
www.AAMDS.org



*Remember - you are
not alone. We are
standing by to support
you in any way we can.*



100 Park Avenue, Suite 108 • Rockville, Maryland 20850

(800) 747-2820 | help@aamds.org
www.AAMDS.org

Fighting Bone Marrow Failure Diseases Through Patient Support and Research Since 1983