Self-Advocacy for Patients with Bone Marrow Failure Diseases

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

- Aplastic anemia
- MDS (myelodysplastic syndromes)
- PNH (paroxysmal nocturnal hemoglobinuria)
- Related bone marrow failure diseases

This booklet outlines action steps patients can take as they advocate for their best care. It has been reviewed by experts to ensure that the information is accurate. You will also want to seek health advice from your healthcare team. This booklet is not meant to be a substitute for the advice of your doctor.

For more information on patient advocacy, visit us online at www.AAMDS.org or call us at (301) 279-7202 or (800) 747-2820.
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What is Standing Up for Your Health?

“You have to be your own best advocate. No one is going to take better care of you than you.”

— Stephen, aplastic anemia and PNH patient

“I’m definitely the kind of patient who just takes charge. It can be a scary thing to have other people be in charge of your healthcare.”

— Valerie, former aplastic anemia patient

“You feel better about your healthcare. I feel you gain more control over your life.”

— Linda, MDS patient

“It’s really important for patients to be strong advocates for themselves. Being in control can lead to better outcomes and better quality of life.”

— Isabel Schuermeyer, MD, psycho-oncologist

Standing Up for Your Health means being a strong self-advocate and an empowered patient. It means taking a more active role in your care to ensure you or your loved one receive the best care and treatment available.

Standing Up For Your Health is also a program created by the Aplastic Anemia & MDS International Foundation to help people with bone marrow failure diseases and their families develop the skills necessary to ensure they receive high quality care. It includes an integrated set of tools, learning experiences, materials and resources for you to examine, evaluate, and engage with, all with the goal of helping you become a more effective advocate for your own healthcare and a more powerful patient.

For additional information, including videos, stories and other interactive components, visit the Standing Up for Your Health Web site at www.AAMDS.org/StandingUp.
As we developed Standing Up For Your Health, our goal was to discover what empowered patients and strong self-advocates do that leads them to consistently receive high quality care. To offer you the most up-to-date information, we turned to the experts. We interviewed patients with bone marrow failure diseases about the skills they use as they effectively navigate the healthcare system. We read the latest research and talked with hematologists, oncologists, nurse specialists, and patients’ families to get their perspective on skills needed for good health advocacy. Then, we compiled what we had learned into teachable blocks—the five pillars of Standing Up for Your Health.

Whether you are newly diagnosed, or have been living with aplastic anemia, MDS, or PNH for many years, you will find the practical strategies offered in this booklet ones you can readily apply as you stand up for your health.

Why Self-Advocacy Matters

Self-Advocacy Helps You Get High-Quality Care

High quality care means getting the right care at the right time delivered by the right healthcare professional for you. When you stand up for your health, you do everything you can to get high quality care.

Self-Advocacy Can Help You Feel in Control

At times, you may feel like your disease is running your life. Standing up for your health can give you back a sense of control. When you stand up for your health, you can get the information you need to make informed choices about your medical treatment and your healthcare providers.

Self-Advocacy Can Help You Get Support

When you stand up for your health, you ask for help from family, friends, and others. Their support can help you cope with your disease.

Ready to Stand Up for Your Health?

Read this booklet and share it with your family and friends. Also, visit our Web site at www.AAMDS.org to view our Standing Up for Your Health patient advocacy section. You’ll find practical tips, patient stories, and other resources and tools you can use to become an empowered patient and strong self-advocate.
Pillar 1: Build a Strong Healthcare Team

“The best thing I ever did? Finding healthcare providers I trust. This way I’m comfortable being an active participant. I truly feel it is not only my right, but also my responsibility to fully participate in making decisions about my care and medical treatment.”

— Kevin, MDS patient

“Make sure your provider is a good fit. You should have a shared understanding of your disease and treatment and be able to communicate well together. It’s a relationship that can last for years.”

— Ruben Mesa, MD, hematologist/oncologist

“Build a strong, trusting relationship with providers and clinicians.”

— Stephen, aplastic anemia and PNH patient

“Patients need to realize that their doctor is their partner.”

— David Steensma, MD, hematologist/oncologist
Be a Strong Player on Your Healthcare Team

Your doctors, nurses, and specialists will offer you much of the information you need to make informed health decisions. Your healthcare team can also include your pharmacist, nurse practitioner, and physician assistant. You may also have a mental health provider such as a social worker, psycho-oncologist, or psychologist on your team. Other team members may include researchers, lab technicians, and naturopaths.

Empowered patients see themselves as the center of their healthcare team. Only you can make sure you get your questions answered. Only you can keep other team members informed about symptoms and side effects. Only you can follow through on treatments. Only you can make the tough choices about your healthcare.

Building a strong healthcare team is important for effective self-advocacy. First, select a care coordinator. Then, put together a team of skilled healthcare providers whom you trust and can talk openly with. Finally, take steps to make sure you are doing your part.
Step 1: Select a Care Coordinator

“Since I live in a rural area, there isn’t a hematologist or oncologist in town who has seen many patients with PNH. Still, I want to see a specialist who knows a lot about PNH—someone who has treated people like me and who stays up-to-date on the latest treatments.

So, I go outside my area a few times a year to see a hem/onc who is very familiar with treating PNH. My local doctor coordinates my care by staying in touch with my specialist.”

— Michael, PNH patient

Since your care may be very complex and involve many specialists, you may find it helpful to choose one healthcare professional who has the main responsibility for coordinating your care. Some people ask their oncologist or hematologist to serve as their care coordinator. Others work with their primary care physician.

Your care coordinator can:

- Help arrange consultations with specialty doctors and supportive care providers
- Maintain your medical records in his or her office (Of course, you’ll also want your own copies of your records.)
- Talk with your other healthcare team members when needed

Care coordinators and health advocates can play different roles. To learn about health advocates, read page 40 in this booklet.
Step 2: Choose Healthcare Providers Who Are a Good Fit For You

“Who says you can’t have it all? My doctor, specialist, and nurse practitioner all have a great bedside manner and keep me up to speed on the information I need. I did a lot of background checking before picking my team, and it has paid off for me. We put our heads together to come up with solutions.”

— Lynn, aplastic anemia patient

You have seen a lot of doctors, nurses and other health care professionals over the years. Some you have liked better than others. Use the worksheet on page 8 to help you understand what is most important to you in the members of your healthcare team.
**Worksheet**

**Determine What You Are Looking For in Your Healthcare Providers**

Use the checklist below to help you assess what you are looking for when choosing members for your healthcare team. You can also use this checklist to assess how satisfied you are with your current healthcare providers.

1. **My doctor considers me an important part of the team and asks me for my feedback.**
   - [ ] Very important
   - [ ] Somewhat important
   - [ ] Not very important to me

2. **My doctor is willing to share information freely with me and with other healthcare providers as needed.**
   - [ ] Very important
   - [ ] Somewhat important
   - [ ] Not very important to me

3. **My doctor talks openly with me about what I can expect about my treatment and my prognosis (life expectancy).**
   - [ ] Very important
   - [ ] Somewhat important
   - [ ] Not very important to me

4. **The office is nearby, and the office hours fit my schedule.**
   - [ ] Very important
   - [ ] Somewhat important
   - [ ] Not very important to me

5. **The time in the waiting room is not too long.**
   - [ ] Very important
   - [ ] Somewhat important
   - [ ] Not very important to me

6. **The doctor takes the time to explain the staff members’ roles.**
   - [ ] Very important
   - [ ] Somewhat important
   - [ ] Not very important to me

7. **My doctor has a back-up healthcare provider I can reach during emergencies or non-office hours.**
   - [ ] Very important
   - [ ] Somewhat important
   - [ ] Not very important to me

8. **My healthcare team members answer my questions and explain things in terms I can understand. If I don’t understand, they will offer examples or rephrase in lay terms.**
   - [ ] Very important
   - [ ] Somewhat important
   - [ ] Not very important to me
9. My healthcare team members refer me to the right source if they don’t know the answers to my questions.
   - Very important
   - Somewhat important
   - Not very important to me

10. My healthcare team members give me articles and brochures about my disease.
    - Very important
    - Somewhat important
    - Not very important to me

11. My healthcare team members return my phone calls and emails in a timely manner.
    - Very important
    - Somewhat important
    - Not very important to me

List other areas that are important to you as you put together your healthcare team.


Know How To Reach Your Healthcare Providers

You need to know how to reach your healthcare providers, day or night. Find out the best ways to contact them. Some healthcare providers like email, while others prefer the telephone. Be sure to get their email addresses and phone numbers.

If your healthcare provider is not available when you call, leave a detailed message. This will help you avoid telephone tag. Tell the office it’s okay to talk to a family member or leave a message if you’re not able to come to the phone. You may need to give the office permission in writing.
Feel Free To Get a Second Opinion

“The doctor is there to serve you, and if you’re not comfortable with what he or she is recommending, you can switch doctors and get a second opinion.”

— Jill, MDS patient

“I was very nervous going to see another specialist. I was sort of feeling like I was betraying my specialist. My sister went with me, and that really helped. Turns out my original specialist didn’t have a problem with me seeking a second opinion. In the end, I wound up switching because I liked working with a female doctor better.”

— Kim, PNH patient

Even if you’re happy with your healthcare team, it’s okay to get a second, third, or even fourth opinion. Getting a second opinion will not offend your doctor. In fact, most healthcare providers appreciate and encourage another point of view. And it’s your right.

Seeking a second opinion can help you and your family with making difficult decisions about your treatment. Be sure to contact your health insurance company to determine if the healthcare provider is covered under your plan. While most insurance companies will cover a second opinion, it is always a good idea to check with your insurance company before seeing a new healthcare provider.

Self-Advocacy When You Are in the Hospital

While you know about the healthcare providers you work with on a regular basis, it is different when you need to go into the hospital. You’ll want to find out what the healthcare providers’ names are and who does what:

• Ask healthcare providers to write down their names and what they do. Or ask if they can leave their business cards.

• Find out who to talk with about:
  - Medical issues
  - Emotional issues
  - Home care
  - Family issues
  - School or job issues
Step 3: Find an Expert in Your Disease

Chances are, you’ve already seen a hematologist or a hematologist/oncologist (hem/onc, for short). That’s an expert in diagnosing and treating diseases of the blood and bone marrow.

In order to receive the best treatment, you’ll also want to see a hematologist or hem/onc who knows a lot about your disease—an expert. This is someone who has treated similar cases and stays up-to-date on treatments. While ideal, it is not always possible to find an expert near you who has experience with aplastic anemia, MDS, or PNH.

You may need to go out of your area to visit an expert who is very experienced with your condition. Ask this expert to keep in touch with your local primary care physician, hematologist, or oncologist. For resources you can use to receive help paying to see an expert, see page 22.

Consider having a mental health provider on your team. A social worker, psychologist, psychiatrist, or psycho-oncologist can help you manage stress, anxiety, depression, and other emotional symptoms. Be sure to let your doctor know if you have any of these symptoms, and don’t be afraid to ask for a referral.
Need help finding an expert in treating bone marrow failure diseases?

- Call AA&MDSIF at (800) 747-2820. Ask to speak to our patient educator, who can assist you with locating a specialist in your area.

- Contact a teaching hospital. Call the hematology/oncology department at a teaching hospital affiliated with a local university. In many cases, the doctors at these teaching hospitals are most familiar with rare diseases. Because they are in a research and teaching setting, they may be able to offer information on both the standard therapies and new investigational treatments.

- Go online. Visit www.Marrowforums.org and ask other patients for names of specialists they suggest.

- Ask the local community hematologist or hem/onc you are seeing. Many times, local doctors will know of specialists in treating bone marrow failure diseases.

- Visit the AA&MDSIF Facebook page at www.facebook.com/aamds

Interview the Expert

Once you find an expert in treating your disease, you will want to interview him or her. In some cases, you can call the office and speak directly to the physician for a couple of minutes at not charge. In other cases, you will need to schedule an initial visit.

Before you go to see an expert, know whether the doctor is covered under your insurance. Some insurance plans allow you to see someone outside your insurance if you get pre-approval first. Others require you to pay out of pocket, or find another expert that is covered by your insurance.

Questions to Ask the Expert

- In what practice areas are you board certified?
- How many patients with my disease have you treated?
- What were the outcomes?
- Could I talk with a nurse or social worker who works with you?
- At which hospitals do you have privileges to practice?

List your other questions here:
Learn About Your Doctor’s Background

To learn more about your doctor’s competence and experience, you may want to visit these two Web sites:

**Federation of State Medical Boards**

This group offers profiles on licensed doctors, osteopathic doctors, and physician assistants. For less than $10, you can find out facts about your doctor’s education, any disciplinary actions and certification, among other areas. To order a report, go to [www.docinfo.org](http://www.docinfo.org).

Some information on licensed doctors may also be available online for free through the state medical board. To find a listing of Web sites for state medical boards, go to [www.fsmb.org](http://www.fsmb.org).

**American Board of Medical Specialties**

This group will tell you for free if your doctor is board certified in the specialty area that treats your disease. A doctor who is board certified has shown great expertise in a specific area of medicine. To find out if your doctor is board certified, call (866) 275-2267. Or, go to [www.abms.org](http://www.abms.org).
Step 4: Do Your Part to Become an Empowered Patient

Remind yourself that you are at the center of your healthcare team. Once you have your medical care in place, you’ll want to concentrate on what you can do to be a strong player on your healthcare team. Try the tips listed below as you do your part:

**Share Information**
- Share information with your healthcare team. Tell them your symptoms—no matter how minor they seem.
- List all medicines (including over the counter medicines), vitamins, and alternative therapies you are taking.
- Discuss any emotional symptoms you are having. If you are feeling anxious or having trouble sleeping, let them know. The more you share, the better your healthcare team can do in helping you.

**Be a Team Player**
- Go to all your scheduled office visits.
- Once you agree to a treatment plan, be sure to follow through. If the treatment is not what you expected, **always** talk to your doctor before stopping the treatment.

**Make the Most of Office Visits**
- Think about what you hope to get out of the visit. Bring your list of questions along with you.
- Ask for a copy of lab results or any health records while you are still at the doctor’s office. It can be time consuming and difficult to get records once you leave the office. Some states charge a fee for photocopying your records after the visit.
- Ask your healthcare providers to give you any medicine or treatment instructions in writing. For more tips on making the most of every office visit, see Section 3.

**Be Politely Assertive**
- Be polite while still being assertive when asking for what you need.
- Try using “I” statements, such as “I think,” “I feel,” or “I don’t understand.”
**Summary:**

Building a strong healthcare team you trust and can talk freely to is key to becoming an empowered patient. Being comfortable with your team can help you get the answers you seek. And remember, you have the right to seek a second opinion.

It can take time to feel at ease when taking the lead in your healthcare. You’ve done other difficult things in the past, and you can do this, too. Be patient with yourself and know that with practice, you can develop solid skills as you advocate for your best healthcare.

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**Skills Checklist**

Use this checklist to assess your skills in building an effective healthcare team.

- I have an expert in my disease on my healthcare team.
- I feel comfortable with each of my healthcare providers.
- I believe I’m doing everything I can to be an empowered team player.
- I’m able to reach my key healthcare providers whenever I need to.
- I feel comfortable getting a second opinion. I find my healthcare team supportive of my seeking a second opinion.
Pillar 2: Learn About Your Disease and Treatment Options

“It’s scary to be diagnosed with a rare disease. Education eases the fear factor. It gives the patient empowerment. You realize, the more I understand this disease, the better I can deal with it.”

— Stephen, aplastic anemia and PNH patient

“If you have a rare disease, it’s important to be well informed—even before you visit the doctor—so you know the right questions to ask.”

— Mikkael Sekeres, MD, hematologist/oncologist

“You know this thing is not going away overnight, and the more you learn about it, the better your situation. You identify your problem, and then you have to do something about it. Sometimes you can solve it and sometimes you can’t. But if you know about your condition you can possibly improve your healthcare.”

— Linda, MDS patient

“There’s a lot of information out there on the Internet that just isn’t accurate. You want to know your source.”

— Isabel Schuermeyer, MD, psycho-oncologist
Get Up-To-Date Information

Bone marrow failure diseases are complex. You need to learn all you can about your condition and the available treatments.

Staying well informed helps you be a powerful player on your healthcare team. It allows you to educate family and friends, get more out of office visits, make choices about your treatment, and keep an eye on your care.

Today, it’s easier than ever to learn about your disease and treatment options. You can get information from books, brochures, newspapers, medical journals, magazines, and—of course—the Internet.
Check off the tips you will try:

- **Request a patient information packet from AA&MDSIF**
  
  You can order a free information packet from AA&MDSIF right on our Web site, or you can call us at (800) 747-2820. The packet will include a plain language booklet with information about your disease and treatment options.

- **Go to www.AAMDS.org**
  
  Our Web site has a wealth of information about bone marrow failure diseases and treatments. Check out patient stories, our electronic monthly newsletter, and patient resources. Find out about conferences and clinical trials.

  In our Online Learning Center, you’ll find video presentations, interviews with medical experts, and interactive learning modules. You can even take part in a live webinar. These are web seminars that allow you to view a real-time presentation by a medical expert and get your questions answered.

- **Talk to your healthcare providers**
  
  Ask questions and request materials. But don’t rely on your healthcare providers as your only source of information.

- **Talk to the AA&MDSIF patient educator**
  
  Call us at (800) 747-2820, option 1.

- **Attend our patient and family conferences**
  
  AA&MDSIF patient and family conferences are great places to learn more about your disease. You can hear from leading medical experts, meet and speak with other patients, and pick up materials.

- **Visit the National Library of Medicine Web site at www.nlm.gov.**
  
  This Web site has reliable and detailed information on many diseases. It has a simple search tool on the main page. From this site, you can also use MedLinePlus, a Web site for patients and their families and friends maintained by the National Institutes of Health.

- **Gather and organize**
  
  Once you’ve gathered all the information you can on treatment options, organize it. Then share what you’ve learned with healthcare providers, family, and friends.
Find Trustworthy and Reliable Information on the Internet

As you know, there is a lot of information on the Internet. You’ll want to find accurate and current information. Use these tips for finding good and reliable information on the Web:

**Is it clear who sponsors the Web site?**

Look for Web sites that end in .gov, .edu, or .org.

- .gov identifies government agencies
- .edu identifies educational institutions
- .org identifies non-profit organizations (such as scientific groups, advocacy groups, and foundations)
- .com identifies commercial Web sites (such as businesses, pharmaceutical companies, and some hospitals)

**Is there a way to contact the Web site sponsor?**

Trustworthy Web sites have contact information. Many even have toll-free numbers to call.

**Is there an editorial board that reviews the information?**

Click on the “About Us” page of a Web site to see if there is an editorial board that reviews the information before putting it online. Government Web sites may not have this page.

**Is the information current?**

New research findings can make a difference in making medically smart choices, so you’ll want to look carefully to find out when the Web site was last updated. Older information isn’t useless, however. Many Web sites provide older articles so readers can get a historical view of the information.
Could the claims on Web sites be too good to be true?

Be careful of claims that any one remedy will offer dramatic cures. Talk with your healthcare team about treatment claims.

Here are two reputable sources of drug and treatment information:

**MedlinePlus**  
www.medlineplus.gov

This Web site offers a wealth of information about health topics, drugs, and supplements. It also provides videos and interactive tutorials. The Web site is maintained by the National Institutes of Health.

**Drugs@FDA**  
www.fda.gov

This Web site, developed by the U.S. Food and Drug Administration (FDA), provides detailed information about all FDA-approved drug products. You can easily search by generic or brand name. To find this site, go to www.fda.gov and search for Drugs@FDA.

To learn more about finding reliable online information that you can trust, go to www.AAMDS.org/OnlineInfo

**Learn About Your Treatment Options**

When the time comes to make a decision about treatment, use reliable information—along with input from your healthcare providers, family, friends, and others. Weigh the pros and cons of each treatment. Think about how well it might work, side effects, and costs. Consider how it might affect your lifestyle.

Then work with healthcare providers to develop a care plan you want to do and feel you can do. Remember: you have the right to choose or refuse treatment.

In the months and years to come, keep track of how well your care plan is working. Note your symptoms and side effects. Review the plan with healthcare providers regularly to see if it can be improved.
Questions to Ask Your Healthcare Team About Treatment

You may have many questions about your treatment. Some patients who are learning advocacy skills find it helpful to take this list with them to their appointments.

1. What kind of treatment will I be getting? Will I be getting more than one treatment?
2. How does this treatment work?
3. How often is this treatment given?
4. Does the treatment hurt?
5. When can I expect the treatment to start working?
6. What are some of the possible side effects I should be aware of? Are there long-term side effects?
7. What happens if the treatment doesn’t work?
8. Where will I be getting the treatment (at your office, at a clinic, in the hospital)?
9. Will I get better?
10. Do you have tips for staying on the treatment plan? (Some people report they feel worse on treatment in the beginning, and then feel better after a few weeks or months. This can be discouraging, yet it is a common side effect of some of the medicines.)
11. How long do I need to take the medicine? What happens if I go off this medicine before the treatment cycle is over?
12. Will this treatment be covered by my insurance plan? If not, what is the cost if I choose to pay out of pocket? Are there other treatments I can consider?

Always talk to your doctor before you stop any medicine. If side effects are tough to handle, your doctor may be able to prescribe a medicine to lower the side effects.
Need help paying for healthcare provider visits or treatments?

What if your health insurance doesn’t cover seeing specialists or certain treatments? Read below to find out where you can get help.

- **Call the Patient Advocate Foundation** at (800) 532-5274 to see if they can help with fees. Ask about their Co-Pay Relief program. Visit their Web site: [www.patientadvocate.org](http://www.patientadvocate.org).

- **Learn about patient assistance programs offered by drug makers.** Go to RxAssist at [www.rxassist.org](http://www.rxassist.org). This Web site has a complete database of patient assistance programs, as well as practical tools, news, and articles.

- **Call the Chronic Disease Fund** at (972) 608-7141 or toll-free at (877) 968-7233. Or look them up on the Web at [www.cdfund.org](http://www.cdfund.org). This non-profit organization provides financial help to seriously ill Americans who have insurance, but cannot afford their medicines.

- **Contact the Leukemia & Lymphoma Society (LLS) Patient Financial Aid Program.** Call (800) 955-4572 or visit [www.lls.org/chapterfind](http://www.lls.org/chapterfind) to locate a chapter near you. The program provides a limited amount of financial assistance to help patients with significant financial need who are under a doctor’s care for a blood cancer disease.

- **Search state insurance and co-pay assistance programs.** Go to Families USA Program Locator at [www.familiesusa.org/resources/program-locator](http://www.familiesusa.org/resources/program-locator). This Web site includes listings of health insurance assistance programs by state. These programs handle many questions about Medicare, Medicaid, and private insurance and may be able to refer you to low-cost or free healthcare (which may include prescription drug assistance).

- **Join a clinical trial.** Find out if there are any free or low-cost clinical trials to participate in. If trial-related costs are of concern to you, the study doctor or nurse can answer questions about what is covered and what costs you or your insurance will be expected to pay. Visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov).
Thinking of Participating in a Clinical Trial?

If you have a bone marrow failure disease, you may want to consider taking part in a clinical trial, also called a research study. These studies can offer good treatment options for some people with bone marrow failure diseases like aplastic anemia, MDS, and PNH.

Clinical trials are used to test new treatments before they’re made available to the public. If the new treatment proves to be better than the current treatment, the new treatment can then be approved for general use by the U.S. Food and Drug Administration (FDA).

Be an Advocate Before You Participate—Get Your Questions Answered

The doctors and nurses running the trials will let you know about the study plan. Make sure to ask about:

- The medicines to be used and the dosage
- How the treatment will be given
- Any lab tests that will be done
- Known side effects of the treatment
- Possible benefits of the treatment

To learn more about clinical trials:

- Call the National Library of Medicine at (888) 346-3656.
- Go to www.AAMDS.org/clinicaltrials to read the clinical trial fact sheet.
- Go to www.ClinicalTrials.gov to get up-to-date information about clinical research that is being carried out all over the world for a wide range of diseases and conditions.

Consider contacting the National Institutes of Health (NIH). They might have a clinical trial that is right for you. If you meet the requirements and are accepted into a clinical trial, they will usually cover medical expenses related to participating in the trial. To find out more, call toll free: (800) 411-1222.
Keep an Eye on Your Care

Healthcare providers are only human—mistakes can happen. As an informed patient, you can keep an eye out to make sure you get the right treatment every time—in the office, at the lab, and at the hospital. Try these 10 tips provided by the U.S. Agency for Health Research and Quality:

10 Tips for Preventing Medical Mistakes

1. Be an active member of your healthcare team. Take part in every decision about your health. Research shows that patients who are more involved get better care.

2. Make sure your doctor knows all the medicines and supplements you take.

3. Make sure your doctor knows about any allergies or adverse reactions you have had to medicines.

4. When your doctor writes you a prescription, read it. If you can’t read it, your pharmacist might not be able to either.

5. Ask for information about medicines and treatments in terms you understand—both when your medicines are prescribed and when you receive them.
   • What is this medicine for?
   • How am I supposed to take it?
   • What side effects are likely? What do I do if they occur?
   • Is this medicine safe to take with other medicines or dietary supplements I am taking?
   • What food or drink should I avoid while taking this?

6. When you pick up a medicine or get a treatment at a medical center, ask: Is this the medicine/treatment that my doctor prescribed?

7. Make sure that all the healthcare providers involved in your care have important information about you. Don’t assume that everyone knows what they need to know.

8. Ask a family member or friend to be there with you and be an advocate.

9. Know that more is not always better. Ask why a test or treatment is needed and how it can help. You might be better off without it.

10. If you have a test, don’t assume that no news is good news. Find out the results.
Summary:

Take the time to learn about your disease and your treatment options. Remember, knowledge is a powerful part of self-advocacy. The more you know, the better off you are to make informed choices about your care.

As you are gaining health advocacy skills, you may find it helpful to take this booklet with you to your doctor visits. Some patients find reading the questions from the list helps them stay on track as they seek answers from their healthcare providers.

Skills Checklist

Use this checklist to assess your skills in learning about your disease and available treatment options:

☐ I’ve sought up-to-date information about my disease by talking to specialists and doing my own research.

☐ I seek information from reliable sources on the Internet.

☐ I ask my healthcare team about treatment options.

☐ I know whom to contact for help paying for medicines or treatment.

☐ I feel able to take the 10 steps to help prevent medical errors.
Pillar 3: Make the Most of Every Office Visit

“I’d love to have two hours with every patient to go through every detail and contingency. But the clock is always ticking, and there is so much we need to discuss and accomplish in such a short time.”

— David Steensma, MD hematologist/oncologist

“If the doctor gets offended by lots of questions, it’s probably the wrong doctor. They may not know enough.”

— Mikkael Sekeres, MD hematologist/oncologist

“Many older patients tend to think what a doctor says is an absolute. Many patients do not comprehend all their doctor tells them. Therefore, I strongly recommend that someone go to appointments with them—a son or daughter, a grandchild, or a close associate.”

— Linda, MDS patient
Prepare for Each Visit

Office visits can run shorter than you hope. To be a strong advocate for yourself, it is critical that you do everything you can to make the most of every visit. You’ll want to do some work in advance. Check off the tips you will try:

- **Set an agenda for the visit**
  Ask yourself, “What do I want to get out of this visit?” Write down the top three things you want to discuss. Focusing on your agenda will help you make the most of your time.

- **Ask for the time you need**
  When you make an appointment, let the staff know if you have special concerns that might require a little extra time with your doctor.

- **Do your homework**
  Learn all you can about your condition and the available treatments.

- **Bring information with you**
  Bring your medical information to the visit. This information should include:
  - A list of questions in priority order (see page 29 for questions to consider)
  - All current and past illnesses, as well as any chronic conditions you may have
  - A list of prescription and over-the-counter medicines, vitamins, herbs, and supplements you have used
  - Notes on symptoms and side effects you are having
  - Test results and transfusion records

- **Form a good relationship with your healthcare team**
  Establishing friendly relationships and showing appreciation for your doctor and the staff is important. When you work well with your healthcare providers, it enables them to focus on your condition and to make the best use of the time they have with you.

- **Bring a member of your personal support team**
  Going to the doctor can be overwhelming. Asking a family member or friend to come along can help. This person can help you ask questions, write down answers, and ensure you get answers you understand—four ears are always better than two. A family member or friend can also provide emotional support. For more on building a strong personal support team see page 38.
Ask Questions, Get Answers

Clear communication is an integral part of good healthcare. In order to make smart choices about treatment and follow your care plan correctly, you need to fully understand your disease and treatment options. These are the things that empowered patients do to make sure they get the best care and treatment.

Ask the Most Important Questions First

Be sure to bring a list of questions and put them in priority order. You may have just a few minutes to ask your questions, so you want to ask the most important ones first. For a list of disease and treatment related questions to consider, see Questions to Ask Your Healthcare Team on page 29.

Ask for Clarification

Don’t worry about offending your healthcare provider. Healthcare providers tend to share more information with patients who pay attention and ask questions. Asking questions shows healthcare providers you care, are actively involved in your own care, and want to stay informed. Let your doctor know if the information is confusing or if there is anything you don’t understand.

If you have trouble understanding your healthcare provider:

- Ask the healthcare provider to say things again or use simpler words until you get it
- Ask a family member or friend to listen for you
- Ask for brochures, drawings, or models
- Ask the provider to write down answers

Take Notes

After the visit is over, it may be hard to recall exactly what your provider said. Take notes, ask a family member or friend to take notes, or use an audio recorder. Keep these notes with your medical information.
Questions To Ask Your Healthcare Team

You may want to take this booklet with you as you ask the following questions:

About the disease

- What subtype of my disease do I have?
- How severe is my disease?
- What is my prognosis?
- What have other people with a similar disease and treatment gone through?

About treatment

- What are all my treatment options?
- What treatment option do you recommend for me? Why?
- How likely am I to get better with the treatment?
- Has this treatment been used a lot or is it a new or experimental treatment?
- How long will the treatment take to work? When and how will I know if it is working?
- What are the potential side effects from treatment?
- Can my disease return, even after successful treatment?

About prescription drug treatment

- Has the drug been approved by the U.S. Food and Drug Administration (FDA) for treating my disease?
- How do I take the medicine? How often do I need to take it?
- How long will I need to take the medicine?
- What are the common side effects of this medicine? What are the most severe side effects? What can be done to control them?
- What are the long-term side effects of this medicine?
- How much does it cost? Is it covered by my insurance?
- Can this prescription drug cause interactions or side effects with any over-the-counter medicines or supplements that I take?

For more questions to ask healthcare providers, visit www.ahrq.gov/questionsaretheanswer. This Web site is maintained by the Agency for Health Research and Quality. At this Questions Are the Answer site, you can create a customized list of questions to take with you to your next doctor’s visit.
Summary:

Have you ever left your doctor’s office not sure of what you need to do next? Not quite sure how to take your medicine? You’re not alone. There is a lot of information to take in at each visit. Using the steps outlined in this section can enable you to get the most from your office visits. While not always easy—asking questions until you get answers you understand is a central part of becoming an empowered patient.

Skills Checklist

Use this checklist to assess your skills in preparing for office visits and making sure you get your questions answered in a way you can understand:

- I take steps to prepare for each visit by writing a list of questions beforehand and bringing them along with me.
- I ask my healthcare team questions.
- I make sure I get answers I understand.
Pillar 4: Keep Careful Track of Health Information

“I notice changes in my body. I know its rhythms. Pay attention to what your body tells you and give that information to your medical team.”
— Stephen, aplastic anemia and PNH patient

“Since I take copies of my lab work with me when I travel, I always make photocopies to leave at home in case I lose this important paperwork. I would suggest making a couple of photocopies of all important medical papers. In my view, being able to put my hands on my health records at a moment’s notice is a critical part of self-advocacy.”
— Harvey, MDS patient

An Organized Patient Is a Powerful Patient

Keeping all your medical information organized and in one place makes it easier to track changes in your health, see if treatments are working, and share information with your healthcare provider. Read this section to learn how to keep track of your health information.
Gather Information

Collect information about your health, office visits, and treatment in one place. Don’t feel that you must gather all of your health information at once. The next time you visit the doctor, simply ask for recent records, and do so each time you visit a healthcare provider.

Here are some of the items you’ll want to hold onto:

- **Health information**
  - Allergies
  - Immunizations you have had
  - Notes on symptoms
  - Personal health history and family health history

- **Office visit information**
  - Dates of office visits
  - Notes on what providers tell you
  - Questions to ask healthcare providers

- **Treatment information**
  - List of medicines, vitamins, herbs, and supplements you have used
  - Notes on side effects
  - Transfusions you have had
  - Treatment instructions

- **Financial and legal information**
  - Insurance claims—paid and unpaid (You can appeal claims that are denied by your insurance company. Call your insurance company for steps to take to appeal.)

- **Contact information**
  - Family and friends
  - Other patients
  - Pharmacy—note when they are open
  - Healthcare providers—note when they have office hours and how to reach them after hours during an emergency
  - Insurance—note when they are available to take calls from members
Ask for Copies of Health Records at Each Visit

It can be difficult to get your health records weeks or months after a doctor’s visit. Different states have different rules. Sometimes, you need to complete an application, and sometimes, there is a fee. It is a good idea to ask for key health records at the end of each visit—ask for test results and transfusion records.

A federal law, the HIPAA Privacy Rule, gives you the right to see, get a copy of, and correct your medical records. Most states also have laws that give you access to your records. The Center on Medical Record Rights and Privacy has information on the laws in all 50 states and how to get copies of your medical records. Visit the Center online at http://ihcrp.georgetown.edu/privacy/records.html.

Take Notes

Keep a log of changes in how you feel. Some of these changes may be symptoms of your disease. Others may be side effects of treatment. This is key information that only you can provide.

Keep a running list of questions to ask providers. And record your healthcare providers’ answers. Include what they say over the phone and via email, as well as during office visits.
Find an Organization System That Works for You

Now that you have all this information, you need to figure out the best way for you to keep it organized and in one place. Here are some tools other patients have found useful:

- 3-ring binder with dividers
- Accordion folder
- Electronic files and spreadsheets on a laptop or desktop computer, tablet, or smart phone
- Manila file folders
- Notebook or journal
- Online tools such as a personal electronic health record, or EHR for short

Remember—there’s no right way to compile or organize. Use the tools that work best for you.

Consider Creating a Personal Health Record (PHR)

If you don’t have one, now may be the time to create a complete personal health record, or PHR for short. The PHR is a tool that you can use to collect, track, and share all your past and current health information. A complete PHR can help you share your health history with healthcare providers, avoid unneeded tests and procedures, and lower the chance of medical errors.

To start your personal health record, you will need to request a copy of your health records from all of your healthcare providers, including your primary care doctor, eye doctor, dentist, and any other specialists you have seen.

Remember, you’re in charge of making choices about your health. A PHR can help you do that.

For detailed instructions on how to create your own PHR, go to www.myphr.com. This Web site is a service of the American Health Information Management Association (AHIMA).
Share Information

Share your medical information with providers, family, and friends. It will help them stay in the loop—so they can assist and support you better.

Take Medical Records With You When Traveling

Are you going on a long trip? Be sure to take your medical information with you. You never know when you might need it. It is also a good idea to have a current medication list in your wallet or purse in case of emergency. Just make sure to make photocopies and leave a set at home in case you lose any of this information.

If you are going on a trip, it is also advised that you locate hospitals, pharmacies, and other medical facilities near your destination. You can include this information in your healthcare files.
Summary:

Keeping track of your medical records and health information can be quite a task. Yet being able to put your hands on paperwork you need with a moment’s notice can be very helpful as you advocate for your health. While it may not come naturally to you to ask for your health records, gaining this assertiveness skill can help you feel in control of your health.

Feeling overwhelmed by paperwork? Read Section 5 to see how your personal support team may be able to help out.

Skills Checklist

Use this checklist to assess your skills in organizing key health information:

- I use a system for organizing my health information.
- I can put my hands on health information when I need it.
- I ask for key health records at the end of each visit.
- I take my health information with me when I travel and make sure I have a second copy at home.
Pillar 5: Build a Strong Personal Support Team

“I encourage my wife to stay active—even when she’s feeling tired. I remind her to take a nap. I try to be helpful and supportive and ask how I can help her.”

— Roger, husband of MDS patient

“You feel lonely. You feel like no one could possibly understand what you’re going through.”

— Ruth, former aplastic anemia and MDS patient

“Joining support groups has been helpful for me because I’ve been able to hear new information. Plus, I’ve been able to share with people who have been recently diagnosed.”

— Jill, MDS patient

“You realize there are other people out there who have dealt with it.”

— Stephen, aplastic anemia and PNH patient

You Don’t Have To Do It Alone!

Having a bone marrow failure disease can be a heavy burden. But you don’t have to carry it alone. There are people in your life—and people you don’t know yet—who would be glad to help you cope with the physical and emotional demands of your disease. With their support, you can become a stronger self-advocate.
Get Support From Family and Friends

Family and friends—the people who love you—can be a tremendous source of strength. They can help you with daily tasks and give you emotional support. It can be hard to accept the fact that you need support—but it is important for your health. Try these tips:

- **Make a list of tasks**
  Keep a list of tasks you could use help with. For instance, you might ask family and friends to:
  - Cook, clean, and shop for you
  - Give you rides
  - Go to healthcare provider and hospital visits with you
  - Look after your children
  - Organize your medical information
  - Research your disease and treatment options
  - Talk with you, or listen while you talk

- **Ask for help**
  Family and friends often want to support you, yet they may not know how. Feel free to tell them what you need.

  Having trouble? Try these conversation starters:
  - “I could use a hand with …”
  - “It would be really helpful if you would …”
  - “I’m not feeling very well today. Would you mind …”
  - “I sure could use some help with …”
  - “I’d really appreciate it if you …”

- **Keep them in the loop**
  Family and friends want to know how you’re doing. But answering their questions can be tiring.

  Think about asking one family member or friend to give updates on your behalf. Or, post updates on a health social networking Web site like www.caringbridge.org.

- **Know your limits**
  Having a bone marrow failure disease takes a lot out of you. Know your limits, and feel free to say “no” to outings and activities planned by family and friends.
Get Support From a Health Advocate

“My older sister and I have always been very close. She lives in an assisted living home near me. She has MDS and was always an excellent advocate for herself until recently. Lately, Janine is feeling overwhelmed. I see how hard it is to cope with a chronic health condition, so I asked Janine if I could go with her to visits and be in contact with her doctor and nurses. She actually seemed relieved to have someone help her through this difficult treatment round.

I heard it varies from state to state, but I became Janine’s official patient advocate (PA). I had to sign a state-approved form to accept this role. Being her PA allows me to review medical changes in any type of healthcare facility.

I know my sis will be back in the swing of things once she is feeling better. For now, I think it works well for both of us that I am taking a role to help her out.”

— Robert, brother of MDS patient
About Health Advocates

A health advocate (also referred to as a patient advocate) is a family member, friend, trusted coworker, or paid professional who can help you advocate for your best care. This person can go with you to your doctor visits, ask questions, and write down information. You may also want your health advocate to speak up for you when needed.

Ask a family member or friend to be your health advocate

A friend or family member may be able to serve as a patient advocate. You may want to ask a few people to share that role. Each person can take on different tasks. One person may be better able to assist you with a doctor’s visit, while another might be able to assist you with insurance issues.

Choose a professional patient advocate

The Patient Advocate Foundation has professional case managers who provide a variety of services to help patients to settle issues with access to care, medical debt, and job retention related to their illness. Their services may be free. To learn more, call them at (800) 532-5274. Or, go to www.patientadvocate.org.

Also, many hospital, community health centers, and long-term care facilities have professional patient advocates on staff. They go by different titles. Some of the more common titles include:

- Care manager, or case manager
- Health advocate
- Healthcare navigator, or health advisor
- Nurse navigator, or oncology nurse navigator
- Patient advocate, patient advisor, patient educator, or patient navigator
- Social worker
Why should you use a health advocate?

“Research shows that quality healthcare means taking an active role in decisions about your care. If you’re facing a difficult medical decision, it’s a good idea to bring someone with you who can help you take an active role in your care when you’re not fully up to it.

As a doctor and a patient, I’ve seen how valuable it is to have ‘another set of ears and eyes’ in the exam room. Having an advocate at medical appointments or during a hospital stay can ensure that you get the information you need to manage your health.

Who makes a good health advocate? Someone who is calm, pays attention to details, and can ask questions and state information clearly.”

— Carolyn M. Clancy, MD,
Director of the U.S. Health and
Human Services Agency for
Healthcare Research and Quality
www.ahrq.gov/consumer

In her article “Why It’s Wise to Use a Health Advocate,” Dr. Clancy states that health advocates can:

- Ask questions or voice concerns to your doctor for you
- Ask the “what’s next” questions, such as: “If this test is negative, what does it mean? If it’s positive, will more tests be needed?”
- Compile or update your medicine list
- File paperwork or assist with insurance matters
- Help arrange rides
- Help you follow treatment instructions, including asking questions about your follow-up care
- Remember your medicine schedule
- Research treatment options, procedures, doctors, and hospitals
Get Support From an AA&MDSIF Patient Educator

Have questions about your disease and treatment options? Call us at (800) 747-2820. Ask to speak to our patient educator. Or, email us at info@aamds.org.

Get Support From Other Patients

More than anyone else, people living with bone marrow failure diseases know what you’re going through. They can let you know you’re not alone. Here are some ways to connect with them:

• Ask your healthcare providers about talking with a peer mentor at your treatment site
• Attend AA&MDSIF meetings and events
• Call us at (800) 747-2820. Ask to speak to a Peer Support Network volunteer
• Go to the AA&MDSIF Facebook page at www.facebook.com/aamds
• Join a support group. If you can’t find one specific to your disease, join a related one—such as a group for cancer patients
• Join an online discussion group like Marrowforums.org

Get Support From Your Healthcare Team

You may be able to get emotional support from a member of your healthcare team. This healthcare provider may be a counselor or social worker. Or it may be a nurse or doctor who goes above and beyond.
Summary:

For many of us, asking for help is not easy. Yet, empowered patients know that help from others can help them get the healthcare services and treatment they need. Some of us have family members or close friends who live nearby and are willing and able to serve as part of our support team. Others choose a professional patient advocate. And some of us find joining online groups or forums offers the level of support we need.

Having a chronic disease can be very difficult. Knowing that someone is in your corner can help you get through the ups and downs. Remember, we at AA&MDSIF are here to help. Call us and we will connect you with other patients, send you educational materials, and offer resources and places to contact as you put together a support team.

Skills Checklist

Use this checklist to assess your skills in building a strong personal support team:

- I ask friends, family, or trusted coworkers to help out when needed.
- I get support by connecting with other patients.
- My healthcare team offers support.
- I have contacted the AA&MDSIF patient educator.
- I get support from a professional advocate.
Stand Up for Your Health—Today!

Standing up for your health is a process. It’s something that happens over time, as you learn more about your disease and gain confidence.

Pull out this booklet when you want to remind yourself of the core skills needed to become an empowered patient. We hope it will help you take steps to become a stronger self-advocate.

We at the AA&MDSIF are standing by to support you—every step of the way. Please let us know how we can help.
Resources

Agency for Healthcare Research and Quality

(301) 427-1104 • www.ahrq.gov
This branch of the U.S. Department of Health and Human Services offers resources for healthcare consumers at ahrq.gov/consumer. To learn about how to be your own advocate, go to www.ahrq.gov/questionsaretheanswer/index.html.

American Board of Medical Specialties

(312) 436-2600 • www.abms.org
This group will tell you for free if your doctor is board certified. A doctor who is board certified has shown great expertise in a specific area of medicine. To find out if your doctor is board certified, call (866) 275-2267. Or, go to www.abms.org.

Center on Medical Records and Privacy

http://ihcrp.georgetown.edu/privacy/records.html
The Center has information on the laws in all 50 states and how to get copies of your medical records. Based at Georgetown University, the Center is a non-partisan group of faculty and staff dedicated to raising awareness of the rights and responsibilities associated with medical records.

ClinicalTrials.gov

www.clinicaltrials.gov
This Web site provides up-to-date information about clinical research that is being carried out all over the world for a wide range of diseases and conditions. It tells the purpose of each trial, who may participate, locations, and contact numbers. It also describes the clinical trial process and reports recent results. The Web site is maintained by the National Institutes of Health.

Federation of State Medical Boards

(817) 868-4000 • www.fsmb.org
This group offers profiles on licensed doctors, osteopathic doctors, and physician assistants. For less than $10, you can find out facts about your doctor’s education, any disciplinary actions, and certification, among other areas. To order a report, go to www.docinfo.org.
**Families USA Program Locator**

**www.familiesusa.org/resources/program-locator**

This Web site includes listings of health insurance assistance programs by state. These programs handle many questions about Medicare, Medicaid, and private insurance and may be able to refer you to low-cost or free healthcare (which may include prescription drug assistance).

**Food and Drug Administration (FDA)**

**(888) 868-4000 • www.fda.gov**

This Web site contains information on drugs, blood products, recalls, and safety alerts. The FDA also has a Web site called Drugs@FDA. This site provides detailed information about all FDA-approved drug products. You can easily search by generic or brand name. To find this site, go to www.fda.gov and search for Drugs@FDA. The FDA is the federal agency in charge of regulating drugs, medical devices, and biologics.

**Healthfinder**

**www.healthfinder.gov**

This Web site offers links to hundreds of sites that provide reliable healthcare information and support to consumers. It is maintained by the U.S. Department of Health and Human Services.

**Marrowforums**

**www.marrowforums.org**

This is a Web site for patients with bone marrow failure diseases and their families, friends, and caregivers. It hosts a forum-style discussion group for patients and the people who support them. It also provides basic medical information and resources.

**MedlinePlus**

**www.medlineplus.gov**

This Web site offers a wealth of information about health topics, drugs, and supplements. It also provides videos and interactive tutorials. The Web site is maintained by the National Institutes of Health.
MyPHR

www.myphr.com
This Web site is a complete resource for anyone interested in creating their own personal health record (PHR). It describes the benefits of creating a PHR, includes tools and tips for creating a PHR, and provides stories from patients about the benefits of using a PHR. The Web site was created by the American Health Information Management Association (AHIMA).

National Institutes of Health

www.nih.gov
This Web site offers extensive information and resources on various diseases and disorders. To learn more about aplastic anemia or MDS, go to http://health.nih.gov/topic/BoneMarrowDiseases. The Web site is maintained by the NIH, the research arm of the U.S. Department of Health and Human Services.

Patient Advocate Foundation

(800) 532-5274 • www.patientadvocate.org
This group can help you find professional case managers who provide a variety of services to help patients to settle issues with access to care, medical debt, and job retention related to their illness. This group also provides resources for how to be your own advocate.

PubMed

www.pubmed.gov
This Web site provides more than 20 million citations for biomedical literature from MedlinePlus, life science journals, and online books. It is maintained by the National Institutes of Health.

RxAssist

www.rxassist.org
This Web site has a complete database of patient assistance programs run by drug makers. These programs can provide free or low cost drugs to patients that qualify. They may also be able to help you work with your insurance company to get your drug covered. The Web site also has practical tools, news, and articles.
More Ways to Get Help

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

- Personalized support from patient educators
- Free educational materials on many topics related to MDS
- Online Learning Center
- Patient and family conferences
- Peer Support Network
- Print and electronic newsletters with important information and updates
- Clinical trials information

Contact us today. Here’s how:

- Call us: (301) 279-7202 or (800) 747-2820
- Email us: info@aamds.org
- Go to our website: www.AAMDS.org

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