Living Well With MDS

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Begin at the Beginning....

• 2009 internet based survey conducted by the AAMDSIF
• 358 patients surveyed
• 55% did not know their International Prognostic Scoring System (IPSS) score
• 42% were unaware of their blast percentage
• 28% were unaware of their cytogenetics

Source: The Oncologist 2011;16:904-911

And, that’s why we’re here!

Objectives:
• Discussion of management of disease symptoms
• Discussion of coping with side effects of therapy
• Discussion of communicating with your health care team
• Connect with other MDS patients

Management of Disease Symptoms

To manage your disease symptoms you need to:
• Understand the disease - What is MDS?
• Understand the common symptoms of MDS
• Understand how these symptoms relate to other healthcare issues you may have

What is MDS?

Myelodysplastic Syndromes are a group of disorders where the bone marrow does not work well and bone marrow cells fail to make enough healthy blood cells.

What is MDS?

People with MDS have low blood cell count for at least one blood cell type. Bone marrow and blood contain blood cells with an abnormal shape, size, or look.
What are the symptoms of MDS?
- Fatigue is the most common symptom - it is not entirely understood and is underreported
  - “If I just get a little more rest, I’ll be fine.”
  - “Maybe I’m depressed.”
  - “I don’t want my doctor to think I’m a complainer.”
  - “I’m just trying to do too much.

Possible causes of fatigue:
- Anemia
- Chemotherapy, medication for other health conditions
- Sleep disturbance
- Pain
- Depression/anxiety
- Poor nutrition
- Hormonal imbalance
- Decreased physical activity

What can you do about fatigue?
- Track and document your symptoms of fatigue between doctor’s visits, and report them to your doctor.
- Get a transfusion if you need it!
- Manage pre-existing health conditions.
- Plan activities such that you can leave, if you become too tired.
- Make certain that you are eating well - this does not mean you should over eat!
- Discuss medications that might improve your symptoms with your doctor

How does MDS affect me?
- Decreased red blood cell count can cause:
  - Shortness of breath
  - Chest pain
  - Increased pulse
  - Tired
  - Pale skin
  - Headaches
  - Difficulty concentrating

Low platelet count can cause:
- Easy bruising
- Nosebleeds, bleeding gums
- Multiple small, flat red spots under your skin, called petechiae

Low white blood cell count can cause:
- More frequent infections that are difficult to “fight off” and take longer to heal
- More likelihood to develop fevers
- Feeling tired
How else can I be affected by MDS?

- All of these feelings are completely normal, but you should always report them your doctor.
- You also might want to consider asking your doctor for referral to a local licensed social worker or psychologist.

Denial — Anger — Sadness — Resolve

Know your medications

- Azacitidine (Vidaza)
- Lenolidamide
- Decitabine (Dacogen)

All approved by the FDA for use in MDS

Know their side effects

Medication side effects may include:

- Low white blood cell count
- Low platelet count
- Low red blood cell count
- Nausea, vomiting, diarrhea, constipation
- Mouth sores
- Injection site reactions

General principles of management of side effects related to MDS medications

- Don’t go it alone!
- Report side effects to your doctor, and ask for help in managing them.
- Some side effects can be managed at home, some require an evaluative visit at your doctor’s office, and some may require a visit to the hospital.
- Always make certain that you have contact information for your doctor at all times.
- Keep a list of all current medications (and the dose) with you at all times.

Side effects should be managed by your doctor, but with your help:

- Low white blood cell count
  - Your doctor: Monitoring, Granulocyte colony stimulating factors, possible prophylactic antibiotics, anti-virals, antifungals.
  - How you can help: Report fever over 100 degrees to your doctor immediately. Know what you should do, if your doctor’s office is closed, know the plan. Fevers, left untreated can be life-threatening. Do not check your temperature every day, unless your doctor tells you to do this.

Side effects should be managed by your doctor, but with your help:

- Low platelet count
  - Your doctor: Monitor CBC, general rule is to transfuse if platelet count is less than 10,000, but transfuse if bleeding.
  - How you can help: Report symptoms of active bleeding to your doctor immediately. Examples of active bleeding: nosebleed, bleed in eye.
General principles of management of side effects related to MDS medications

Side effects should be managed by your doctor, but with your help:

**Low red blood cell count**

**Your doctor:** Erythropoietin stimulating factors, transfusion of red blood cells

**How you can help:** Report symptoms of shortness of breath, headaches, chest pain, difficulty concentrating to your doctor. If you require transfusions, track your transfusion history—were you getting transfused once every 3 weeks, and now you are getting transfused every 2 weeks?

**Additional things to ask and think about:**
- **Vascular access**—is it difficult, or getting more difficult to place an IV when you are receiving a transfusion?
- **Iron chelation**—how many transfusions have you received? Is it time to think about medication to remove excess iron stores from your body?

**General principles of management of side effects related to MDS medications**

Side effects should be managed by your doctor, but with your help:

**Nausea, vomiting, diarrhea, constipation**

**Your Doctor:** Will treat your symptoms and based on severity. This can include increasing fluids as tolerated, temporarily altering your diet, and prescribing medicine to help control your symptoms, or you may be asked to go to your doctor’s office for blood work, and/or intravenous fluids.

**How you can help:** Track and write down your symptoms. Note when your symptoms started, and the frequency, color, consistency, time of day, and relationship to meals and medication. What makes it better, what makes it worse?

**General principles of management of side effects related to MDS medications**

Side effects should be managed by your doctor, but with your help:

**Mouth sores**

**Your Doctor:** May prescribe mouth rinses to make you feel more comfortable. May recommend temporary diet changes such as avoiding acidic foods and drink like citrus, tomato.

**How you can help:** Report symptoms early. The sooner you start taking care of them, the faster you’ll start to feel better.

**Taking control**

- Educate yourself regarding your disease and your treatment. Use reliable sources of information—ask your health care team or advocacy group for a list.
- Keep a journal of your symptoms.
- Maintain a frank, open dialogue regarding goals of therapy with your doctor and how this fits in with your values and beliefs. Remember health changes, and with that, so will your goals.
- Have the same discussions with your family and close friends.
- Involve others—family, close friends—give them jobs to do!
Taking control
• Get involved with a support network.
• Consider talking to a licensed clinical social worker, psychologist, or a member of the clergy.
• Try to stay positive.
• Maintain a healthy diet. Do not make any drastic changes without consulting with your doctor first.
• Get regular exercise - you don’t have to run a marathon, but you might feel better if you simply take a short walk.
• Continue to take care of your appearance.
• Accept that you have to make changes to your normal routine, that office visits, transfusion appointments and chemo visits are all disruptive, but that the purpose of each visit is to achieve your own personal health goals.

Preparing for office visits
To make best use of time spent with your health care team:
• DO: write down questions before your visit.
• DO: report symptoms you have been experiencing.
• DO: ask for lab results and an explanation of what they mean.
• DO: let the health care team know if you are running out of medication.
• DO: bring someone with you to listen. Two sets of ears are better than one.
• DO: use each visit as an opportunity to learn something new.
• DO: ensure that all of your doctors are communicating with each other.

SO......
MDS is a complex disease, and management takes a lot of time, understanding, vigilance, active participation, and communication
You and your health care team can manage this disease, but it is a good idea to include your friends and family to help
Communicate with others who share the same issues that you do - there IS strength in numbers

Final thoughts
Stay positive, and take a look around you...
You are not alone!

www.AAMDS.org