English Edition

# Building Blocks of Hope®

## Strategies for Patients & Caregivers LIVING with MDS

by Sandra Kurtin

A global MDS Foundation print and online patient advocacy initiative, providing a personalized educational program for the patient and caregiver to prepare, participate, and *LIVE* with MDS.

Book 5

## MY MDS PLAN

Published by the Myelodysplastic Syndromes Foundation, Inc.

You or someone you know has been diagnosed with MDS. Hearing the words Myelodysplastic Syndrome or MDS can be frightening. The diagnosis of MDS is often unexpected and filled with both immediate and long-term challenges. You probably have many questions. We are pleased that you have requested a copy of the Building Blocks of Hope booklet. It is designed to help get you the information that you are looking for and take an active part in your MDS journey.

There are individual booklets included in the Building Blocks of Hope:

- **Book 1—Understanding MDS**: A complete description of the disease process of MDS and answers to common questions.
- **Book 2—Seeking Treatment**: The treatment of MDS can vary based on the type of MDS you have and how severe it is. This section will provide details about the various approaches to treatment.
- **Book 3—Quick Tips**: The quick tips offered in this section include guidelines for monitoring and managing your symptoms.
- **Book 4—Iron Overload**: Iron overload is a possible outcome of receiving repeated red blood cell transfusions. This section answers common questions, including how iron overload can be treated.
- **Book 5—My MDS Plan**: Understanding the diagnosis of MDS will help you and your caregiver take an active part in your individual treatment plan. My MDS plan provides several tools to allow you to track and manage your journey. You may want to make extra copies of some of these tools before writing on them so that you can continue to track your progress.
- **Book 6—The MDS Foundation**: The MDS Foundation is an international publicly supported organization dedicated to serving the MDS patient, their caregivers, and the professionals that are working to improve the lives of patients living with MDS. The MDS Foundation provides a number of resources which support the Building Blocks of Hope program.

There are several components to the Building Blocks of Hope program. You have received the printed version. These printed materials, along with digital materials, videos, brief educational slides sets, links to online resources, and a number of very practical tools, can be accessed online on the MDS Foundation website *www.mds-foundation.org*. You can also view the complete handbook in a beautiful page-turning format at *http://buildingblocksofhope.com*. This includes a search feature and thumbnail views that will help you quickly find the information that you are looking for, and is a great way to share information with others. This is a continuously updated document. You can visit the MDS Foundation website or contact the MDS Foundation directly to lean more and check for any new information (see contact information below).

Allow yourself time to adjust to the diagnosis of MDS. Take time to explore the Building Blocks of Hope. We wish you the best in your journey, and hope that the Building Blocks of Hope program will provide you and your caregivers with tools and strategies for LIVING with MDS.

**The MDS Foundation**
1-800-MDS-0839 *(within US only)*
1-609-298-1035 *(outside US)*
1-609-298-0590 fax
website: *www.mds-foundation.org*
email: *patientliaison@mds-foundation.org*

# MY MDS PLAN

*Understanding the diagnosis of MDS will help you and your caregiver take an active part in your individual treatment plan. My MDS Plan provides several tools to allow you to create an individualized profile about your MDS diagnosis, your health profile, and the members of your health care team. Tools for tracking your progress are included.*


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# MY MDS PLAN

# Taking an Active Part in Your Care

## The diagnosis of MDS

The Myelodysplastic Syndromes represent a group of bone marrow diseases that have variable prognoses, treatment options, and expected survival rates. Being told that you have MDS can bring on many emotions including fear and uncertainty. Uncertainty about the diagnosis of MDS, what treatments might be right for you, how they will work, and what side effects you may experience may contribute to your fear and anxiety. Understanding your MDS diagnosis will help you and your caregiver take an active part in your individual treatment plan, as well as help you make an informed decision on the best treatment options.

## Explore the Building Blocks of Hope

Allow yourself time to adjust to the diagnosis. Take time to explore *Building Blocks of Hope* which provides a number of resources to help you better understand your diagnosis and offers strategies to take an active part in your MDS journey. Forming a partnership with your health care team, caregivers, and friends can help you LIVE with MDS. Ask for help from family, friends, or professionals. Consider joining a support group either in person or online. Others living with MDS may have good suggestions for how to better cope with this disease.

## Daily activities

Eat well, stay active, and spend time with loved ones. Eating right, exercising, sleeping well, and participating in activities with friends and family help improve overall wellness.

# Initial Laboratory Results

| Diagnostic Test | Normal Result | My Result | Date | Notes |
|---|---|---|---|---|
| Hemoglobin | Women: 12.5–16.5 gm/dL<br>Men: 13.5–17.5 gm/dL | | | |
| White Blood Cell Count | 3,500–10,000/mm3 | | | |
| Absolute Neutrophil Count | 1,500–8,000/mm3 | | | |
| Platelet Count | 150,000–450,000/mm3 | | | |
| Serum Erythropoietin | 2.6–18.5 IU/ml | | | |
| Serum Iron | 50–170 mcg/ml | | | |
| Serum Folate | > 2.76 ng/ml | | | |
| Serum B12 | 239–931 pg/ml | | | |
| Thyroid Stimulating Hormone | 0.35–4.00 | | | |
| **Diagnostic Test** | **Normal Result** | **My Result** | **Date** | **Notes** |
| WHO Classification | | | | |
| FAB Classification | | | | |
| Blast % | | | | |
| Cytogenetics | | | | |
| IPSS/IPSS-R Score | | | | |

Normal ranges may vary amongst different laboratories.

WHO – World Health Organization Classification System FAB – French-American-British Classification System
IPSS – International Prognostic Scoring System IPSS-R – Revised International Prognostic Scoring System
(see: *How Severe Is My MDS?)* and the *IPSS-R calculator*)

*patient identification sticker*

## MDS Treatments

| Date | Treatment (medication, dose, days) | Notes/Side Effect |
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# Bone Marrow Results, Blood Type, and Other Diagnostic Testing

| Date | Bone Marrow Blasts % | Cytogenetics *include reports in your MDS Plan* |
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| Blood Type and Any Antibodies/Where Tested |
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| Date | Radiology or Other Testing *include reports in your MDS Plan* |
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## Blood Counts and Transfusions

| Date | Hgb | WBC | ANC | Platelets | Ferritin/Other Labs | Transfusion(s) | Notes |
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*Hgb = hemoglobin  WBC = White blood cells  ANC = Absolute Neutrophil Count (Total WBC x % segs and bands)*

# Appointments and Questions

This section will assist you in planning your appointments for physician visits, transfusions, medical tests, and other treatments including any necessary preparations that are required for your appointment. It will also provide you with a way to remember items that you would like to discuss with your health care providers or questions that you or your family members/support person(s) have for your physician. You may need to write your questions on another sheet of paper.

| Date | Day of the Week | Time | Provider/Location | Notes/Questions/Preparation |
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| MY HEALTH PROFILE | | |
|---|---|---|
| Name | | |
| Date of Birth | Social Security # | |
| Address | | |
| City | State | ZIP Code |
| Home Phone | Cell Phone | |
| Work Phone | Email | |
| **Caregivers** | | |
| Name/Relationship | | Phone |
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| Emergency contacts | | |
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| Marital status/Living situation | | |
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| MEDICAL HISTORY | |
|---|---|
| **Diagnosis** | **Date** |
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| Surgical History | Date |
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| PRESCRIPTION MEDICATIONS | | | |
|---|---|---|---|
| **Medication/Dose/Schedule** | **Prescribed by** | **Start Date** | **Stop Date** |
| Ondansestron 8mg every 8 hours as needed | Dr. Smith | 12/13/12 | |
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| OVER-THE-COUNTER MEDICATIONS | | | |
|---|---|---|---|
| **Medication/Dose/Schedule** | **Prescribed by** | **Start Date** | **Stop Date** |
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| **Herbal/Complimentary Medications** | | | |
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# My Health Profile

Building Blocks of Hope

*see also card holder insert for business cards*

| MY HEALTH CARE TEAM | | | |
|---|---|---|---|
| **Health Care Provider and Specialty** | **Address** | **Phone** | **Fax** |
| Referred by | | | |
| Primary Care | | | |
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| EMPLOYMENT INFORMATION | | |
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| Employer | Job Title | |
| Address | Supervisor | |
| City | State | ZIP Code |
| Phone | | |

| INSURANCE INFORMATION | | |
|---|---|---|
| Insured or Guarantor ○self ○spouse ○parent | | |
| Date of Birth | Social Security # | |
| Employer | Phone | |
| Address | | |
| City | State | ZIP Code |
| Insurance Name | | ID Number |
| Contact | | |

| Insured or Guarantor ○self ○spouse ○parent | | |
|---|---|---|
| Date of Birth | Social Security # | |
| Employer | Phone | |
| Address | | |
| City | State | ZIP Code |
| Insurance Name | | ID Number |
| Contact | | |

# Frequently Asked Questions

## What is MDS? *(MDS Foundation, 2011)*

MDS is a group of bone marrow disorders. The bone marrow is the factory for the production of blood cells including red blood cells, white blood cells, and platelets. In MDS, the bone marrow is abnormal because of a variety of malignant changes. The result is ineffective production of normal mature blood cells, resulting in low blood counts (cytopenias). Various subtypes of the disease exist with variable prognoses, treatment options, and risk of developing leukemia.

## Is MDS cancer? *(Bejar et. al., 2011)*

The diagnosis of MDS requires a bone marrow biopsy and aspirate. The specimen is analyzed by pathologists specializing in blood disorders. The diagnosis of MDS requires specific malignant features such as dysplasia or cytogenetic abnormalities. Research has identified molecular abnormalities thought to play a role in the development of MDS. Given the underlying malignant features of the disease, MDS is considered a form of blood cancer.

## What causes MDS? *(Greenberg et. al., 2011; Sekeres, 2011; Sekeres et. al., 2011)*

The cause of MDS is unknown in more than 80% of diagnosed patients. It is more common in men (male to female ratio is 4.5:2 per 100,000). As with many types of cancer, older age is a predisposing factor. The majority (86%) of patients with MDS are older than age 60. Exposure to chemicals such as benzene and other solvents and tobacco smoke are known to increase the risk of developing MDS. Patients who receive certain types of chemotherapy or radiation treatment for other cancers may be at increased risk of developing treatment-related MDS.

## Is MDS inheritable? *(Sekeres, 2011)*

Inherited genetic predisposition for developing MDS and congenital abnormalities is rare. Before 1973, only 143 cases of MDS were reported. Today, based on data analysis techniques, the estimated incidence varies from 15,000–162,000 *(USA data)* cases per year. The wide variation in this data highlights the challenging diagnostic features of MDS. As diagnostic features of MDS become more familiar to clinicians, MDS is detected more often in patients presenting with cytopenias (low blood counts). The development of therapeutic options may increase the number of patients considered for diagnostic evaluation. Increasing numbers of patients are being treated with cytotoxic therapies, raising the potential for secondary malignancies, including MDS (Cogle, et. al., 2011; Ma, et. al., 2007; Sekeres, 2011).

## What are the symptoms of MDS? *(Kurtin, 2011)*

Many patients are asymptomatic and are diagnosed on routine screening. Others present with vague symptoms associated with one or more cytopenias (low blood counts).

- Fatigue, shortness of breath, palpitations (common anemia symptoms)
- Fever, recurrent or prolonged infections (common neutropenia symptoms)
- Bruising, petechiae, or bleeding (common thrombocytopenia symptoms)

## How is MDS diagnosed? *(Kurtin, 2011; National Comprehensive Cancer Network, 2011)*

The initial patient evaluation most often includes a complete blood count (CBC), which reveals normocytic or macrocytic anemia, normal to decreased numbers of neutrophils, and variable platelet counts. Anemia is observed in 90% of patients with MDS, either at initial presentation or during the course of their disease. A careful history and additional laboratory analysis should be pursued to exclude other causes of cytopenias.

## What are my treatment options? *(Greenberg et. al., 2011)*

Treatment selection for MDS is individualized based on recognized disease characteristics and risk analysis. Treatment options vary by region based on approval mechanisms. The goals of therapy for MDS are based on individualized disease characteristics, patient characteristics, and risk category. In the United States, the International Prognostic Scoring System (IPSS) categorizes the MDS subtypes into two major groups: low- and intermediate-1 risk or intermediate-2 or high-risk. The goal of therapy for each category differs based on expected survival and risk of leukemic transformation. A revised IPSS (IPSS-R) is being developed to further refine these risk categories and guide treatment selection. The World Health Organization Prognostic Scoring System, with similar treatment guidelines, is commonly used in Europe.

## Are blood transfusions dangerous? *(Kurtin, 2011; National Comprehensive Cancer Network, 2012)*

The normal body mechanism for control of iron stores is highly efficient. Each unit of transfused blood delivers iron in excess of the normal daily requirements. After repeated transfusions, excess iron storage exceeds the levels that can be controlled by normal iron homeostatic mechanisms, leading to the formation of toxic iron storage and subsequent cellular damage.

A strong correlation exists between transfusion intensity (number of units received over time) and organ damage. Iron accumulation may result in end-organ damage.

| | |
|---|---|
| **heart** - congestive heart failure | **endocrine glands** - diabetes |
| **liver** - elevated liver function tests, hepatomegaly, pain | **bone marrow** - dysfunctional hematopoiesis |

Based on this data, and the concern for increasing bone marrow failure, transfusion dependence is considered an indication to initiate disease modifying treatment for MDS.

## How likely am I to get better with the treatment?

The response to treatment for patients with MDS varies according to IPSS risk categories as well as other prognostic indices. Allogeneic bone marrow transplantation remains the only potential cure to date. However, patients may benefit from currently available therapies, and durable responses have been reported.

## How long will the treatment take to work?

A minimum of four to six months of treatment is required to evaluate initial response, and the best response may not be evident until after as many as nine months of therapy.

## How long can I expect to be treated? *(Kurtin, 2011)*

Because of the limited number of treatment options and the incurable nature of the disease, disease modifying treatments for MDS are continued until disease progression or unacceptable toxicity.

## What are the common side effects of treatment, and what can be done to control them?

*(Kurtin, 2011; Kurtin & Demakos, 2010)*

- The most common side effect for all therapies for MDS is myelosuppression, including anemia, neutropenia, and thrombocytopenia.
  - Weekly complete blood count, differential, and platelet counts are recommended for the first eight weeks of treatment.
  - Cytopenias are expected to get worse before they get better.
  - Supportive care strategies are encouraged, including growth factors and transfusions.
  - Drug-specific guidelines for dose modifications or holidays are provided by each drug manufacturer based on clinical trials.

- **Nausea and vomiting:** all agents
  - Administration of anti-nausea medication is an effective strategy to minimize nausea and vomiting.
- **Constipation:** hypomethylating agents—also thought to be related to administration of 5HT3 antagonist anti-emetics
  - A regular bowel regimen that includes a stool softener and laxatives, as needed, will reduce the severity of constipation associated with treatment.
  - In addition, a good diet management and exercise routine will help.
- **Renal and hepatic toxicities**—more common in older adults
  - Baseline and ongoing laboratory analysis will allow early identification and prompt intervention for potential renal and hepatic toxicities associated with treatment.
- **Drug-specific adverse events**
  - Azacitidine: injection-site reactions
  - Lenalidomide: rash, pruritus, diarrhea, safety program for lenalidomide
- **Iron overload**
  - Chelation therapy may be associated with cytopenias and renal and hepatic toxicities.

## What new treatments are on the horizon to treat patients with MDS? *(Garcia-Manero, 2011, Kurtin, 2011)*

Clinical trials continue to explore treatment options for MDS and are always recommended for diseases that have limited treatment options, such as MDS. These trials offer hope to patients who have had limited benefit from approved therapies or have high-risk disease thought to have limited potential for benefit from these therapies. Each country has approved mechanisms for clinical trial oversight and drug approval.

## How do I select a bone marrow transplantation center? *(National Marrow Donor Program, 2011)*

There are many factors to consider when choosing a transplantation center. Some patients look at a center's experience with certain diseases or ages of patients. Other patients choose a center close to their family and friends. Some things that you and your referring doctor can find out about transplantation centers are the following.

- What experience does this transplantation center have?
- What do transplantation center survival statistics mean?
- How does the number of transplantations conducted for your disease at this center compare with other centers?
- What are the patient- and donor-matching levels required at this center?
- What are some of the pre-transplantation costs at this center?
- Is this center covered under your insurance plan?

## What can I do to keep myself healthy?

The general principles of a healthy lifestyle remain important. A balanced diet, daily activity and exercise as tolerated, and participation in activities of enjoyment are important to maintain optimal health and well-being. Ongoing management of other health conditions is important to optimal health and continued eligibility for future treatment options.

Living with low blood counts

# Suggested References


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## Eating healthy

Healthy eating begins with a plan. By eating the proper foods, your body receives nourishment and energy to get through the day. A balanced diet can help combat fatigue and illness. Adequate intake of food and fluids also helps individuals tolerate treatment. The key pieces of a healthy diet are hydration, fruits and vegetables, whole grains, low-fat dairy products, and limited amounts of sugar and processed foods.

Being diagnosed with MDS affects people's nutrition differently. Some have a difficult time eating, and lose weight, while others do not. Each person has a unique cancer experience, with varying goals for nutrition. A registered dietitian can help work through your goals to eat well and maintain your weight. Another good place to start is with the Dietary Guidelines for America 2010 at *www.dietaryguidelines.gov.*

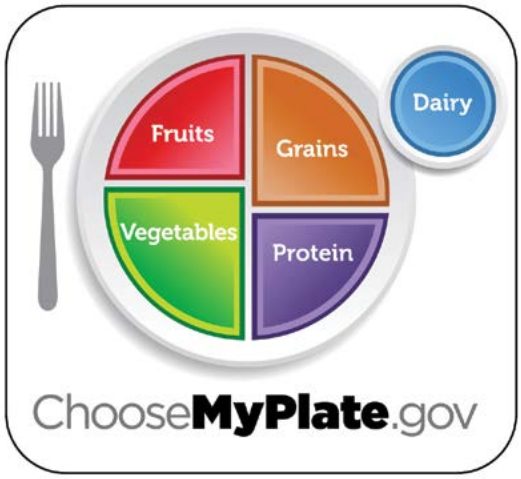
### Do I need to follow a special diet with MDS?

People with MDS may need to follow a special diet if they have a very low white blood cell count or are undergoing a stem cell transplant. Check with your health care provider to see what they recommend because the guidelines for a neutropenic diet vary by cancer center.

## General dietary guidelines

The most important thing to keep in mind is to maintain a balanced diet and adequate hydration. Each person will have unique needs based on their normal diet (vegetarian, vegan, kosher, gluten-free, diabetic, etc.), and any additional individual needs (previous bowel surgeries, dental health, irritable bowel syndrome, food allergies, etc.). It is helpful to meet with a registered dietician to determine your daily caloric needs and how you might get these in the foods you like to eat.

## Guidelines for healthy eating




- Eat fruits and vegetables.
  - They can be fresh, frozen, or canned.
  - Eat more dark green vegetables like leafy greens or broccoli and orange vegetables like carrots and sweet potatoes.
  - Wash all fruits and vegetables well prior to eating.
- Vary your protein choices with more fish, beans, and peas.
- Eat at least three ounces of whole-grain cereals, breads, crackers, rice, or pasta every day.
- Have three servings of low-fat or fat-free dairy (milk, yogurt or cheese) that are fortified with vitamin D to help keep your bones healthy.
- Make the fats you eat healthy ones (polyunsaturated and monounsaturated fats).
- If you are undergoing a stem cell transplant—you may need to follow a specific neutropenic diet (a diet for patients with very low blood counts due to stem cell transplants or leukemia treatment).
  - Avoid raw or rare meat and fish and uncooked or undercooked eggs. Cook meat until it's well done. Thoroughly cook eggs (no runny yolks).

- Avoid salad bars and deli counters. Buy vacuum-packed lunch meats instead of freshly sliced meats.
- Consume only pasteurized milk, yogurt, cheese, and other dairy products.
- Avoid soft mold-ripened and blue-veined cheeses such as Brie, Camembert, Roquefort, Stilton, Gorgonzola, and Bleu.
- Avoid well water or boil it for one minute before drinking. At home, it's okay to drink tap water or bottled water.

## Hydration

Fluids are an essential part of a healthy diet. Your body needs fluids to function properly, like a car needs gas to run. Adequate hydration varies from one person to another. The goal of hydration is to avoid dehydration without drinking too many fluids. The following tips can help you improve hydration.

- Carry fluids with you wherever you go.
- If drinking a full glass causes bloating, take small sips throughout the day.
- Drink most of your fluids between meals.

## Exercise

The most frequently reported symptom in MDS patients is fatigue. One of the best strategies for fighting fatigue is exercise, so move to improve your fatigue! In several studies, exercise has been shown to decrease fatigue and emotional distress. Exercise improves functioning and overall quality of life. A variety of exercise interventions have been studied in cancer patients during different phases of treatment, including aerobic exercise, strength training, and stretching. Examples of studied aerobic exercises are walking and bicycling.

Prior to starting a new exercise program, it is a good idea to discuss your plans with a health care provider to make sure that it is safe for your condition. Individual exercise programs can be designed to fit most needs. An exercise program can be modified to fit each person based on their age, sex, type of MDS and treatment, and physical fitness level. Blood counts should be taken into account prior to exercise. If neutropenic, it is best to avoid community swimming pools and hot tubs. For severe anemia, aerobic exercise should be performed following a transfusion, when the hemoglobin is in a safe range. When the platelets are less than 50,000 high impact sports should be avoided, in order to prevent problems with bleeding. When in doubt, discuss with your health care team. In general, the primary objective is to get moving. Start slowly and try to make progress by setting realistic goals along the way. Recruit the support of family and friends.

## Sleep

Wellness begins with a good night's rest, which can be challenging when diagnosed with MDS. It may be reassuring to know that you are not alone in having a difficult time sleeping. One-third to one-half of cancer patients experience changes in their sleep patterns. Difficulty sleeping has been linked to physical illness, pain, hospitalization, medications, and the psychological impact of being diagnosed with cancer. Poor sleep interferes with your ability to function well and increases the likelihood of depression and anxiety. Sleep deprived states have also been linked with decreased pain tolerance. It is clear that adequate sleep improves quality of life.

### How much sleep is enough?

The general rule of thumb is 7-9 hours of sleep per night, according to the National Sleep Foundation. However, like exercise, sleep needs are individual. One person may function well with 7 hours of sleep, while another may need 10 hours. Research also supports that each person has basal sleep needs and sleep debt. Basal sleep needs are the normal amounts of sleep needed nightly, and sleep debt is the amount of sleep lost due to work, illness, or other reasons. When sleep is consistently short, it affects all areas of life, and can lead to illnesses.

### Make sleeping well a priority.

This begins with an evaluation of the current sleep habits including number of sleep hours, quality of sleep, and environment. If sleep is altered by symptoms related to MDS, discuss these symptoms with the health care team. There are various strategies and medications that can improve the quality and quantity of sleep. The following suggestions may be helpful:

- Keep regular bedtime and awakening hours.
- Avoid stimulants and caffeine 2 hours prior to bedtime.
- Exercise for 30 minutes three to five times per week.
- Limit day time napping to 30 minutes.
- Spend 30 minutes to an hour of quiet time prior to going to bed.
- Discuss problems sleeping with the health care team. Medications for anxiety, depression, and insomnia may be necessary.

## Going out

Being diagnosed with MDS changes your life. Like many other cancers, there is a lot of uncertainty. How long do I have to live? The next question is usually how MDS will affect your quality of life. Changes in the blood counts can limit the activities that you are able to participate in. This is a frequent question posed to health care providers.

## What can I safely do when I am neutropenic?

Remember, neutrophils are a type of white blood cell that protect the body from infection. Neutrophils are a part of the total white blood cell count. The number of neutrophils can be found in the differential section of the complete blood cell count (CBC). Neutropenia refers to a neutrophil count of less than 1,000. If your total white blood cell count is only 1,000, then you have neutropenia. Your nurse can help you understand your blood work.

Guidelines for activities while neutropenic are related to the risk of being exposed to people or things that would increase the chance of developing an infection. As expected, crowded places with close personal contact creates the opportunity for catching an illness. However, whether an infection occurs depends on many factors. The majority of

infections that neutropenic patients experience are not related to exposure to other people or places. Instead, most infections are from bacteria that already live inside the body that turn into problems when the neutrophils are low. Most cancer centers have neutropenic precautions, which vary.

Listed below are common recommendations that can be used as a guideline to follow when neutropenia occurs. These are only guidelines, and quality of life should be weighed against the benefit of "following the rules."

- Common sense: Avoid people who are obviously ill, avoid crowded enclosed places when your counts are low, maintain a healthy lifestyle.
- Avoid exposure to people with respiratory infections—this does not mean that you can't go out, just avoid close contact with individuals who are ill.
- Avoid areas of large crowds if your counts are very low. This does not apply to all patients with MDS, only those undergoing stem cell transplants, leukemia therapy, or who have very low blood counts.
- Carry hand sanitizer—use it in public places or when using phones, toilets, etc.
- Wash hands frequently.

## Being around children

The time spent enjoying the company of family, including children, is important. Most patients with MDS can enjoy their family without restrictions. Discuss any recommendations for limiting contact with children with your health care team.

Specific recommendations for contact with children are recommended for patients undergoing a stem cell transplant, leukemia therapy, or who have very low white blood cell counts (neutropenia). These guidelines include avoiding exposure to:

- Any child that is running a fever, or showing signs of infection, such as runny nose or cough. Viral infections are common in children who attend daycare and increases the chance of transferring infections to their close contacts.
- Children receiving live vaccines (e.g., polio vaccine) may shed the virus in the first few hours following immunization. Check with your health care provider when you have questions concerning risk of infection.
- You should be aware that small children might be incubating chicken pox or measles. If you find that you have been in contact with a child who goes on to get chicken pox or measles soon after, you should notify your health care provider.

## Medications

It is important to keep a current list of all medications, who prescribed them, the dose and frequency of administration, and any medications that have been discontinued and why (see: *My MDS Plan*). This includes over the counter medications and any "natural medicines."

All medications, whether prescribed, over the counter, or "natural," have potential and, in some cases, serious side effects. Some of the common over the counter medications that should be used with caution include:

- **Acetaminophen (Tylenol):**
  - Most commonly used over-the-counter medication in the United States.
  - Very often included in combination medications. Check labels to see if the names Acetaminophen or Tylenol appear in the list of active ingredients.
  - Doses in excess of 3gm per 24 hours may be toxic to the liver.
  - Check with your health care team about the use of Acetaminophen for fevers when your white blood cell count is low—this may interfere with monitoring any fevers.

- **Anti-inflammatory medications** are commonly used to alleviate pain from arthritis, headache, and fever. Examples include ibuprofen, aspirin, Naprosyn, and meloxicam.
  - This class of drug can cause problems by masking fevers during periods of neutropenia, and interfere with platelet function.
  - When the platelet count is less than 50,000, medications in this class should not be taken. This can increase the risk of bleeding.
- **Antihistamines**: Diphenhydramine (Benadryl) is often used prior to transfusion of packed red blood cells and platelets to help prevent transfusion reactions. The main side effect reported by patients is sedation. It can also cause problems with restless legs and agitation with higher doses of the medication. If you experience unpleasant side effects, discuss alternative medications or dose adjustments with your health care team.

## Complementary therapies

Complementary therapy is treatment used in addition to standard therapy, that is assumed to be safe, and not a risk for causing harm. Common forms of complementary therapies include:

- Acupuncture
- Aromatherapy
- Art therapy
- Biofeedback
- Labyrinth walking
- Massage therapy
- Meditation
- Music therapy
- Prayer and spirituality
- Tai chi
- Yoga

## Other alternative treatments

Wheat grass juice has been studied for its ability to remove excess iron in patients with MDS, and found to provide a benefit. The study was small, with only 20 patients. The participants drank a tablespoon of fresh wheat grass juice daily for 6 months. There was noted to be a reduction in their ferritin levels, on average from 2,250 to 950 ng/mL. There were no reported negative side effects.

Evening primrose oil has also been found to decrease injection site reactions for patients who are receiving subcutaneous azacitadine. This was tested on ten patients by German researchers. Six of the ten patients experienced a reduction in the injection site redness and irritation. The oil was applied to the injection sites every evening. It is relatively inexpensive, and can be purchased in many health food stores. Side effects that were mentioned are headache and stomach upset.

Staying well

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Cancer treatments may be given in a variety of ways: by mouth (oral) or as an intravenous (in the vein) or subcutaneous (in the fatty tissue) injection. Insurance coverage for each of these methods of treatment delivery may vary. We have assembled a listing of financial assistance programs available to MDS patients in the United States. We hope that this new resource will be beneficial in helping you with your medical needs.

## Medicare

### Medicare Part A (hospital insurance)

Part A covers inpatient hospital stays, care in a skilled nursing facility, hospice care, and some home health care.

### Medicare Part B (medical insurance)

Part B covers certain doctors' services, outpatient care, medical supplies, and preventive services. Medicare covers services (such as lab tests, surgeries, and doctor visits) and supplies (such as wheelchairs and walkers) considered medically necessary to treat a disease or condition.

If you're in a Medicare Advantage Plan or other Medicare plan, you may have different rules, but your plan must give you at least the same coverage as Original Medicare. Some services may only be covered in certain settings or for patients with certain conditions.

### Medicare Part B covers 2 types of services

**Medically necessary services:** Services or supplies that are needed to diagnose or treat your medical condition and that meet accepted standards of medical practice.

**Preventive services:** Health care to prevent illness (like the flu) or detect illness at an early stage, when treatment is most likely to work best.

## How will Medicare B work for treating MDS?

### Infused drugs

Medicare covers drugs infused through an item of durable medical equipment, such as an infusion pump or nebulizer.

### Oral anticancer drugs and oral supportive care medications

Oral drugs used for cancer treatment should be covered under Medicare part B provided they are approved by the Food and Drug Administration for the treatment of cancer (such as MDS) or other illnesses (such as iron overload or nausea). Medicare helps pay for oral anti-nausea drugs used as part of an anti-cancer treatment. You must take the drugs immediately before, at, or within 48 hours of chemotherapy, and use them as a full therapeutic replacement for intravenous anti-nausea drugs you would otherwise take. Most plans include co-pays. The amount of these co-pays may vary according to your individual plan.

### Erythropoietin (EPO)

Erythropoietin agents are injectable medication covered for the treatment of anemia for persons with chronic renal failure who are undergoing dialysis when given in the dialysis center or when given "incident to" a physician's service for other approved uses. Coverage for use in patients with anemia due to MDS is restricted to individuals who meet specific criteria including: low bone marrow blasts (<5%), no other identified cause of the anemia (iron, B12, or folate deficiency), and who have a low serum erythropoietin level.

### Durable medical equipment (DME) supply drugs

Drugs that require administration with an infusion pump in the home if medically necessary such as some chemotherapeutic agents.

### Drugs furnished "incident to" a physician's service

Drugs that are prescribed under Medicare Part B and administered at the time of a provider visit (incident to a provider visit).

For covered Part B prescription drugs that you get in a doctor's office or pharmacy, you pay 20% of the Medicare-approved amount. They must accept assignment for Part B drugs, so you should never be asked to pay more than the co-insurance or co-payment for the drug itself.

For covered Part B prescription drugs you get in a hospital outpatient setting, you pay a co-payment. If you get drugs not covered under Part B in a hospital outpatient setting, you pay 100% for the drugs, unless you have Part D or other prescription drug coverage. What you pay depends on whether your drug plan covers the drug, and whether the hospital is in your drug plan's network.

## Medicare Part D: supplemental prescription drug coverage

If you want broader prescription drug coverage, you must also join a Medicare Prescription Drug Plan (Medicare Part D). There are several different types of Medicare Part D plans, each with different levels of coverage and different drugs as a part of their formulary (preferred drugs for the plan). These plans are voluntary except for people who have both Medicaid and Medicare. It is important to consider the costs of prescription medications and co-pays needed during your treatment when deciding on participation in these plans. Out-of-pocket expenses can be quite high. Discuss this with your health care team to assist you in making an informed choice.

## Medicare Advantage Plan (Part C)

If you join one of the Part C programs, much like and HMO or PPO group insurance plans they will generally include a prescription drug plan. In most cases, you must take the drug coverage that comes with the Medicare Advantage Plan. These programs must be approved by Medicare.

## Original Medicare

Your yearly income and the amount of assets you have (not including the home you live in or your car) determine how much of the Part D costs Medicare will pay. The doughnut hole occurs when Medicare stops paying for part of your drug costs and you pay all of this yourself. Most states have many, many plans from which to choose, making it difficult to make a decision. All plans have to offer what Medicare calls a basic package, but some companies will offer more than one plan. You should pick a plan carefully. Compare plan formularies. Research drug plans to take advantage of lower co-pays. You may pay a little more each month, but you will probably save money in the long run. About 40 states have assistance programs to help low-income patients, who can also get help with Medicare Part D costs, either through their state or Medicare. Check with your Area Agency on Aging (to find your local agency call 800-677-1116).

# Write Your Legislators

## Letters do make a difference — There is power in numbers

To locate your legislator: *www.house.gov/writerep/*

*For a Representative of the House:*

**The Honorable** *(First and Last Name)*
**United States House of Representatives**
**Washington, DC 20515**

**Dear Representative** *(Last Name)*:

*For a Member of the Senate:*

**The Honorable** *(First and Last Name)*
**United States Senate**
**Washington, DC 20515**

**Dear Senator** *(Last Name)*:

### Tips for writing Congress

1. State your purpose for writing in the first sentence of the letter. For example: As your constituent, I am writing to urge your support for increased funding for [health care concern].
2. Include personal information about why the issue matters to you to make your point.
3. If your letter pertains to a specific piece of legislation, identify it. Make sure that you are referencing the correct legislation to the correct body of Congress.
   - House bills are H.R._____.
   - Senate bills are designated as S._____.
   - It is also important to know the status of the bill.
4. Be courteous.
5. Close your letter with a restatement of your purpose and indicate the response that you expect.

# Additional Resources

## Medicare

*www.medicare.gov* Official Medicare website

*www.mymedicarematters.org* Questions and answers to help explain Medicare

*www.medicarerights.org* Resources for the Medicare consumer

*www.ssa.gov* Website of the Social Security Administration. Apply here for Part D extra help.

## Formulary finder

The Formulary Finder for Prescription Drug Plans tool will allow you to find plans in your state that match your required drug list. This site is maintained by the Centers for Medicare and Medicaid Services. This document also available in Spanish.

*www.medicare.gov/find-a-plan/questions/home.aspx*

## General prescription assistance programs

**Medicare and Medicaid Prescription Drug Programs** 800-633-4227

Centers for Medicare and Medicaid Services
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

**Information about prescription drug coverage:**
*www.medicare.gov*
*www.cms.hhs.gov/home/medicaid/asp*

**Social Security Disability Programs** 800-772-1213
The Social Security and Supplemental Security Income disability programs are the largest of several federal programs that provide assistance to people with disabilities.
*www.ssa.gov/disability*

**Medication & Underinsured Assistance**
Chronic Disease Fund: 877-968-7233
This program provides assistance to those underinsured patients who are diagnosed with chronic or life-altering diseases.
*www.cdfund.org*

**HealthWell Foundation** 800-675-8416
This charitable organization offers co-pay assistance for MDS medications.
Hours are Monday to Friday from 9:00am to 5:00pm EST.
*www.healthwellfoundation.org*

**National Organization for Rare Diseases** 800-999-6673 or 203-744-0100
Medication Assistance Program
*www.rarediseases.org/programs/medication*

**Needy Meds** 978-281-6666
A resource for people who cannot afford medicine or other health care costs.
Needy Meds has information on over 600 programs.
*www.needymeds.org*

**Partnership for Prescription Assistance** 888-4PPA-NOW (888-477-2669)
Prescription assistance programs, often sponsored by drug makers, to help patients who qualify based on financial need. Search this website for a comprehensive listing of more than 475 public and private patient assistance programs including nearly 200 programs offered by pharmaceutical companies.
*www.pparx.org*

**Patient Access Network Foundation** 866-316-PANF (866-316-7263)
This foundation assists patients with their coinsurance associated with MDS treatments/medications.
Hours are Monday to Friday from 9:00am to 5:00pm EST.
*www.patientaccessnetwork.org*

**Patient Advocate Foundation** 800-532-5274
This program provides direct copayment assistance for pharmaceutical products to insured Americans who financially and medically qualify.
*www.patientadvocate.org*

**Patient Services, Inc.** 800-366-7741
A nonprofit charitable organization primarily dedicated to subsidizing the high cost of health insurance premiums and pharmacy copayments for persons with specific chronic illnesses and rare disorders.
*www.uneedpsi.org*

**RxAssist** 401-729-3284
This program provides a comprehensive database of patient assistance programs.
*www.rxassist.org*

**Together Rx Access** 800-444-4106
This program is free and offers savings of 25-40% on over 300 brand name and generic prescription drugs.
*www.togetherrxaccess.com*

## Specialty pharmacies that carry MDS medications

**Accredo Nova Factor** 866-289-7577
Offers specialized care and support for patients. Their clinical, educational and reimbursement services are tailored to meet each patient's individual needs. They will even help untangle your insurance coverage.
*www.accredonovafactor.com*

**BioPlus** 888-292-0744
This is a free service to assist patients in obtaining medicines. This service also works with various prescription funding programs, pharmaceutical manufacturers, and other resources to find financial assistance for patients.
*www.bioplusrx.com*

**BioScrip** 866-807-0516
Your complete source for effective specialty pharmacy solutions, from personalized patient support services to medication management programs for health plans.
*www.bioscrip.com*

**Diplomat Specialty Pharmacy** 877-977-9118
Provides clinical and reimbursement solutions to patients with oncologic and hematologic disorders. Diplomat's Oncology Navigator Program provides a dedicated team to help patients and health care professionals gain access to required oncology medications.
*www.diplomatpharmacy.com*

**US Bioservices** 877-263-7089
Delivers nationwide specialty pharmacy and nursing services that meet the unique needs of patients.
*www.usbioservices.com*

## Pharmaceutical company assistance

### Amgen

**Amgen Assist Online** 888-4ASSIST (888-427-7478)
Amgen's patient assistance programs provide replacement product for uninsured or underinsured qualifying patients with limited financial resources. Program includes Aranesp®, Neulasta®, NPlate®, Epogen®, Vectibix®, and XGEVA™.
*www.AmgenAssistOnline.com*

### Centocor Ortho Biotech, Inc.

**ProcritLine** 800-553-3851
Resources to help patients or caregivers learn more about treatments or financial programs.
Hours of operation are Monday to Friday from 9:00am to 8:00pm EST.
*www.procritline.com*

### Celgene Corporation

**Celgene Patient Support™** 800-931-8691
A dedicated central point of contact helping providers and patients identify resources to gain access to Celgene products, including Revlimid® and Vidaza®. Available to answer your questions Monday to Friday from 8:00am to 7:00pm EST.
*www.CelgenePSC.com*
*www.Revlimid.com*
*www.Vidaza.com*

**The RevAssist® Program** 888-423-5436
A proprietary risk-management education and restrictive distribution program for patients who have been prescribed Revlimid®. Information about Revlimid® can be obtained by calling the Celgene Customer Care Center toll free Monday to Friday from 8:00am to 8:00pm EST and Saturday from 9:00am to 3:00pm EST.
RevAssist® registratlon may be completed by visiting RevAssist Online® or by calling the Celgene Customer Care Center.
*www.Revassistonline.com*
*www.Revlimid.com*

## Eisai, Inc.

**Dacogen® Patient Assistance and Reimbursement Program** 877-644-6270
Provides information on Dacogen® reimbursement services. Available Monday to Friday from 8:00am to 8:00pm EST.
*www.Dacogen.com*

## Genzyme

**Leukine® Reimbursement Program** 888-479-5385
Provides answers to reimbursement and coverage policy questions. Hours of operation are Monday through Friday from 9:00am to 7:00pm EST.
*www.leukine.com*

## Novartis Oncology

**EPASS™ Advantage®** 888-90 EPASS (888-903-7277)

**EPASS (EXJADE® Patient Assistance and Support Services)**
EXJADE® prescription and reimbursement program helps ensure that patients receive their prescriptions on time at home or the location of their choice. The EXJADE® ScriptAssist Program provides assistance and support services hotline for patients already receiving EXJADE®. Contact your specialty pharmacy to determine your eligibility and to enroll in this cost savings program. Eligible patients can receive up to $100 toward out-of-pocket expenses for prescriptions. Contact EPASS Advantage Monday through Friday 9:00am to 8:30pm EST.
*www.epassrx.com*
*www.us.exjade.com*

# Living with MDS

*video testimonial*

My name is Bob Weinberg. I was diagnosed in 1998 at age 48 with MDS–RARS (refractory anemia with ringed sideroblasts). Here are my numbers: Since then I have received over 850 units of packed red blood cells. My white blood cells hover around 2.0, my absolute neutrophil count (ANC) between 500 and 700, and my platelets between 30,000 and 40,000. My blast count is under 5%. My current transfusion frequency is 7-8 days. I take 2,500 mg of Exjade® daily. My ferritin level, checked monthly, ranges from 450 to 700. I have an MRI every year on my heart and liver, looking for embedded iron in those organs.

My MDS story began in the water. During my 30's and 40's, I was an avid swimmer. Every morning before going to work at a large high-pressure law firm in Philadelphia, I would sleepwalk my way to the local Y to swim my daily mile -thirty-six laps. I was only one of a group of groggy people who began their day with a swim. Side by side, we would glide through the water, and being competitive by nature, we each knew which swimmers would pass us and which swimmers we would pass. Until the winter and spring of 1997-98. That is when I found the morning swim's natural order of things out-of-whack. Those I usually passed started passing me. Those who would pass me once every four laps would pass me twice as often. So to build-up my stamina, I thought that I should jog, as well. After running less than a city block, I had to stop, almost keeling over with a sharp pain in my chest, severe breathlessness, aching calves, a pounding heart and dizziness. Something was wrong, so I gave up jogging after one try and went back to the pool. Over a couple of months, my stamina and strength declined to where every one of my fellow swimmers passed me. I could not even swim six laps. I started to need a nap in the afternoon–at 48 years old. It was time to see the doctor and have my first ever physical.

That was on a Friday, and by Tuesday morning I learned the words "myelodysplasia" and "sideroblastic anemia." I went right to Google. The first thing item that came up was an article on Carl Sagan. I knew I was in for a game-changer. My siblings were tested for a bone marrow match and both failed. My internist called to ask me if "my affairs were in order." That is when the hematologist at the local hospital told me that he had patients like me with low hemoglobin, but manageable platelets and white cells, who lived on transfusions for 15 years. I then visited a specialist in MDS at a major university medical center for a second opinion. He said that I should not expect to live more than five years. I told him that I had a better offer from the hematologist at my local community hospital, and he said he could not match that. So, of course, I took the higher offer and my community hospital is where I have been treated for the last 14 and one-half years.

Not that I didn't visit the best of best in experts over the next 10 years-Stanford University, Memorial Sloan Kettering, Moffitt Cancer Center, University of Rochester, Mt. Sinai. I remember my first visit with an international expert. I asked him what causes MDS. He quickly replied, "Bad luck." I took Revlimid® on a clinical trial, but all it did was lower my blood counts, cause boils and make my hair itch. I took Vidaza® , and it worked for 5 months, but within less than a year of starting it, I was back on a 14-day transfusion frequency.

So the family flew to Seattle in early 2006. We visited the Fred Hutchinson Cancer Center, which I was told was the place for MUD (matched unrelated donor) transplants. The doctor sat my wife, my 23-year-old daughter, and me down at a small round table in a small windowless conference room and told us that I had only six months to live unless I submitted myself to a *mismatched* unrelated donor bone marrow transplant. Chances of surviving 5 years were 65%. So I gave notice at work and my wife and I leased an apartment in Seattle. But first, I took a 10-day motorcycle trip in Europe, where I conveniently broke my ankle when my Ducati spilled on gravel and landed on my foot. That set back the transplant schedule. Bones won't heal when your immune system is suppressed as it is in a BMT. By the time my ankle had healed, however, I decided against the unrelated mismatched procedure. That was 6 and half years ago. I recently had the donor search re-run, and I learned that with the donors available and the billions of antibodies I have garnered from so many past transfusions, I should consider a BMT only if it is my very last option. So I am sticking with the transfusions.

By year 2009, transfusion frequency was down to 10 days, and I was faltering in meeting the pressures at work what with the interruptions for blood tests, feeling lousy and transfusions. So I cut my workload by 80%, became further involved in the MDS Foundation and spent much more time walking my dog. Meanwhile, antibodies seem to be destroying the transfused blood more quickly and preventing me from getting quite the same energy lift I used to get from a transfusion. But time marches on, and I have no sense that anything is coming to a close.

Recognizing that MDS comes in many shapes and sizes, I have lived by the following points.

- Don't worry about something that may happen in the future. I can worry about it when it happens.
- Do everything I can to be informed so that I can make intelligent choices.
- Don't get caught up thinking that I am in a battle in which I have some control over whether I win or lose. We are in the realm of those things over which we don't have control.
- If things don't work out, it is not because I did not fight enough, or I did not have faith enough, or others weren't praying for me enough.

Bob Weinberg

Building Blocks of Hope

# Living with MDS

*video testimonial*

Hello. My name is William Pearson. I am 76 years old and live in Hamilton, Ontario, Canada. I was born and raised in Nelson, British Columbia. Following school, I played hockey for two years and after that worked in the steel manufacturing sector for 45 years. Following my retirement, I started up a consulting business. My consulting projects took me to different parts of Canada, Germany, and Poland. When I was in Krakow, Poland our office was within walking distance from our hotel and then arranged transportation to different steel plants in that area. One week into the project, I started to labor in my morning walk to the office. At this point I found it difficult and started to taxi back and forth. Walking about the steel plants became more difficult. Climbing stairways to operating decks became difficult. I found myself having to stop every 5 or 6 stairs before I could continue.

On my return to Canada, my first visit was to my family doctor who ordered blood tests. She called me after receiving the results. My hemoglobin was 88mg/dL (or 8.8 g/dL), well below the normal range. She referred me to a hematologist. Thankfully, I wasn't going to a stranger as I had seen the hematologist in the past with other problems. I find it more comfortable if you know the doctor you're about to see. The hematologist repeated the blood tests and at the next visit, I had a bone marrow biopsy and aspiration. (January/2003 hg.81 (8.1)

In a follow-up appointment 6 weeks later, she indicated that the results didn't look good. She also needed to repeat the bone marrow test to get more information to compare. I still kid her that she bent the needle during the second bone marrow aspiration on purpose but she maintained it was my bone structure being so hard nothing to do with her. At this point I started red blood cell transfusions to maintain my hemoglobin. (March 19, 2003)

On the next visit, she indicated the results of the two bone marrow procedures indicated a diagnosis of MDS. I don't remember any fear or concern other than what's next. We discussed the option of a stem cell transplant. If that was to proceed, my sister would be the most suitable candidate. I called my sister to discuss this with her. My sister Jane lives on the west coast, about 5 hours by plane, her response was, "How soon do you want me there?" Bone marrow transplants take time to plan and not all patients are able to have an allogeneic bone marrow transplant. My age at the time being 60+ was a factor, just outside the range recommended for this type of transplant. So, the doctor suggested a pill, Danazol®, which might help my bone marrow function better. She indicated that based on her experiences, it was working in about 5% of her patients.

After a period of time, the drug stopped working and I was being transfused 2 units of blood at two-week intervals (between April 2007 and January 2008). I had developed iron overload as a result of all of these transfusions. She referred me to a major cancer hospital in Toronto, about 60 kilometer away. The hospital (Princess Margaret Hospital) has the reputation of being one of the top cancer hospitals in the world. My first appointment was early in September 2007. I was referred to this hospital in hopes of being fit into a clinical trial for new treatments for MDS. After another bone marrow procedure and several visits, it was determined that I did not meet the criteria for any of the drug trials.

In December 2007, she wanted to try a drug called Cyclosporine (autoimmune suppressant). After reading all of the literature on the drug, I determined it was not for me. Big mistake on my part. My wife and I got to know the doctor very well, seeing her every 2 weeks for 3 months. We developed an admiration and a dear respect for her. When she said it was the best treatment for me at that time and that we needed to consider it, our "yes" came very quickly. The results were very positive. At one of my appointments, the doctor and Janet (wife) said phlebotomy in unison. I had a total of 3 which brought my iron overload out of the critical area.

Today I am still on cyclosporine and it is holding my hemoglobin in the range of 105 mg/dL (10.5g/dL). We can't increase the dosage because it has affected my kidney function.

**How is my quality of life?**

To sum it up, for the most part there has been little change. Some days are worse than others. An example is walking a kilometer one day without stopping and others having to stop for a moment every 5 meters. Lifting is also a chore, house work exhausts me–sometime my excuse works but not too often as Janet knows it is a poor excuse to avoid it.

We still travel. In 2010, we went to Scotland for a holiday in conjunction with the MDS Foundation International Symposium. Janet and I spoke at an MDS forum for patients and their caregivers from all the European countries. We travel across Canada to the west coast yearly. I still play golf with the use of a power cart. The golf club puts a flag on my cart to allow me to take it to as close to my ball as possible excluding the greens.

**What are my fears?**

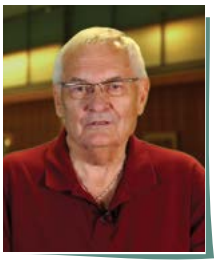
I am apprehensive about my life with MDS. I don't dwell on it and, for the most part, have little fear. The only time I get a bit edgy is after blood tests while I am waiting for results.

Early in my diagnosis, I enrolled in the Leukemia Lymphoma Society first connection program (until about a year ago). The LLS would contact me that X person would like to talk to someone with MDS. Being the only name in the databank, I would be asked if I would contact a person regarding MDS–95% of the folks were from the United States. I think that my sense of helping someone else took away my anxieties.

I have seen a major change in the past 1½ years. MDS is no longer in the closet, so to speak. A significant example is Robin Roberts, anchor for ABC Good Morning America. Robin went public on her show, and many stories about MDS were in newspapers across the country. ABC continues with updates.

What are my hopes for the future? I'm not sure how a 76-year-old man should feel, quality of life and longevity of life are my biggest hopes and I would be satisfied with status quo. I do hope in my lifetime I see research that would treat and maintain MDS of all types.

William Pearson



Building Blocks of Hope

# Living with MDS

*video testimonial*

My name is Janet Pearson and my husband William has Myelodysplastic Syndrome.

The initial diagnosis was 10 years ago (the internet description and prognosis of MDS was more frightening than hopeful). In 2002, William was in Poland for two weeks and on his return he saw his family doctor. The blood work from that visit showed hemoglobin of 88mg/dL (8.8g/dL). He was then referred to a hematologist.

A bone marrow aspiration was done in January 2003. William's hemoglobin at that time was 81mg/dL (8.1g/dL). We spoke with the hematologist about a bone marrow transplant, but his age was a concern.

The doctor put William on a drug which maintained his hemoglobin counts, and sustained his and my quality of life for about 4½ years.

Our lives carried on as if nothing was threatening our longevity together. We played golf together, vacationed, and socialized. William travelled to Europe on business trips, and his life was visibly unaltered. I was working, playing piano, painting, going to yoga and enjoying the daily activities that were a part of a relaxing lifestyle.

In April of 2007, our lives were altered with a 4:00 am, hospital visit. William's hemoglobin was 80mg/dL, which meant another bone marrow aspiration, transfusions and other diagnostic testing to check for a possible source of bleeding.

Diagnostic tests proved normal. The bone marrow confirmed MDS had evolved to a more critical level, a more aggressive treatment would be required. Transfusions continued every two weeks. An appointment was arranged at a major cancer centre in September of 2007. This initial appointment required another bone marrow test, and weekly appointments which were then followed by biweekly appointments. These bone marrow results confirmed that this type of MDS did not fit the criteria for any of the drug trials that were currently in place. This information was expressed to us at one of our October meetings. The hematologist at that time talked about Cyclosporine being an option; however, it would require approval from the government for insurance coverage. Treatment was approved and William began the medication in January 2008. The side effects were frightening.

This was a very difficult time for me. I would call home from work several times a day to check on him. If he didn't answer the phone, I would call my neighbor so that she could reassure me, and let me know that he was okay. Often times she would find him asleep in his chair in the yard. He was so pale that she would check to see if he was breathing. She would call his name to stir him awake. Everyone noticed a difference in William.

When William had iron overload I spoke with a dietician and asked about diet and foods to avoid. Tea was something she recommended and if eating red meat always have a glass of cab-sauvignon wine, not Merlot, not Shiraz but cabernet sauvignon. When William's hemoglobin reached 140 (14.0) I thought of phlebotomy and shared this with him and the hematologist. He had three phlebotomy sessions to help remove the excess iron. I also believe in movement, the importance of getting out for maybe 3/10 minute walks a day, keep moving. When creatinine starting creeping up, drinking more water was important. I still bug him about drinking water.

I am not here to tell his story but that's what I find I am doing, MDS has consumed so much of me. How has it affected me? I work, I worry. Fear sometimes consumes me. Fear of being alone, fear of what he has to go through, fear of the unknown. I know I cannot do anything about it. It is difficult to share this fear with others who do not understand MDS. You see on the outside, I project a well put together woman. I appear to be calm, but my insides are continually racing. I have been told that I am a patient and kind person, and I care so much.

I feel that I have been compromised out of fear. We used to walk for miles, chatting and laughing. Walking at a good pace, and in all kinds of weather, be it sun, rain or snow. We would sit out on summer evenings, but West Nile Virus has precipitated a fear in William and me. Walking is now a slow to medium pace. Distance depending on the day may be very short. This past Sunday evening William initiated a walk, he said, "Let's go down to the lake." We walked for 2 kilometers. It was a beautiful evening. The following night however was different. Walking any distance was impossible and he was sure it was from the walk the night before. So you see, I grab impulsive and special moments.

Last year in September, (this is usually when we vacation), we did not travel. William had an old sports injury that flared up and restricted his mobility. Therefore, rest, ice and heat were in order. During that time I started walking with my neighbor from 7-8 am Monday to Friday for 3 weeks. It felt great. We are still walking on the days that I have off from work. This is my time.

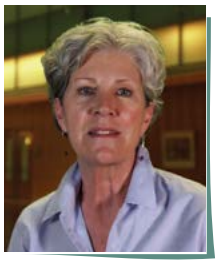
I have written letters to William regarding my fears and my frustration, but have never shared them with him.

I love my life with William; I grab the moments that we share together. I enjoy the little things like cooking together, shopping, short walks, and whatever vacation time that we can have.

My job is in the Intensive Care unit in an administrative position. Due to the fact that this is a high risk floor in the hospital, I feel the daily stresses that encompass the patients and their families also contribute to my fears.

With the fears, frustration and uncertainty, it is important to take care of yourself as a caregiver. Take time for yourself. I like to read, have lunches with friends, knit, walk and have started a quilt. I will be starting a yoga class in November with a friend.

Janet Pearson



Building Blocks of Hope

# Living with MDS

*video testimonial*

Hello, my name is Ryan Szanto. I am 74 years old and have been an MDS patient for 15 years. I hope to convey to you my experiences with MDS. I also hope my longevity with MDS will give you hope and encouragement as you live with MDS.

During a routine wellness check, I was diagnosed with anemia in July 1996. I was a very active outdoor person and did not feel that there was anything wrong with me, so I did nothing about it. The next year, during another routine wellness check, the doctor wrote in red pen and circled: Significant Anemia. He recommended that I see my primary doctor. I saw him on August 1997, and had blood tests run over a 5-week period. I was told that they didn't know what was wrong with me. My doctor recommended that I see a hematologist/oncologist, which I did.

A bone marrow biopsy was performed and it was determined that my anemia was due to MDS. This doctor had me come in once a week for a CBC for the next 15 months. In January 1999, I started on Procrit injections, 30,000 units once a week. During the next 5 years and 9 months, the Procrit injections increased gradually from 30,000 to 80,000 units to keep my hemoglobin at healthy levels. In December 2005, I was switched from weekly Procrit to bi-weekly Aranesp® injections. This was a blessing. The Aranesp® dosage started at 300mcg for 28 injections and now continues at 400mcg. I have had a total of 176 Aranesp® injections as of October 2012.

In June 2001, I started on blood transfusions. As of October 2012, I have received 377 units of blood. By June 2004, I was in iron overload. My ferritin was 2,990 due to the number of blood transfusions, so I started iron chelation with a drug called Desferal®, which is dispensed with an infusion pump for 12 hours a day, 5 days a week. I continued this treatment for 1½ years.

In the fall of 2005 the MDS Foundation notified me that there was a new oral drug, Exjade®, used to treat iron overload. Exjade® was up for FDA approval in Washington, DC and I was asked to testify as to why the drug should be approved. I was thrilled to go. It would be wonderful to get off that pump. I went with 14 other patients who also developed iron overload as a result of chronic transfusions for MDS, Aplastic Anemia, and Thalassemia. Thankfully, it was approved. I started taking Exjade® 1,500mg daily in January 2006. Hurray!!! This was another blessing. Every morning, I dissolve the Exjade® tablets in water and drink it. I've been on Exjade® ever since, except for 6 months when the Ferritin level went low enough (312) for me to come off. The dosages have varied over the last 7 years. I am currently taking 1,000mg a day.

In September 2004, Dr. Alan List of the Moffitt Cancer Research Center stopped the Procrit injections so my system would be clean to start the CC5013 (Revlimid®) drug trial. My diagnosis was MDS sub-type Refractory Anemia with Ringed Sideroblasts or RARS. The drug did not work for me. It did work for patients with 5q- chromosome malfunction. Results for these patients were amazing. Most of the patients with the 5q- had a significant reduction in their transfusion needs; some no longer needed transfusions at all. Halfway through the trial, I had a sense it wasn't working for me, but I went ahead and completed the trial because I knew that the research collected from me might benefit other MDS patients later on.

During these past 15 years, I have had 7 bone marrow biopsies. MDS is classified as high or low risk. I am in the low risk category and my biopsies have not changed during these 15 years.

During my first 3 years, I could not find any non-MDS specialists who knew anything about the disease. Also during this time, there wasn't much or any research on MDS. The first research that took place was for high-risk patients. I totally agree with this because they are at greater risk to come down with Leukemia. There is now research taking place for high and low-risk patients. The good news is that there is 100+ MDS research centers worldwide.

When I was first diagnosed with anemia and then with MDS, I was in denial. This went on for 1½ years. As time went on, I realized that not many people knew about this disease, so I decided to find out all I could and I began to keep detailed records of what was going on. I knew that my body was the temple of the Lord and I had a responsibility to take care of it. This is when my denial shifted to a positive attitude. I started by reading everything I could, looking up on the Internet, talking to my doctor, and attending the MDS patient forums put on by the MDS Foundation. In fact, I continue to try to attend one or two a year. These forums have been very educational; we hear from doctors and nurses in the field and from patients who share their experiences, ask, and discuss questions.

I have also done several videos for the drug manufacturer of Exjade®. This involvement has caused me to realize how much I appreciate what was taking place to find better ways to deal with iron overload.

I joined "data for national MDS registry" in June 2008. This is a registry that collects detailed information on MDS patients nationwide. Their goal is to help MDS patients by determining what the similarities and differences are in patients. (What works and what doesn't work.)

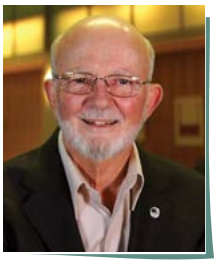
Besides learning all that I can about MDS from multiple avenues and getting involved, I have also used my faith to pray for and encourage other patients. Each time that I get out of my vehicle to enter the Oncology Center or Infusion Center, I pray the Lord will put someone in my path that He wants me to speak to, encourage, or pray for. He honors this request each time. I also thank the nurses who attend to me and if they need to pray, I pray with them. When I go to the blood bank, I introduce myself to the donors and thank them for keeping me alive.

I believe that this involvement is what is keeping me going. My positive attitude and faith has been strengthened every day.

To summarize, I would say, learn all that you can about MDS, stay up to date on the research, stay positive, be motivated, and get involved especially in patient forums. Ask questions of your doctor and nurses, and, most of all, keep God as your pilot.

Yes, it is true, I have not been healed physically, but God has healed me spiritually and my spirit is what will live on for eternity. I thank the MDS Foundation for allowing me to share this time with you. May God bless you now and forever.

**Ryan Szanto**



Building Blocks of Hope

**Building Blocks of Hope** is a global print and online patient advocacy initiative providing a personalized educational program for patients and caregivers to prepare, participate, and *LIVE* with MDS. The colors of the Building Blocks of Hope include Tucson Teal, Navajo Red, and Desert Sand. They are reminiscent of a Southwest landscape with the beauty of the night sky over the sand swept deserts and stunning mountain ranges. The colors represent welcoming, warmth, stability, healing, passion, and protection. These colors form the base for the Building Blocks of Hope logo constructed in a wave-like pattern indicating the fluidity of life, health and illness. The single red band which continues up into the plant symbolizes strength and improvement in bone marrow function. The idea of hope for the future and extension of life is emulated in the sprouting plant.

Building Blocks of Hope was created by Sandra Kurtin, Nurse Practitioner and Clinical Assistant Professor of Medicine and Nursing at the University of Arizona Cancer Center, Executive Committee and Board Member of the MDS Foundation, and advocate for patients and caregivers *LIVING* with hematological malignancies. The individual pages have been developed in collaboration with members of the International Nurse Leadership Board of the MDS Foundation and members of the MDS Foundation Board of Directors. Creative and technical support was provided by Adam Nichols and his team at Markations. Organizational and communications support was provided by Tracey Iraca, Sue Hogan, Lea Harrison and the MDS Foundation staff. Bone marrow illustrations provided by Kirk Moldoff.

A special thanks to our MDS patients and their caregivers for sharing their life experiences within their MDS journey. Additional thanks to the Executive Committee for the MDS Foundation, Peter Greenberg, M.D., Alan List, M.D., Stephen Nimer, M.D., and Pierre Fenaux,M.D., Ph.D., and to John Bennett, M.D. for ongoing contributions to the MDS Foundation. In memory of Bob Weinberg, who generously donated his time and legal expertise, and shared his own personal journey with MDS. Thanks to the scientists, health care professionals, and volunteers who continue to work towards improving the lives of MDS patients and their caregivers. To the countless numbers of patients and their caregivers who have participated and continue to participate in clinical trials that have led to a better understanding of and improved treatment strategies for MDS; we would not be where we are without your continued involvement. Thank you to our International Colleagues for their work in adapting the Building Blocks of Hope incorporating translation and integration of their culture for regions throughout the world.

We are grateful to all of our supporters; your contributions make the work of the MDS Foundation and support of patients and caregivers LIVING with MDS possible. A special thanks to my family for understanding my passion for this work.

We hope this project will provide a useful tool for health care professionals working with MDS patients. Most importantly, we hope the Building Blocks of Hope will empower MDS patients and their caregivers to *LIVE* with MDS.

Best regards and best wishes,
Sandy Kurtin