

# Living with MDS - Managing the Disease, Treatment & Side Effects

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# Living with MDS

- \* The symptoms and course of MDS vary greatly from person to person and many patients are asymptomatic
- \* The symptoms depend on what blood cells are affected and how low the blood counts have fallen

# Living with MDS

## **YOU ARE NOT ALONE**

- \* What are your concerns/needs/goals – what resources are available
- \* Fatigue, infection, bleeding (cytopenias)
- \* QOL
- \* Stress/anxiety/coping
- \* New “normal”

# Living with MDS

- \* Lifestyle plays a key role in managing your MDS
- \* Maintain good care of your mind and body for optimal health
  - \* Eat a healthy and well balanced diet
  - \* Exercise within your limitations
  - \* Protect yourself from infections
  - \* Relax and reduce stress

# Managing the Disease - Fatigue



# Managing the Disease

## Fatigue

- \* 90% of people will suffer from fatigue – tiredness, feeling less alert, trouble concentrating or with memory, weakness and lack of motivation
- \* On a scale of 1(no fatigue)-10(extreme fatigue), those with MDS the average rating of fatigue was 5.8 compared to the “normal” average of 2.2

# Managing the Disease

## Fatigue

- \* Fatigue is related to anemia (low red blood cell counts)
- \* 39% of low-risk patients and 79% of high-risk patients are transfusion dependent
- \* Contributing factors – emotional distress, inadequate nutrition, other comorbidities, pain, other medications, and sleep disturbance

# Managing the Disease

## Fatigue

### Strategies for managing fatigue:

- \* Balance activity with rest
- \* Prioritize your day, do the things that mean the most to you first
- \* Take short naps during the day or planned rest periods before activities
- \* Stick to a routine
- \* Limit alcohol and avoid stimulants and caffeine 2 hours before bedtime
- \* Have a light snack prior to bed to avoid waking up hungry in the middle of the night



# Managing the Disease

## Fatigue

### Strategies for managing fatigue:

- \* Conserve energy by pacing yourself and asking for or accepting help from others
- \* Manage stress, try relaxing activities such as gentle massage, meditation, or yoga
- \* Do some light exercise as approved by your doctor – gentle activity can give you more energy
- \* Get the nutrients needed for energy, eat a balanced diet and drink plenty of fluids

# Managing the Disease

## Fatigue

- \* Other signs and symptoms of anemia – dizziness when moving or getting up from lying or sitting too quickly, heart palpitations, SOB, and pale skin
- \* Treating the anemia – Your doctor may chose to offer you a blood transfusion, start erythropoietin injections or to start you on medication to treat the disease

# Managing the Disease - Infection



# Managing the Disease

## Infection

- \* MDS is associated with an increase risk of fever and recurrent or prolonged infections
- \* Infections are related to neutropenia (low neutrophils) which are the most common type of white blood cells -white blood cells help fight infection
- \* Contributing factors – age, other comorbidities, impaired immune system, and medications used to treat the disease

# Managing the Disease

## Infection

- \* Infection has long been recognized as a cause of morbidity and mortality in MDS patients
- \* Infections are mostly bacterial in origin
- \* Pneumonia is the most common infection associated with neutropenia and MDS
- \* FEBRILE NEUTROPENIA IS A MEDICAL EMERGENCY AND SHOULD BE REPORTED TO YOUR HEALTHCARE PROVIDER IMMEDIATELY

# Managing the Disease

## Infection

### Symptoms of Infection:

- \* Frequent infections or infections that linger
- \* Fever - 38 degrees or higher (100 degrees F)
- \* Low blood pressure
- \* Shaking chills and or unusual sweating
- \* Severe cough and or sore throat
- \* Pain/urgency/frequency with urination
- \* White patches or coating in your mouth
- \* Feeling unwell/warm or flushed

# Managing the Disease

## Infection

### Strategies for minimizing risk:

- \* Maintain good hygiene including washing your hands frequently, especially before eating and after going to the bathroom
- \* Avoid large crowds during cold and flu season and people who are obviously ill
- \* Avoid uncooked or unpasteurized meat or dairy products and wash all fruit and vegetables before eating them

# Managing the Disease

## Infection

### Strategies for minimizing risk:

- \* Use an electric shaver instead of a razor to prevent cutting your skin
- \* Clean cuts, scrapes or burns right away with warm soapy water
- \* Avoid cleaning up after animals, such as cat litter boxes or birdcages and wash your hands after touching animals
- \* Stay hydrated

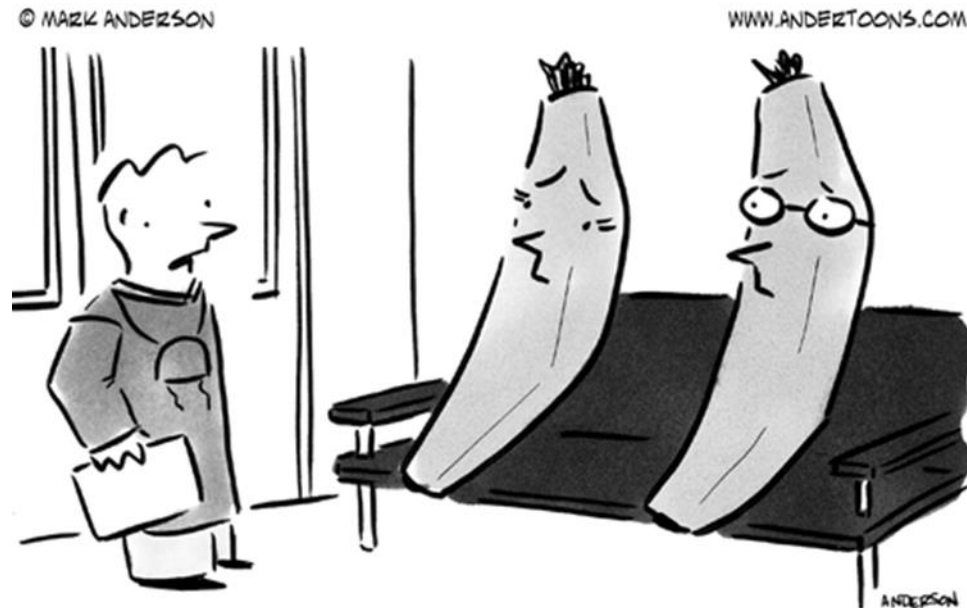


# Managing the Disease

## Infection

- \* Treating the infection – your doctor will treat you with antibiotics and hospital admission may be considered
- \* Treating the neutropenia – your doctor may consider the use of growth colony stimulating factor (GCSF), or starting you on active treatment for your disease

# Managing the Disease – Bruising/Bleeding



"It's going to be touch and go for a while -  
there's a lot of bruising."

# Managing the Disease

## Bruising/Bleeding

- \* Bruising and bleeding is caused by a low platelet count (thrombocytopenia)
- \* Platelets help your blood to clot and help maintain normal blood vessel health
- \* Over 50% of people with MDS report easy bruising and or bleeding
- \* Contributing Factors – excess alcohol, the use of blood thinners, aspirin or other anti-inflammatory medications

# Managing the Disease

## Bruising/Bleeding

### Symptoms of thrombocytopenia:

- \* Excessive bruising
- \* Nose bleeds, bleeding gums, and cuts that wont stop bleeding
- \* Tiny, flat, red spots under your skin called petechiae
- \* Heavy menstrual periods
- \* More serious - coughing up or vomiting blood, or blood in the urine or stool

# Managing the Disease

## Bruising/Bleeding

### Tips to help avoid bleeding:

- \* Avoid activities that may increase your risk of injury or bleeding (ie contact sports)
- \* Use an ultra soft toothbrush and avoid flossing if it causes the gums to bleed
- \* Use an electric shaver instead of a razor
- \* Avoid chiropractic or massage therapy that uses excess pressure

# Managing the Disease

## Bruising/Bleeding

### Tips to help avoid bleeding:

- \* Be extra cautious when using a knife, scissors or other sharp tools
- \* Be very gentle when blowing your nose
- \* Take measures to prevent constipation to avoid straining and rectal bleeding
- \* Avoid aspirin and other NSAIDS (unless otherwise instructed by your doctor)

# Managing the Disease

## **Bruising/Bleeding**

- \* Treating the thrombocytopenia – your doctor may recommend a platelet transfusion, however the benefits are very temporary and repeated transfusions are necessary

# Managing the Disease – Stress/Anxiety





# Managing the Disease

## Stress/Anxiety

- \* Feeling stressed and anxious is a normal and a common reaction to being diagnosed with MDS
- \* Anxiety is feeling afraid, overwhelmed or worried, and ranges from being mild to overwhelming and affecting your ability to function properly
- \* Uncertainty about the diagnosis, the treatment and side effects may contribute to stress and anxiety

# Managing the Disease

## Stress/Anxiety

How stress and anxiety may affect you:

- \* Interferes with memory and ones ability to concentrate
- \* Causes changes in appetite and eating
- \* Sleep pattern changes
- \* Difficulty in making decisions or problem solving
- \* Irritability
- \* If severe – headaches, diarrhea, shortness of breath or heart palpitations may occur

# Managing the Disease

## Stress/Anxiety

### Things you can do to help:

- \* Allow time to adjust to the diagnosis
- \* Talk to someone you can trust (family, friends or professionals) and ask for help if needed
- \* Try relaxation techniques such as gentle massage, meditation, yoga, light exercise or relaxing music
- \* Consider joining a support group either in person or by computer. Others living with MDS may have good suggestions on coping strategies

# Managing the Disease

## Depression

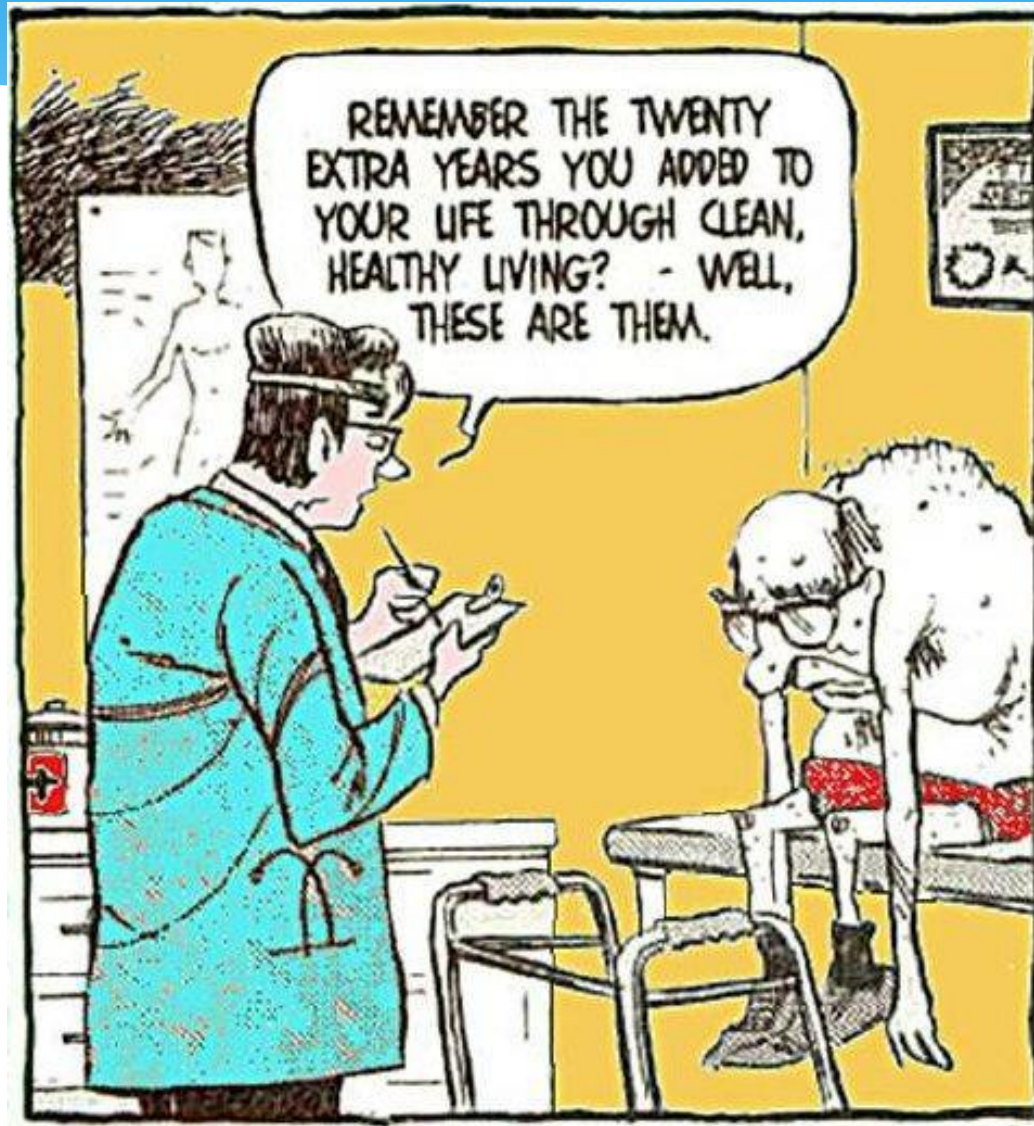
- \* Depression can be described as feeling sad, hopeless and tearful, and these feelings can come and go, but when these feelings don't go away or become worse and interfere with your daily life, they could be a sign of clinical depression

# Managing the Disease

## Depression

- \* Possible signs of depression include sleeping too little or too much, overeating or having no interest in eating, crying a lot, feeling hopeless or thoughts of harming yourself
- \* Depression can and should be treated
- \* Only a doctor can diagnose depression and suggest medication, therapy or both

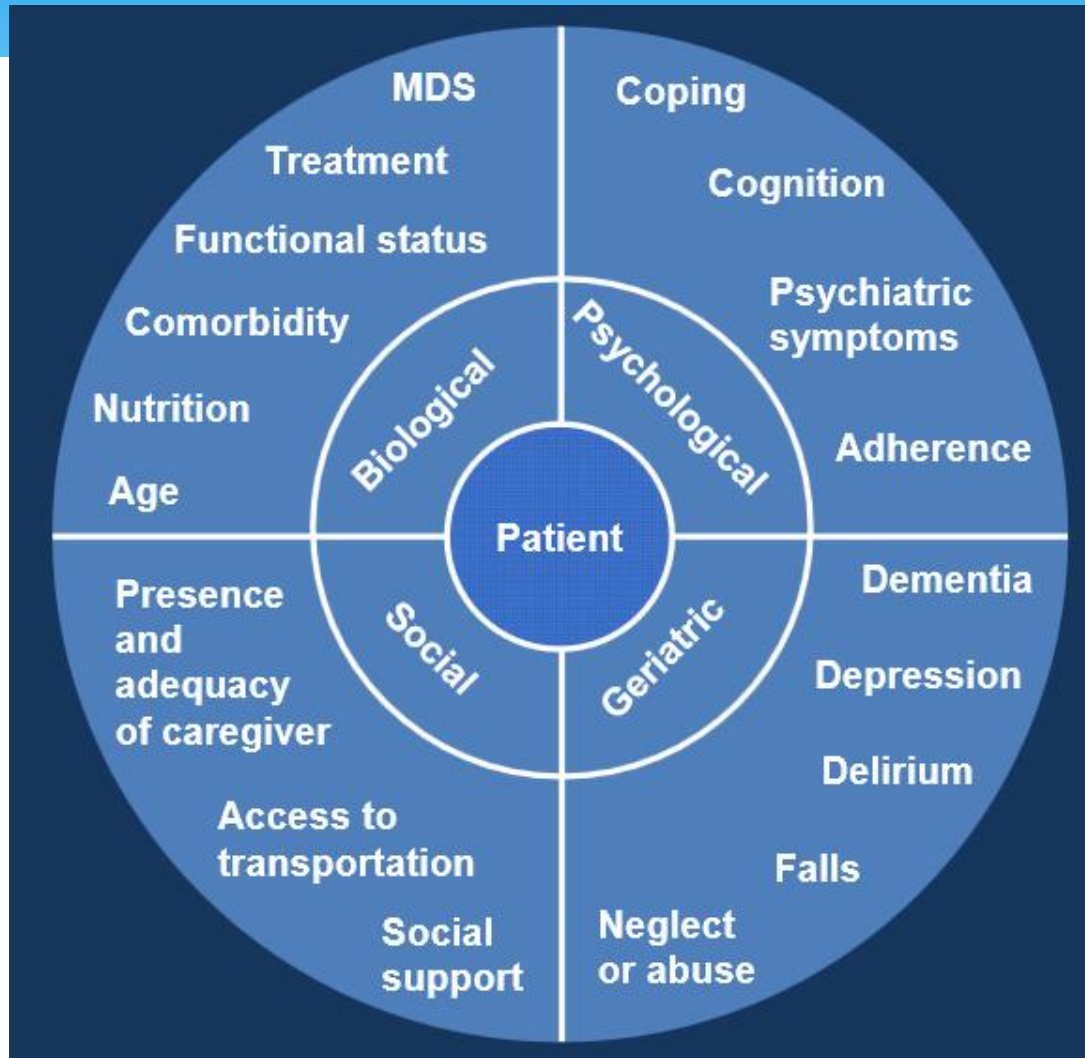
# Managing Treatment



# Managing Treatment

The standard of care for patients with MDS is dependent on many different factors, but the main goal of MDS treatment is consistent – to help patients live longer with good quality of life

# Managing Treatment





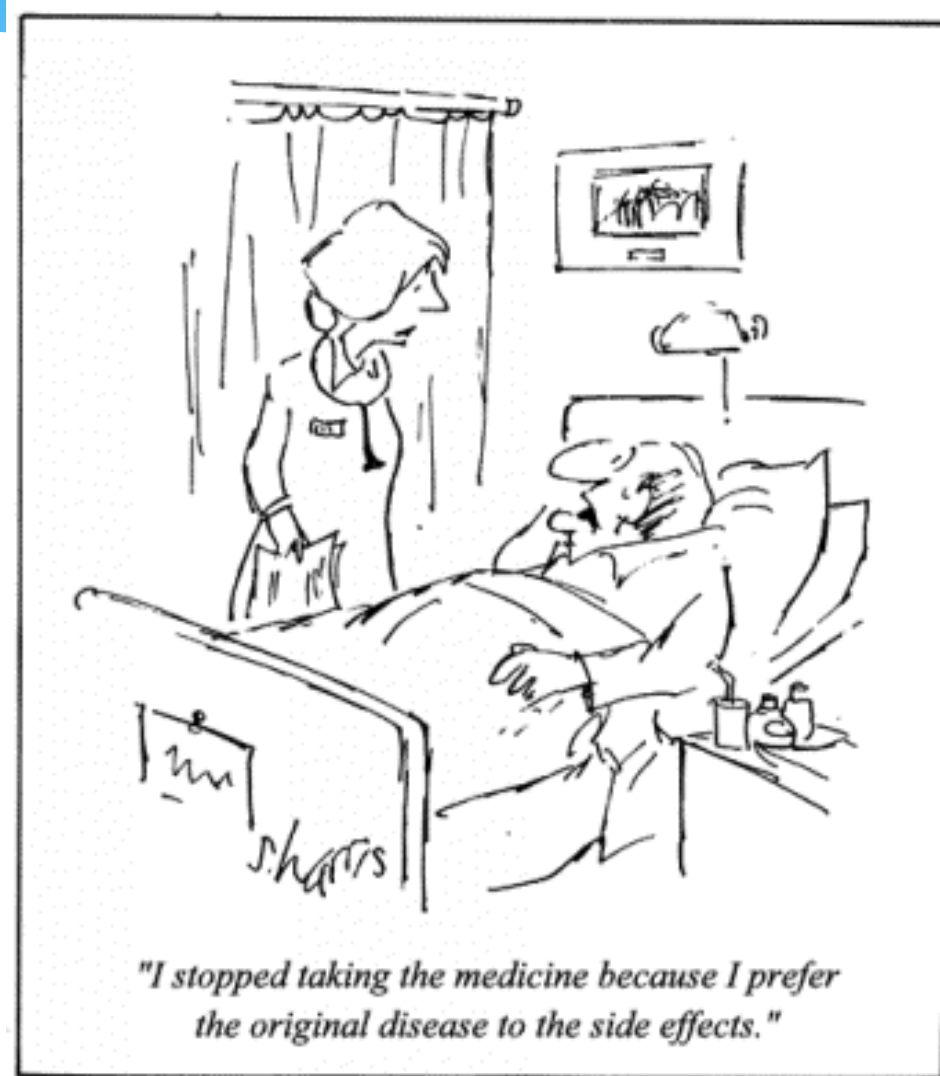
# Managing Treatment

- \* Watch and wait approach
- \* Supportive therapy and symptom management may include transfusion of blood products (RBC's or platelets), or use of erythropoietin, treatment of infection and or the use of GCSF
- \* Cytotoxic chemotherapy in appropriately selected patients with Lenalidomide (Revlimid) or Azacitidine (Vidaza)

# Managing Treatment

- \* Bone marrow transplant is the only treatment for a potential cure but it is not an option for the majority of patients
- \* Participation in clinical trials may be considered, historically older adults have often been underrepresented in clinical trials for fear of exposure to extreme toxicities, limited expectation of benefit and strain on patient and or their caregiver.
- \* More recent trials have not included advanced age in the exclusion criteria from participation

# Managing Side Effects



# Managing Side Effects

## Erythropoietin

- \* Erythropoietin injections may be used to try and stimulate your bone marrow to produce more red blood cells
- \* Injected into the tissue of your abdomen, arm or leg weekly
- \* Side effects include – diarrhea, nausea, bone pain, flu-like feeling, headache, injection site reactions and increased risk of blood clots
- \* Benefits include - avoidance of RBC transfusions and gradual improvement in fatigue

# Managing Side Effects

## RBC Transfusions

- \* Blood transfusion(s) may be recommended to help improve anemia and associated symptoms
- \* Transfusions are time consuming and results are temporary - repeated transfusions may be necessary

# Managing Side Effects

## RBC Transfusions

- \* Risks associated with transfusions include - transfusion reactions, congestive heart failure, virus transmission, bacterial contamination and iron overload
- \* Benefits to RBC transfusions include a rapid increase in hemoglobin resulting in a rapid improvement of fatigue and other symptoms associated with low red blood cells, which correlates positively with quality of life

# Managing Side Effects

## RBC Transfusions

### Transfusion reactions

- \* Allergic reactions can range from mild to life threatening and occur in 1-3% of transfusions. Most often the reactions are mild, resulting in hives and itching – usually treated with antihistamines
- \* Febrile transfusion reactions – fever usually develops quickly during the transfusion (but can occur up to 24 hours after transfusion) and may include chills and shaking, transfusion will be stopped, acetaminophen will be used to treat the fever, and the doctor will decide whether or not to continue with the transfusion

# Managing Side Effects

## RBC Transfusions

### Congestive heart failure

- \* Transfusion-associated circulatory overload is the result of receiving a blood volume that is more than the circulatory system can handle
- \* More at risk if you have a previous cardiopulmonary compromise, renal failure or chronic anemia
- \* Signs and symptoms include cough, increased heartrate, SOB, and increased blood pressure
- \* Treated with diuretics to decrease volume load and by slowing down the rate of the transfusion



# Managing Side Effects

## RBC Transfusions

### Iron overload

- \* Repeated blood transfusions may cause too much iron in your blood, excess iron can damage tissues and may accumulate in the heart and liver putting you at risk for irreversible damage
- \* Onset of iron overload is variable, but as a general rule it occurs after receiving approximately 20 units of red blood cells
- \* Your physician will be regularly monitoring your serum ferritin levels

# Managing Side Effects

## RBC Transfusions

### Iron overload

- \* Fortunately iron overload can be treated with chelation therapy or phlebotomy
- \* Phlebotomy involves removing a unit of blood and therefore removing the iron but this would only be reserved for patients who no longer require RBC transfusions as a result of treatment for their MDS
- \* Chelating agents include Desferal (given IV over 8-24hours/day, 3-7 days/week and Exjade (given orally once/day)
- \* Chelating therapy is continued until an adequate serum level (<1000ng/ml) is achieved, this may take months or even years

# Managing Side Effects

## RBC Transfusions

### Iron overload

- \* To help decrease iron overload, consume milk products, eggs, certain high fiber foods, and tea which contains polyphenols
- \* To help prevent further increase in iron levels, avoid alcohol and tobacco, avoid taking iron supplements or iron containing medications (ie vitamins with iron), avoid excess sugars, and limit your intake of foods with high iron content (beef, lamb and venison)

# Managing Side Effects Growth Colony Stimulating Factor (GCSF)

- \* GCSF (Neupogen or Neulasta) is sometimes used to help prevent infection by stimulating the production of white blood cells
- \* GCSF is injected into the subcutaneous tissue in the abdomen, arms or legs
- \* Most common side effects are aching in the bones or muscles
- \* Can use non narcotic analgesic if necessary

# Managing Side Effects

## Platelet Transfusions

- \* Platelet transfusions are sometimes recommended to reduce the risk of bleeding caused by thrombocytopenia
- \* Generally platelet transfusions are well tolerated, but side effects can occur and may include fever and chills or allergic reaction
- \* The symptoms may be managed with acetaminophen for fever and chills or antihistamines for allergic reactions

# Managing Side Effects

## Lenalidomide (Revlimid)

- \* Lenalidomide is used to treat patients who have low or intermediate-1 risk MDS where a part of chromosome 5 is missing (del 5q) and are transfusion dependent
- \* It is a capsule taken whole, orally with water, once/day (do not open, break or chew capsules) for 3 out of 4 weeks
- \* Shown to greatly decrease transfusion dependence and to even achieve transfusion independence

# Managing Side Effects

## Lenalidomide (Revlimid)

- \* Response rate is quite rapid (4-5 weeks)
- \* Some common side effects include rash, itching, fatigue, diarrhea and nausea
- \* Lenalidomide is an analogue of thalidomide and is associated with a slight potential for birth defects – all patients must be registered with the RevAid Program to access Lenalidomide

# Managing Side Effects

## Lenalidomide (Revlimid)

### Rash/Itching

- \* Change of the skin affecting the color, appearance or texture – may be localized in one part of the body, or affect multiple areas
- \* Most commonly, people taking Lenalidomide, experience patches of dry skin, itchiness, mild swelling and redness



# Managing Side Effects

## Lenalidomide (Revlimid)

### Rash/Itching

- \* What your health care provider may do:
  - \* Evaluate the rash to determine the most likely cause and level of severity
  - \* Recommend antihistamines or steroid creams to reduce irritation and itching
  - \* Make dose modifications to your Lenalidomide

# Managing Side Effects

## Lenalidomide (Revlimid)

### Rash/Itching

- \* What you can do:
  - \* Examine your skin regularly
  - \* Avoid sun exposure and use sunscreen with minimum SPF15
  - \* Wear hats, sunglasses and cover your skin as much as possible
  - \* Use mild, non perfumed, soaps and lanolin based creams to hydrate your skin
  - \* Avoid long, hot showers

# Managing Side Effects

## Lenalidomide (Revlimid)

### Diarrhea

- \* Frequent (more than 3xtimes/day), loose or watery bowel movements
- \* Sometimes associated with cramping, bloating, abdominal pain, urgency, and a foul smell
- \* Can lead to dehydration, weakness, loss of electrolytes and weight loss

# Managing Side Effects

## Lenalidomide (Revlimid)

### Diarrhea

- \* Things to help manage diarrhea:
  - \* Stay hydrated by drinking 2-3 liters of fluids/day (non-carbonated, caffeine free liquids like water, juice, sports drinks, and clear broth)
  - \* Antidiarrheal medications may be recommended
  - \* Eat small frequent meals – avoid dietary fiber (fruits, vegetables, whole grains), spicy and greasy foods and dairy products containing lactose, consider BRAT diet
  - \* Probiotic supplements and food containing probiotics (natural gut bacteria) may improve diarrhea

# Managing Side Effects

## Azacitidine (Vidaza)

- \* Azacitidine is approved for treating intermediate -2 or high-risk MDS
- \* Given subcutaneously into the tissue of the abdomen, arms or legs, or intravenously
- \* It is given daily for 7 consecutive days every four weeks
- \* Can take up to 6 cycles to see a response

# Managing Side Effects

## Azacitidine (Vidaza)

- \* Has shown to significantly increase overall survival, improve blood cell counts and decrease transfusion dependence, decrease the number of infections requiring hospital treatment, and delay the progression to more serious disease
- \* Most common side effects include nausea, constipation, myelosuppression, and injection site reactions

# Managing Side Effects

## Azacitadine (Vidaza)

### Nausea

- \* Approximately half (48%) of patients receiving Azacitidine experience nausea
- \* Nausea can be well controlled with anti-emetics like Ondansetron or Stemetil, and should be taken prior to each injection

# Managing Side Effects

## Azacitidine (Vidaza)

### Nausea

- \* Other strategies to help minimize nausea include:
  - \* eating small, frequent meals
  - \* staying hydrated by drinking lots of fluids throughout the day
  - \* avoid strong smelling, greasy, spicy or acidic foods
  - \* try to consume ginger



# Managing Side Effects

## Azacitidine (Vidaza)

### Constipation

- \* Approximately half the patients receiving Azacitidine will experience constipation, it varies between patients but it is mostly mild to moderate
- \* May be made worse by use of narcotics and anti-nausea pills

# Managing Side Effects

## Azacitidine (Vidaza)

### Constipation

- \* Tips to minimize/alleviate constipation include:
  - \* Drinking plenty of fluids throughout the day - warm/hot fluids, fruit and vegetable juices, and tea or coffee may stimulate the bowels.
  - \* Try natural laxatives like prunes, rhubarb and papaya
  - \* Eat foods high in fiber (whole grains, fresh fruits and vegetables)
  - \* Increase activity level if you can
  - \* Use laxatives or stool softeners as recommended
  - \* Do not use enemas or suppositories

# Managing Side Effects

## Azacitidine (Vidaza)

### Injection site reactions

- \* Local irritation or inflammation in the skin and subcutaneous tissue
- \* They are common and can vary from bruising to red welts
- \* In most cases they are mild and not particularly painful
- \* In more severe cases there may be painful lumps or involvement of a larger area of skin or soft tissue
- \* Most injection site reactions clear completely with time and are not considered a drug allergy

# Managing Side Effects

## Azacitidine (Vidaza)

### Injection site reactions



# Managing Side Effects

## \* **Azacitidine (Vidaza)**

### Injection site reactions

- \* What your health care provider may do to help minimize reactions:
  - \* Select a site where you can “pinch an inch” or where there is adequate fatty tissue
  - \* Rotate the sites to limit the severity at any one site and allow previous sites to heal
  - \* Avoid areas prone to friction such as the belt-line
  - \* Avoid areas with scarring, birthmarks, inflammation or breaks in the skin
  - \* Use the “air sandwich” technique

# Managing Side Effects

## \* Azacitidine (Vidaza)

### Injection site reactions

- \* What you can do to manage injection site reactions:
  - \* Wear loose clothing to avoid friction
  - \* Avoid body lotion on injection days
  - \* Avoid rubbing, scratching or picking at the skin where the medication was injected
  - \* Ice or heat should not be applied to the inject site as heat may increase irritation and ice may limit absorption of the medication, try applying warm or cool gel packs to the site
  - \* Evening primrose oil may be applied to the skin
  - \* Over the counter antihistamines or anti-itching creams may be helpful

# Managing Side Effects

## Serious Side Effects

- \* When to call your health care provider
  - \* Ensure you understand when to call for immediate medical care, who to call during normal business hours and who to call after business hours and how to get ahold of the appropriate person
  - \* Symptoms requiring emergency medical care include, fever, shaking chills, chest pains or difficulty breathing, unusual or uncontrolled bleeding or bruising, severe headache or sudden vision changes, or uncontrolled nausea or vomiting



**QUESTIONS???**