Living with MDS

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What brings quality to your life?
What brings quality to your life?

- Loving relationship
- Family
- Home
- Professional fulfillment
- Financial security
- Ability to travel
- Ability to engage with friends and family
- Successful season for the Giants
Quality of life changes over time

- Childhood
- Young adult
- Middle age
- Seasoned adult
How does MDS impact your quality of life?
Quality of Life

- Physical
- Spiritual
- Functional
- Social
- Emotional
Physical well-being

- Symptoms related to anemia
- Symptoms related to therapy
- Interference with treatment for other conditions
- Focus of physicians
Functional well-being

- Fatigue
  - Physical - stamina
  - Cognitive
  - Motivational

- Alteration in pre-existing roles
  - Employment
  - Family
  - Social
Functional well-being

• Work associated with office visits
  o Dealing with numerous health care providers
• Work associated with interpreting and managing
  o Medical terminology
  o Lab results
  o Symptoms
  o Side effects
  o Complications
• Work associated with patient advocacy
• Work associated with insurance coverage
Emotional well-being

• Uncertainty
• Anxiety & fear
• Depression
• Frustration & anger
• Loss of control
• Loss of self-esteem
• Shock at the diagnosis
Social Well-being

- Time associated with office visits, treatment
- Planning for the future
- Activity restrictions
- Relinquishing roles
  - Employment, family, social, societal
- Normalcy
- Sexuality
- Strained interpersonal relationships/social isolation
- Employment
- Financial strain
Spiritual well-being

- Hopelessness
- Enhanced faith and beliefs
- Renewed appreciation for relationships
- Renewed appreciation for life
- Ability to re-establish priorities
- Finding meaning in illness
Managing fatigue

- Exercise/mobility
- Hydration
- Nutrition
- Depression
- Sleep disturbance
- Pain

- Improve anemia
Some questions to consider

• Does your spouse/other family members share your view regarding quality of life?
  o Is this helpful?

• Does your doctor understand how MDS impacts your quality of life?
  o Why or why not?

• Do you use your thoughts about quality of life in making decisions about treatment?

• Do you use your thoughts about quality of life in planning for the future?
Taking inventory

• How does MDS impact your quality of life beyond aging?
• How do financial problems interfere?
  o Is your job a help or a hindrance?
• How do your family and friends help?
  o Or interfere?
• How does your faith help?
  o Or interfere?
• How does your attitude help?
  o Or interfere?
Taking inventory

• Decide what’s important
  o And what isn’t
• Can you still do some things that provide you quality to your life?
  o How does your treatment interfere?
  o How does MDS interfere?
  o How do your other health issues interfere?
Questions?