

Living with MDS

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What brings quality to your life?

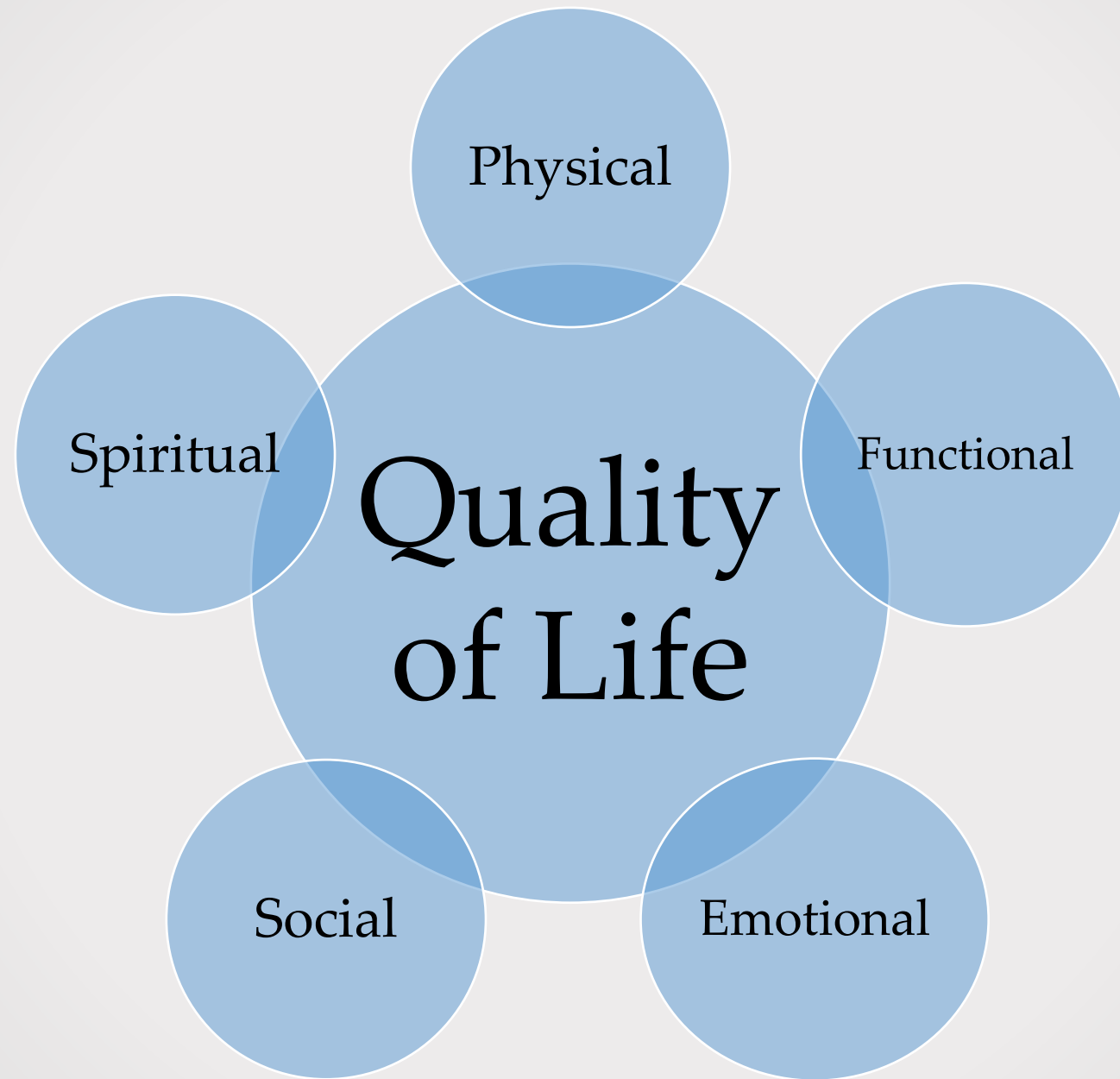
What brings quality to your life?

- 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?



Physical well-being

- Symptoms related to anemia
 - Symptoms related to therapy
 - Interference with treatment for other conditions
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- 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
 - Dealing with numerous health care providers
- Work associated with interpreting and managing
 - Medical terminology
 - Lab results
 - Symptoms
 - Side effects
 - 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?
 - Is this helpful?
- Does your doctor understand how MDS impacts your quality of life?
 - 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?
 - Is your job a help or a hindrance?
- How do your family and friends help?
 - Or interfere?
- How does your faith help?
 - Or interfere?
- How does your attitude help?
 - Or interfere?

Taking inventory

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

Questions?