MDS and Quality of Life

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Quality of life?

The gap between ones life expectations and life experiences
MDS and Quality of Life:

Negative impact on Quality of Life (QoL):
→ diminished physical and mental capabilities
→ fatigue
→ loss of independency
→ relationships with family and others
→ diminished role within the family
→ emotional toll
→ time spend on health related care
→ employment challenges
MDS and Quality of Life:

Positive impact on Quality of Life (QoL):
→ reassessing life’s priorities
→ improved relationships with family and friends
→ adoption of positive health behaviours
→ positive brighter outlook on life in general
→ deeper more meaningful spiritual life
→ feelings of hope when treatments or managements achieve positive results

Heptinstall K, 2008 MDS Foundation Inc.
Internet based survey 2008

• Fatigue affects most MDS patients

• Fatigue present despite variety of treatments

• Fatigue did not correlate with Haemoglobin levels
2012 Oliva et al

- Transfusion dependent patients had worse QoL scores

- Haemoglobin levels and other illnesses were major determinants of the QoL

- Clinicians assessment of QoL in general correlated with the patients perceived QoL
Rosemary, 75, from Canada

“I have learned to value every day and not to worry about the future. I find an enormous amount of joy in life and welcome each day that I can get out of bed and say well, I’m still here. The small things of life don’t bother me anymore and although it might sound odd I can honestly say that right now I am happier and enjoying life more than I did before my diagnosis as I appreciate life more and value the life and friends I have.”