

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

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.”