


## Your Journey to Wellness

Taking Care of Your Body, Mind and Spirit

Presenters:  
 Paul Scribner, MSW, LCSW-C  
 Karen Bosse - Two time, 35 year survivor (aplastic anemia, MDS and PNH)



### Learning Objectives

- Define the dimensions of wellness
- Consider what might be compromising their wellness
- Develop a simple action plan to promote wellness
- Define initial steps they can take now
- Recognize that your mind is very powerful



### Consult with Your Doctor First

#### Consult with your doctor before:

- Starting any new exercise program
- Making changes to your diet
- Taking any herbal remedy or supplement not prescribed by your physician

#### Keep in mind:

- There is no one-size fits all
- Pay attention to what your body is telling you
- If it sounds too good to be true, it probably is
- Do not underestimate the power of your thoughts



### Acknowledgements



Isabel Schuermeyer, MD  
 Psychosomatic Medicine Staff  
 Department of Psychiatry and Psychology  
 Cleveland Clinic



Joanna Myers Casale, RD, CSO  
 Clinical Oncology Dietitian  
 MD Anderson Cancer Center



### Assumptions

- **This is a your personal journey.**
- **Wherever you are right now is OK. Be gentle with yourself.**
- **Change is an effortful process.**
- **Simple things done consistently over time can make a big difference in overall wellness.**
- **You are not your diagnosis.**



## Thinking About Your Personal Wellness Plan

1. **Be honest with yourself** about where you are now. What is most impacting your personal wellness?
2. **Explore** what will make the biggest positive impact on your wellness over the next year.
3. **Make a simple and achievable plan** - First action?
4. **Discuss** your ideas with a trusted friend or supporter and revise as necessary.



## The Dimensions of Wellness



## Wellness Defined

The quality or state of being in good health especially as an actively sought goal.

- Merriam Webster Dictionary



What does wellness mean to you?



## Factors Most Impacting Wellness in Bone Marrow Failure

1. Fatigue
2. Emotional health (anxiety, depression, stress.)
3. Uncertainty (fear of the future)
4. Disruption to life caused by treatment/care (time-consuming therapies; strain of chronic disease)
5. Family and relationship issues
6. Financial concerns

References:  
 Abel, Gregory A. et al. Patient-reported outcomes for the myelodysplastic syndromes: a new MDS-specific measure of quality of life. *Blood* 2014 123:451-452.  
 Groth, Martha. Development of a Disease Specific Quality of Life Questionnaire For Patients With Acute, Chronic, and/or Paroxysmal Neutrophil Hemoglobinuria (UK). *AAOHN*. *Blood* 2013 122: 29 3480.

**NOTE:** Mutual trust between patient and treating physician(s) is very important to patients in improving self-reported well-being and QOL.



## Deal With Fatigue - There is Help!

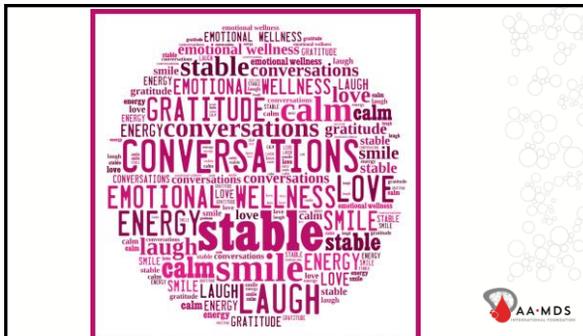
- Work with your healthcare team - there are many treatment options
- Rule out reversible causes of fatigue. (Anemia, sleep disorders, low thyroid, heart issues and depression.)
- Start exercising - even though it might not make sense logically
- Pace yourself, delegate and set priorities
- Get the best rest possible

...See "[Tips for Managing Fatigue in Bone Marrow Failure](#)" handout for more ideas.



## Emotional Wellness (Mind)

- A positive sense of emotional well-being enables an individual to function in society and meet the demands of everyday life
- People in good emotional health have the ability to recover effectively from illness, change or misfortune



## Emotional Wellness Tips

- Engage in regular exercise
- Get enough sleep (8 hours ideally)
- Engage in relaxation and stress reduction practices (yoga, meditation, progressive relaxation, gratitude journaling)
- Seek ways to manage your anger and worry - positive coping and stress management strategies
- Be proactive – taking positive action to get things done
- Talk with someone about your feelings and seeking professional counseling if necessary

See "[Tips for Managing Emotional Health and Well-Being in Bone Marrow Failure](#)" handout for more ideas.



## Deal With Depression - Quickly

Research looking at depression and treatment adherence shows:

- Compared with non-depressed patients, depressed patients are 3 times more likely than non-depressed patients to be noncompliant with medical treatment recommendations.
- Depression is a significant risk factor for poor outcomes among patients in general.
- Important to recognize and address depression early.

...see, "[Tips for Managing Your Emotional Health and Well-Being](#)" handout for specific recommendations

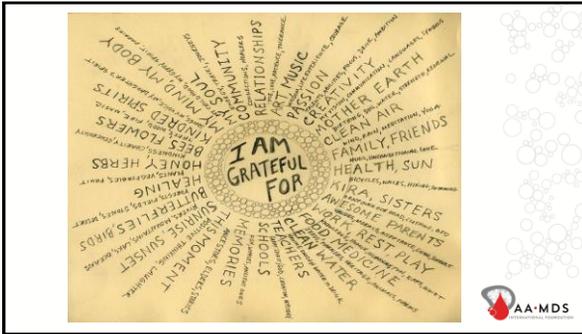
Reference:  
Chikara, MR, Lapper, HS, Craghan, TW. Depression is a Risk Factor for Noncompliance With Medical Treatment: Meta-analysis of the Effects of Anxiety and Depression on Patient Adherence. Arch Intern Med. 2006;166(14):2303-2307. doi:10.1001/archinte.166.14.2303



## Proven Stress Management Techniques

- In addition to what we have already discussed (diet, exercise, healthy social interactions, and other lifestyle factors):
  - Creative Expression (writing, painting, coloring, singing)
  - Meditation
  - Mantras/Affirmations
  - Gratitude Journaling
- Our bodies are designed to heal themselves, but we must do our part
- How are you going to initiate the relaxation response in your body to make your body ripe for healing and well-being?





### Evidence for Gratitude

**You will feel happier**

- 25% happier for six months after writing one statement of gratitude/day

**You will boost your energy levels**

- Gratitude journaling v. regular diary = increased sense of vitality

**You will be more resilient**

- Our brains are wired to seek out the positives in any situation = better at bouncing back from trauma

**You will improve your relationships**

- You can't be grateful and resentful at the same time

Reference:  
Emmons, RA, et al. Counting Blessings Versus Burdens: An Experimental Investigation of Gratitude and Subjective Well-Being in Daily Life. *Journal of Personality and Social Psychology* (Feb. 2003): Vol. 84, No. 2, pp. 377-89.

### Physical Wellness (Body)

Evidence suggest the following leads to physical wellness:

- **A balanced diet:** Include a variety of fruits and veggies, whole grains, beans, moderate protein, healthy fats; avoid high-sugar or heavily processed foods.
- **Regular exercise/movement:** Start small and build up.
- **Good sleep:** Experts recommend 7 to 8 hours of quality sleep.
- **Avoid drug and alcohol abuse.**
- **Good self-care:** Not waiting to deal with aches, pains and other medical issues and concerns.



### The Case for Exercise: Looking at the Evidence

- Exercise programs improve both physical functioning and quality of life
- The scientific benefits of exercise (*slower aging - better mood - less chronic pain - less inflammation - stronger vision - better memory*)
- NIH study started in 2015 studies the impact of exercise on health...*"This program will lay the foundation for our understanding of how physical activity affects the human body, and ultimately, advance our understanding of how activity improves and preserves health,"* - NIH Director Francis S. Collins, MD, PhD

Reference:  
McClellan, R. Exercise programs for patients with cancer improve physical functioning and quality of life. *J Physiother* Vol 59(1): 57.

### Nutrition/Diet

**There is no specific diet that is best for all people living with a bone marrow failure disease.**

Nutrient needs vary from person to person. Your healthcare care team can help you identify your nutrition goals and plan ways to help you meet them.

Eating well before, during and after your treatment may help you:

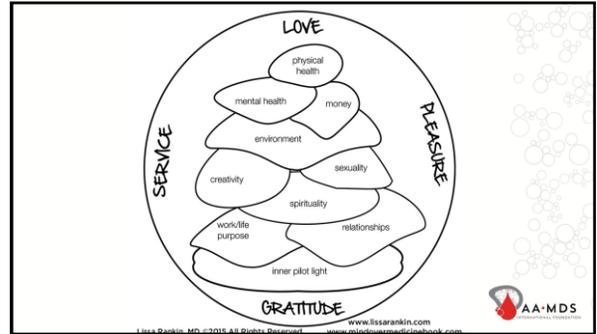
- Feel better
- Maintain your weight
- Keep up your strength and energy
- Better tolerate treatment and have less side-effects
- Lower your risk of infection
- Heal and recover more quickly

...see "Nutrition Tips for People Living with Bone Marrow Failure" handout for specific recommendations

## Spiritual Wellness (Spirit)

Spiritual Wellness results from:

- Seeking and finding meaning and purpose in your life
- Aligning actions with your deepest values and beliefs
- Keeping in mind that your illness is part of your journey and doesn't define who you are



## Your Personal Wellness Plan

1. **Be honest with yourself** about where you are now. What is most impacting your personal wellness?
2. **Explore** what will make the biggest impact on your wellness over the next year.
3. **Make a simple plan - First Action?**
4. **Discuss** your ideas with a trusted friend or supporter and revise as necessary - **OVER LUNCH**

REVIEW  
REVISE  
START MAKING  
YOUR PLAN  
**MAKE IT EASY  
TO SUCCEED &  
HARD TO FAIL**



## Final Resources and Recommendations



## Final Take Aways

1. Deal with fatigue; there is hope.
2. Get some exercise daily. This has huge benefits to physical and emotional.
3. If you are feeling depressed, anxious or overwhelmed seek help.
4. Eat a balanced diet. Focus on whole foods.
5. Stay social.
6. **DO NOT** ignore health problems or symptoms; get them checked out right away.



## Final Take Aways (cont'd)

7. **Become a strong advocate for your best health care.** Seek experts you trust, ask questions, get answers, seek help when you need it.
8. **Manage your internal dialogue.**

**BELIEVE THAT YOU CAN IMPACT YOUR JOURNEY!!  
YOUR MIND IS VERY POWERFUL!!**



### Reference Handouts

- Tips for Managing Fatigue in Bone Marrow Failure Patients
- Tips for Managing Your Emotional Health and Well-being in Bone Marrow Failure Patients
- Diet and Nutrition Tips For People with Bone Marrow Failure
- Bibliography of Suggested Books



### Visit the AAMDS "Online Academy"

#### Programs Include:

- How can I conquer fatigue?
- Managing Side Effects in Bone Marrow Failure
- Relax, Relate, Release: Restoring Life Balance When Marrow Failure Disrupts Your Life
- Nutrition in Bone Marrow Failure

[www.aamds.org/learn](http://www.aamds.org/learn)



### Questions

