



## Your Journey to Wellness

Taking Care of Your Body, Mind and Spirit

Presenters:

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### Learning Objectives

Participants will be able to:

- Define the dimensions of wellness
- Identify an area(s) of wellness that may be compromising your current and future wellness
- Develop a simple action plan to promote wellness in a high-priority area
- Define steps you can take now to address some common barriers to wellness in bone marrow failure, including fatigue and emotional issues, like stress, and depression



### 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



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## Assumptions

- This is a your personal journey. It's important to recognize and acknowledge:**
  - Where you are starting?
  - Where do you want to be?
  - What is most important to you? - values, likes, dislikes
  - How are you going to get there? - your plan
- Wherever you are right now is OK. Be gentle with yourself. There is no right answer – just what is right for you.**
- Change is an effortful process. To change your overall level of wellness you need do something differently (mindfully)**
- Simple things done consistently over time can make a big difference in overall wellness**



## Thinking About Your Personal Wellness Plan

- Be honest with yourself** about where you are now. What is most impacting your personal wellness?
- Explore** what will make the biggest impact on your wellness over the next year
- Make a simple plan**
  - What will you do?
  - By when?
  - Who will support you?
  - What is the first step?
- Discuss** your ideas with a trusted friend or supporter and revise as necessary



## Clarification of Terms

### Integrative Medicine

- Healing-oriented treatment approach
- Considers the whole person
- Emphasizes the therapeutic relationship
- Informed by evidence and makes use of all appropriate therapies

### Complementary Medicine

- Range of medical therapies that fall beyond the scope of traditional western medicine
- Used alongside standard treatment of disease
- Examples include acupuncture, osteopathy, meditation, aromatherapy, diet, exercise etc.



What does wellness mean to you?



## Wellness Defined

- The quality or state of being healthy in body, mind, and spirit, especially as the result of deliberate effort – essentially making mindful decisions every day
- The process of learning about and engaging in behaviors that are likely to result in optimal health across various dimensions
- Wellness and wellbeing are often used interchangeably; for our purposes they are the same



## The Dimensions of Wellness



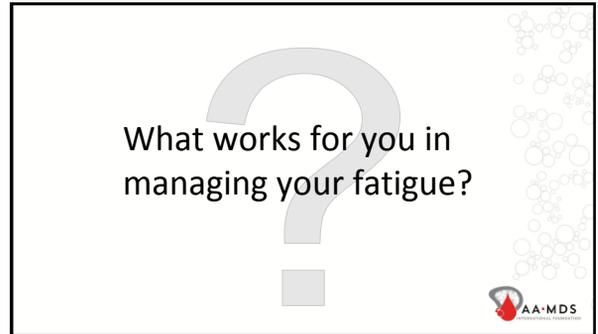
## Factors Most Impacting Wellness in Bone Marrow Failure

1. **Fatigue**
2. **Emotional health** (anxiety, depression, stress, overwhelm)
3. **Uncertainty** (fear of the future, stress, not knowing what to expect)
4. **Disruption to life caused by treatment/care** (dependency on time-consuming therapies; emotional strain related to chronic disease)
5. **Family and relationship issues**
6. **Financial concerns**

References:  
Abel, Gregory A. et al. Patient-reported outcomes for the multidisciplinary approach: a new MDS-specific measure of quality of life. *Blood* 2014; 123:451-452  
Goeth, Martha. Development Of a Disease Specific Quality Of Life Questionnaire For Patients With Aplastic Anemia and/or Paroxysmal Nocturnal Hemoglobinuria (QoL-AA/Phn). *Blood* 2013; 122: 231680

**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
- 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.



AA-MDS



## Physical Wellness (Body)

Evidence suggest the following leads to physical wellness:

- **A balanced diet.** Include a variety of fruits and veggies (various colors), whole grains, beans, moderate protein, healthy fats (PREDIMED Study); avoid high-sugar or heavily processed foods
- **Regular exercise/movement.** Start small and build up. Both aerobic and strength training are important.
- **Good sleep.** Experts recommend 7 to 8 hours of quality sleep. Consistent sleep and wake times can help.
- **Avoiding drug and alcohol abuse.** (including cigarettes)
- **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 for patients who have had cancer improve both physical functioning and quality of life
- People with low levels of physical activity are at higher risk for depression and anxiety, lower-back pain, many kinds of cancer, heart disease, Alzheimer's disease and early death by any cause.
- The scientific benefits of exercise = slower aging, better mood, less chronic pain, stronger vision, and 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:  
McChikan, R. Exercise programs for patients with cancer improve physical functioning and quality of life. J Physiother 101 50(1) 57



## The Exercise Cure

The surprising science of a life-changing workout

# TIME



## 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



## Emotional Wellness (Mind)

If you have Emotional Wellness you:

- Accept yourself for who you are
- Are able to cope with normal life stresses in healthy ways
- Can set and achieve goals
- Share the full range of emotions
- Have satisfying relationships

**Serious illness can push some people beyond their ability to cope emotionally.**



## Emotional Wellness Tips

**Evidence suggests that the following can help improve Emotional Wellness:**

- Regular exercise
- Getting enough sleep (8 hours ideally)
- Engaging in relaxation and stress reduction practices (yoga, meditation, progressive relaxation, gratitude journaling)
- Seeking ways to manage your anger and worry - positive coping and stress management strategies
- Being proactive – taking positive action to get things done
- Talking with someone about your feelings and seeking professional counseling if necessary

**What works (or has worked) for you? What helps you cope?**



## Deal With Depression - Quickly

Meta-Analysis looking at depression and treatment adherence:

- 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

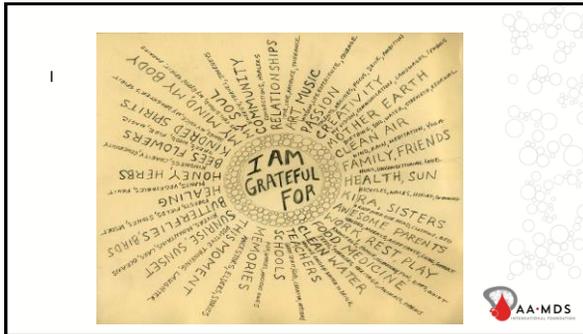
Reference:  
GONZALEZ, MR, Lepper, HS, O'nehan, TW. Depression Is a Risk Factor for Noncompliance With Medical Treatment: Meta-analysis of the Effects of Anxiety and Depression on Patient Adherence. Arch Intern Med. 2000;160(14):2101-2107. doi:10.1001/archinte.160.14.2101



## Proven Stress Management Techniques

- In addition to what we have already discussed (diet, exercise, healthy social interactions, and other lifestyle factors):
  - Creative Expression
  - 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
- Decreased symptoms of depression for a month following personally delivered letters of gratitude

### 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, R.A. 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.



## Spiritual Wellness (Spirit)

Spiritual Wellness results from:

- Seeking and finding meaning and purpose in your life
- Aligning your actions with your deepest values and beliefs
- Considering the possibility that your illness is just a chapter of your journey and doesn't define who you are



What brings you a sense of spiritual wellness?



## Contributors to Spiritual Wellness

- Taking time for yourself to clarify your deepest values and beliefs
- Consistently acting in line with your values and best self
- Meditation, prayer and deep relaxation exercises
- Practicing forgiveness
- Being loving and doing random acts of kindness
- Focusing on gratitude
- Engaging in activities that give your life meaning and purpose



## Social & Intellectual Wellness

### Social Wellness

- Ability to relate to and connect with others and to establish and maintain positive relationships with family, friends and co-workers.
- **Loneliness and social isolation can kill!**

### Intellectual wellness

- Active participation in educational, cultural, and community activities
- Includes traditional learning and life experience learning
- Valuing and nurturing your creativity, curiosity and lifelong learning are part of intellectual wellness.



## Revisiting 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**
  - What will you do?
  - By when?
  - Who will support you?
  - What is the first step?
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. Talk with your doctor about ways to address it.
2. **Get some exercise daily.** This has huge benefits on your physical and emotional health. Start with walking - preferably outside and in nature - with a friend.
3. **If you are feeling depressed, anxious or overwhelmed seek help.** There are good treatment options.
4. **Eat a balanced diet** – Reduce refined carbs and don't be afraid to eat healthy fats (avocado, butter, eggs, grass fed meats, coconut oil, olive oil, nuts).



## Final Take Aways (cont'd)

5. **Stay social.** Isolation and loneliness increases risk of death.
6. **DO NOT ignore health problems or symptoms.** Get them checked out right away.
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!!**



## 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 and Music



## Visit the AAMDS "Online Academy"

- Some 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)



