

Welcome to...

real  
talk

real  
answers

*living with **ms** in your 20s and 30s*

sponsored by:



**MS** *LifeLines*

Services sponsored by  

- 
- **All content provided by health and allied professionals has been reviewed for accuracy by the National MS Society and MS LifeLines<sup>SM</sup>**
  - **The viewpoints expressed tonight by our three speakers represent their own opinions, and not necessarily those of the National MS Society and MS LifeLines**

# Get the Career Edge: Tips for Job Success with MS

Rosalind Joffe  
Founder & Principal,  
Clcoach.com



*living with ms in your 20s and 30s*

# What We'll Cover

---

- ***Identify*** what makes this difficult
- ***Describe*** what you can do to prepare and respond
- ***Offer*** a strategy that allows you to thrive

# Do You Wonder...

---

- **How do I talk about this and when?**
- **How do I manage expectations?**
- **How do I perform this job successfully?**
- **How do I plan my career?**

# I Can See Clearly Now

---

- **Illness must be viewed as a challenge to be met**
- **A clear vision gives the strength and clarity to move forward**
- **Workplace success in the face of illness is transforming**

# What Are Your Work/Life Concerns?

---

- **Managing your job and health**
- **Talking with others about your health**
- **Planning your career**

# Managing Your Job and Your Health

---

- **Manage your own expectations**
- **Manage the expectations of others**
- **Manage your message**

# Talking With Others About Your Health

---

## If You Disclose:

- **Keep it simple**
- **Keep it clear**
- **Keep it unemotional**

# Planning Your Career

---

- **Develop your options**
- **Expand your competencies**
- **Set realistic expectations**

## A Final Thought...

---

**Today is the Moment to  
Take Charge of Your Life!**

# A Total Approach to Healthy Living with MS

Carol Sames, Ph.D.

Director, Vitality Fitness  
Program, SUNY Upstate  
Medical University



*living with **ms** in your 20s and 30s*

# Defining “Wellness”

- **Wellness combines 6 interrelated dimensions of well-being into healthy living**
  - Each is equally vital in pursuit of healthy living
- **Ability to live life to the fullest potential**
- **Involves individual responsibility for self-evaluation and assessment**
- **Dynamic process of change and growth**



# Dimensions of Wellness



# Dimensions of Wellness

---

- **Physical**
  - Keeping the body functioning at its maximum capacity
  - Exercise, nutrition, weight management, self-care, sleep, medical assistance and prevention behaviors
- **Emotional**
  - Experiencing & expressing a wide range of feelings and becoming comfortable with personal emotions
  - Adjusting to change, coping with stress in a healthy way and developing coping skills
- **Intellectual**
  - Embracing lifelong learning, thinking critically, being curious and creative and open to new ideas



# Dimensions of Wellness

---

- **Social**
  - Being able to create and sustain relationships with family, friends, peers and acquaintances over time
  - An interest in humanity and the environment as a whole
- **Occupational**
  - Integrating a commitment to an occupation into a total lifestyle that is satisfying and rewarding
- **Spiritual**
  - The sense that life is meaningful and has a purpose.



# Living Well with MS

---

- **The National MS Society defines wellness as:**

***“A dynamic state of physical, emotional, spiritual and social well-being that can be achieved even in the presence of a chronic illness or disability.”***



# Key Wellness Concepts

---

- 1. Wellness is an active, lifelong process**
- 2. Requires self-evaluation and self-assessment**
- 3. It's a dynamic process that is constantly changing and adapting**
- 4. Places responsibility on the individual**
- 5. All dimensions are interrelated and equally important for optimal healthy living**
- 6. Can be achieved in the presence of a chronic illness or disability**



# Physical Dimension of Wellness

---

- **How can you maintain a healthy body?**
  - **Regular physical activity**
  - **Eating a well-balanced diet**
  - **Maintaining proper weight**
  - **Getting enough sleep**
  - **Avoiding harmful activities**
  - **Making informed decisions about health**
  - **Seeking medical assistance when necessary**

# Physical Activity & MS

---

- The old way of thinking
  - Prior to the mid-1990's, people with MS were often told to avoid physical activity for fear it could increase disease activity, fatigue and symptoms due to thermosensitivity
- The new way of thinking
  - Landmark study in 1996 by Jack Petajan & colleagues put the importance of physical activity and MS on the map

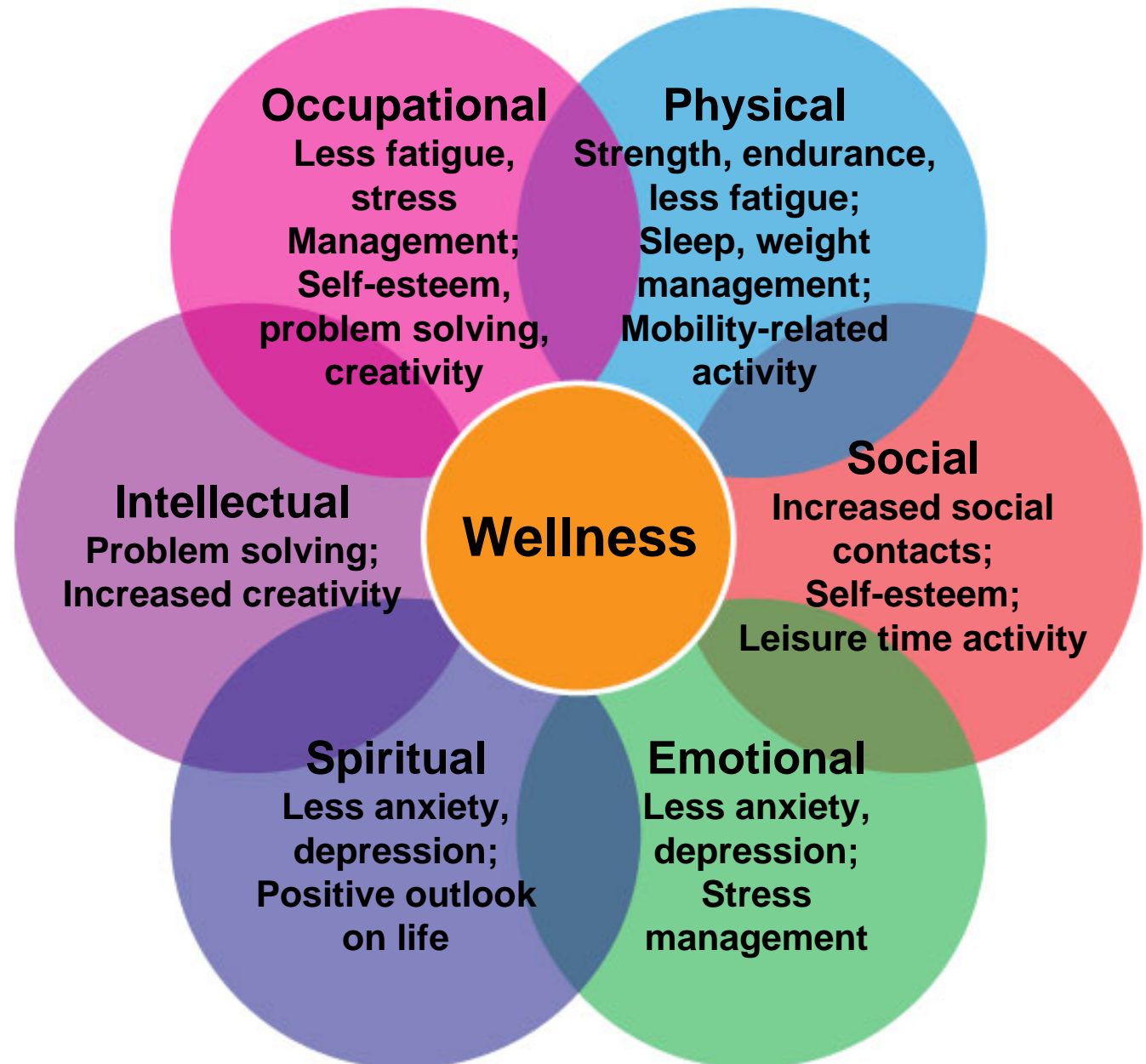


# Physical Activity & MS

- **Physical activity is NOT A CURE for MS, but research in the past decade has shown it has many benefits:**
  - Can improve endurance, strength and mobility-related activities such as time to transfer, walking cadence and balance
  - May reduce fatigue, anxiety and depression
  - May improve quality of life and cognitive function
- **In most research studies, less than 6% of participants dropped out due to exacerbations, increased fatigue or worsening of clinical symptoms**



# Impact of Physical Activity on the Dimensions of Wellness



# Why Should I Become Physically Active?

1. Being physically active may directly impact the six dimensions of wellness
2. A healthy lifestyle cannot be achieved without including some form of physical activity
3. Inactive vs. active women with MS have greater risk factors for cardiovascular disease<sup>1</sup>
4. Obesity is a growing epidemic in the US -- approximately 66% of adults are overweight and 33% of those are obese
5. Unknown long-term benefits of physical activity on MS progression



# How Do I Become Physically Active?

1. National MS Society has excellent information online and in publications
2. Know yourself and what type of program is right for you
3. Avoid exhaustion both during and after physical activity
4. Plan for success – remove barriers, keep a log book, set realistic goals
5. Reward yourself
6. Be prepared for bumps in the road
7. Eating healthy is vital to physical activity
8. Start slow, break into short periods, and remember that **CONSISTENCY** is the **KEY** to **SUCCESS**



# A Final Thought...

**Go Confidently in the Direction of Your Dreams! Live the Life You've Imagined.**

- Henry David Thoreau



# Relationships, Intimacy & Sex: Where Does MS Fit?

Peggy Crawford, PhD

Clinical Psychologist and Director,  
Health Psychology Services,  
Mellen Center for MS Treatment,  
Cleveland Clinic



*living with **ms** in your 20s and 30s*



# Relationships, Intimacy & Sex: Where Does MS Fit?

Peggy Crawford, PhD


Clinical Psychologist and Director,  
Health Psychology Services,  
Mellen Center for MS Treatment,  
Cleveland Clinic



real  
talk



real  
answers



*living with **ms** in your 20s and 30s*

# Characteristics of Healthy Relationships

- **Trust**
- **Respect**
- **Shared goals/expectations**
- **Mutual concern**
- **Tolerance and patience**
- **Effective communication**
  - **Clear and direct messages**
  - **Active listening**
  - **Recognizing agreement**
  - **Acknowledging differences**



# Impact of MS Diagnosis

---

- **Initially, you may feel like damaged goods, assume no one will want you, and avoid relationships**
- **You may stay in a bad relationship out of fear of the future, need for insurance**
- **Your partner may decide he/she cannot deal with your MS**
- **On the other hand, you may make better choices in partners after MS**



# Starting New Relationships After MS

- **MS is part of life but not all of it**
- **How you feel about your MS affects how you present yourself and what others see**
- **First dates don't require show-and-tell**
- **If worth pursuing, it's worth telling**
- **Tell when you would want to know**
- **Half-truths lay a shaky foundation**
- **Risk is easier up front**
- **Invisible symptoms can be a Catch 22**
- **Some will be frightened off; many will not**



# Barbara

- 30 years old, divorced mother of 8- and 10-year-old daughters
- MS diagnosed one year ago
- Told everyone at work immediately about MS and co-workers avoid her
- Dated three men in the past year and told each one about MS on the first date



# Cindy

- **32 years old, single teacher with MS diagnosis 4 years ago**
- **On chemotherapy for past year after multiple exacerbations with primarily invisible symptoms**
- **In 2-year relationship but didn't tell boyfriend about MS until after engagement**



## Disclosure is a personal decision, the whole world doesn't need to know but...

- People need information, not a label
- Telling can be stress reducing
- Tailor the information to fit the person
- Remember it takes time for people to absorb what you've said
- Coping with your MS can be shared
- This is an ongoing process



# How MS Challenges Relationships

- **MS changes the “rules”**
  - “I don’t feel like myself any more”
  - “This isn’t the way it was supposed to be”
- **The “uninvited guest” is ever-present**
- **MS introduces additional unpredictability**
  - “What can we count on from each other?”
  - “What can we count on today, tomorrow, and in the future?”
- **A chronic disease strains resources (time, \$\$, energy)**
- **MS can interfere with communication**



# Barriers to Healthy Communication

- **Lack of information - “I don’t know *how* to talk about this”**
- **Different coping/communication styles:**
  - “I want to know everything about MS”
  - “He/She doesn’t want to know from MS”
  - “I’m a talker - he/she is the silent type”
  - “I’m a planner - he/she wants to wait and see”
- **Secrecy - “No one can know about this”**



# How MS Affects Intimacy

- **Changes roles and responsibilities**
- **Shakes up the partnership**
- **Intensifies feelings**
  - Anxiety – “This is too scary to talk about”
  - Depression – “I can’t deal with that now”
  - Denial – “There’s nothing to talk about”
  - Protectiveness – “I don’t want to upset him/her”
  - Guilt – “My [resentful] feelings aren’t *nice*”
  - Embarrassment – “I can’t talk about \_\_\_\_\_”
- **Can change sexual function**

***Silence is often misinterpreted as NOT CARING and tears as a SIGNAL TO STOP TALKING***



# Primary Sexual Dysfunction

## *Results from direct effects of demyelination*

- Both men and women report:
  - Decreased interest/arousal
  - Sensory changes
  - Decreased intensity or frequency of orgasms
- Women also report:
  - Decreased vaginal lubrication and engorgement
  - Decreased vaginal muscle tone
- Men also report:
  - Inability to achieve or maintain erections



# Secondary Sexual Dysfunction

***Results from the indirect effects of other MS symptoms and medications used to treat them***

- Medications such as anticholinergics, antispasticity agents, and antidepressants
- Fatigue
- Spasticity
- Bladder/bowel symptoms
- Tremor
- Depression



# Tertiary Sexual Dysfunction

*Related to feelings, attitudes, body image, and cultural messages*

- “Disabled people aren’t sexually attractive”
- “I can’t be both a caregiver and a lover”
- “If I don’t like myself any more, how can I expect someone else to find me attractive?”
- “This isn’t the same person I married”
- “He/she doesn’t find me attractive now that I’m a burden”
- “With everything else that’s going on, sex is the last thing I care about right now”



# Treatment for Primary Sexual Dysfunction

---

- **Men**
  - Injection therapy
  - Erectile dysfunction therapies
  - Penile prostheses
- **Women**
  - Water-soluble lubricants
  - Body-mapping exercises
  - Vibrator
  - Medication



# Treatment for Sexual Dysfunction

- **Secondary**
  - Symptom management
  - Medication management/scheduling
- **Tertiary**
  - Education
  - Counseling
  - Support



# Karen and Bob

---

- **Married 20 years and kids are out of the house**
- **Karen was diagnosed with MS 8 years ago and has bladder symptoms, spasticity, and depression**
- **During an evaluation for depression, it's revealed they haven't had sex for 4 years and never talked about it!**



# Thank you



*living with **ms** in your 20s and 30s*

**sponsored by:**



**MS** *LifeLines*<sup>™</sup>

Services sponsored by  