

WEBINAR & TELELEARNING SERIES



GPS For Your MS

January 10, 2017

Presented by:



Acorda Therapeutics

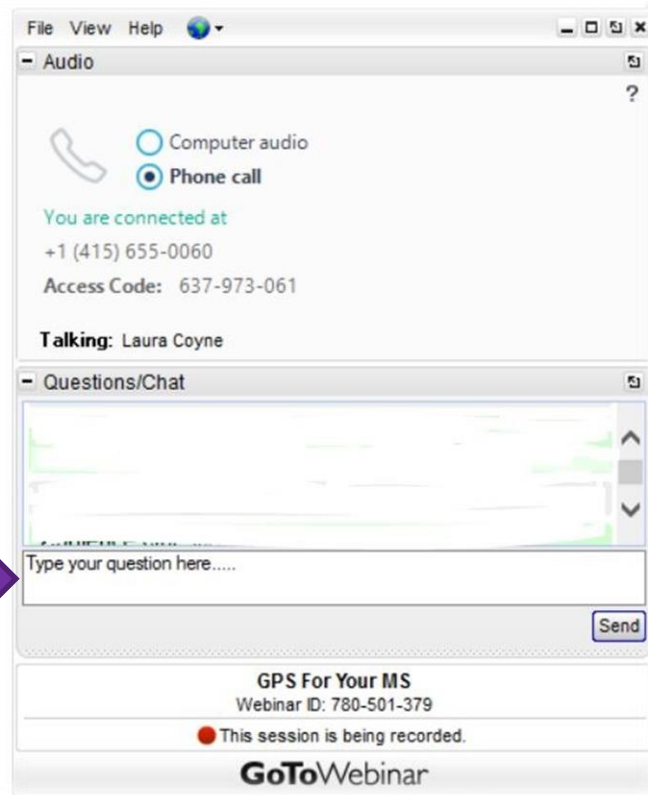
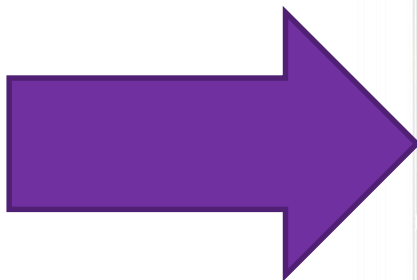


**National
Multiple Sclerosis
Society**



How to Ask Questions During the Webinar:

- Type in your questions using the **Questions/Chat** box
- If box is closed, click **+** to expand



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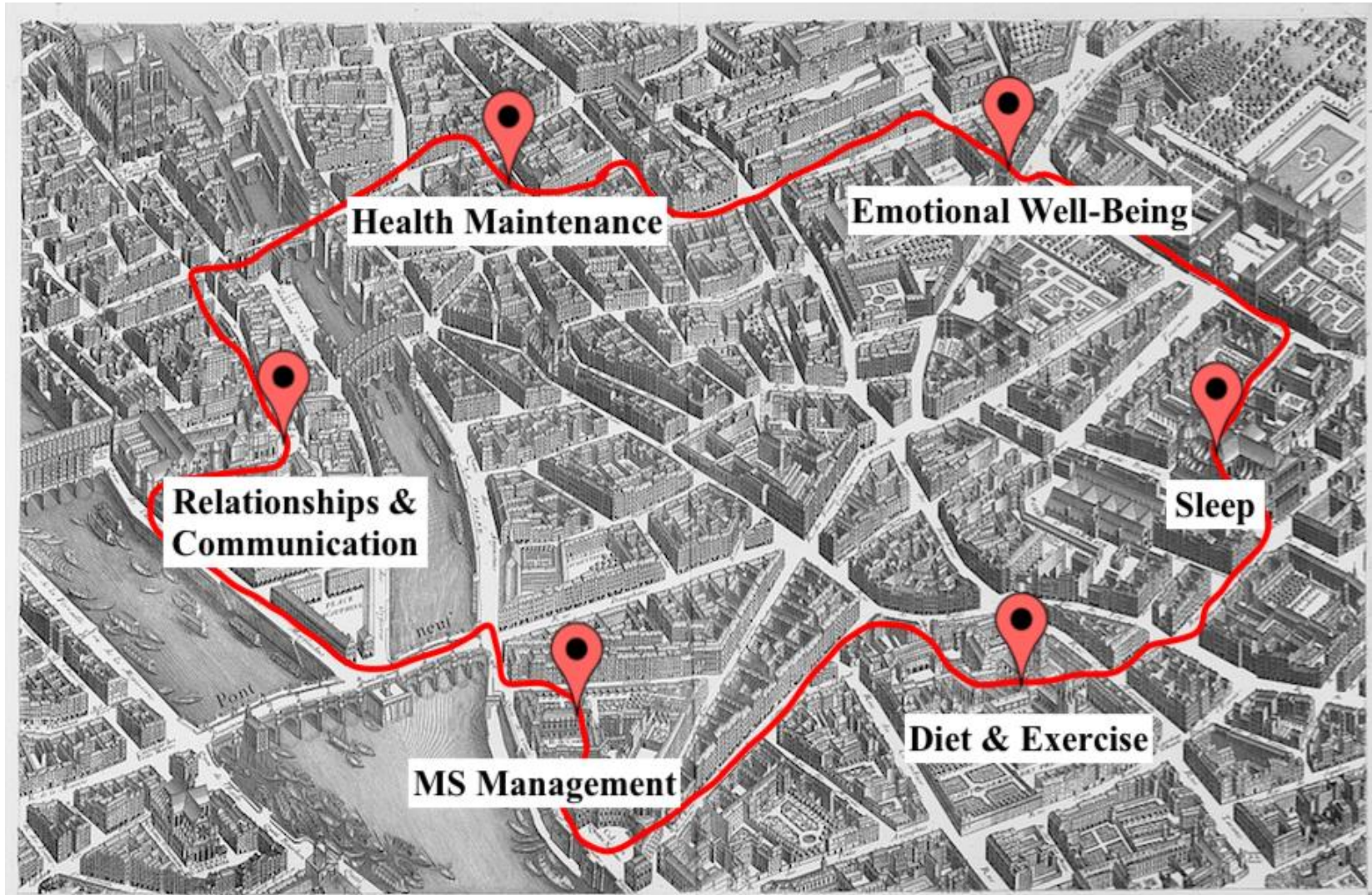
What is Wellness?

A lifelong personalized process through which people make informed choices about their lifestyle behaviors and actions across multiple interrelated dimensions in order to lead their best lives.

It is attainable for everyone & is achieved by each person living with MS within the context of their priorities, abilities, and limitations.

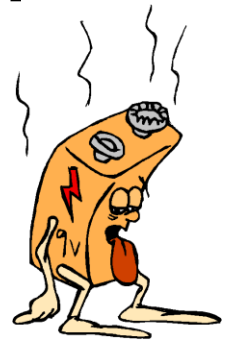


Our Wellness Destinations



MS Can Affect Your GPS

- Too many signals from too many sources
- Some signals feel blocked
- Little or no warning about unexpected events along the way
- Sometimes you just feel lost
- Unexpected detours
- Too many choices and choosing a direction feels overwhelming
- Few things feel under your control
- Hard to keep your battery charged





Choosing A Direction

Set “**SMART**” goals that are

- **S**pecific rather than vague
- **M**easurable so you know when you have met your goal
- **A**ttainable and realistic to increase your chances of accomplishing your goal
- **R**elevant to the problem you have identified
- **T**ime-based to reduce procrastination



Health Maintenance



Primary Care

- Routine primary care is essential to your overall health
- Preventative care is just as important as your neurological care!
 - vaccinations, physicals, gynecological/prostate exams, and other age-appropriate screening tests
- The goal of routine primary care is to decrease your risk for other chronic illnesses, such as heart disease, stroke, diabetes, and cancer
- Your primary care provider is also essential for the management of acute illnesses and conditions that may affect your MS



Smoking



- Smoking increases your risk for developing MS
- People with MS who smoke are at a higher risk for disease progression and disability
- Smokers are more likely to develop secondary-progressive MS
- Smokers are more likely to develop antibodies against Interferons and Tysabri
- Quitting, even after being diagnosed, can slow your disease progression

Alcohol & Other Substances

- Alcohol is not necessarily contraindicated if you have MS
- Alcohol can interact with medications used for symptom control
- Cannabis may help reduce pain and increase quality of life, but it is also known to have some of the same negative health consequences of cigarette smoking
- Acute intoxication impairs balance, coordination, and cognition
- Regular consumption can worsen several MS symptoms (such as spasticity, cognition, depression, and fatigue)



Goals for Health Maintenance

- “I will make an appointment for my annual physical by the end of the month”
- “I will abstain from alcohol on days that I take pain medication”
- “I will cut back my smoking by 4 cigarettes a day by February 1st”

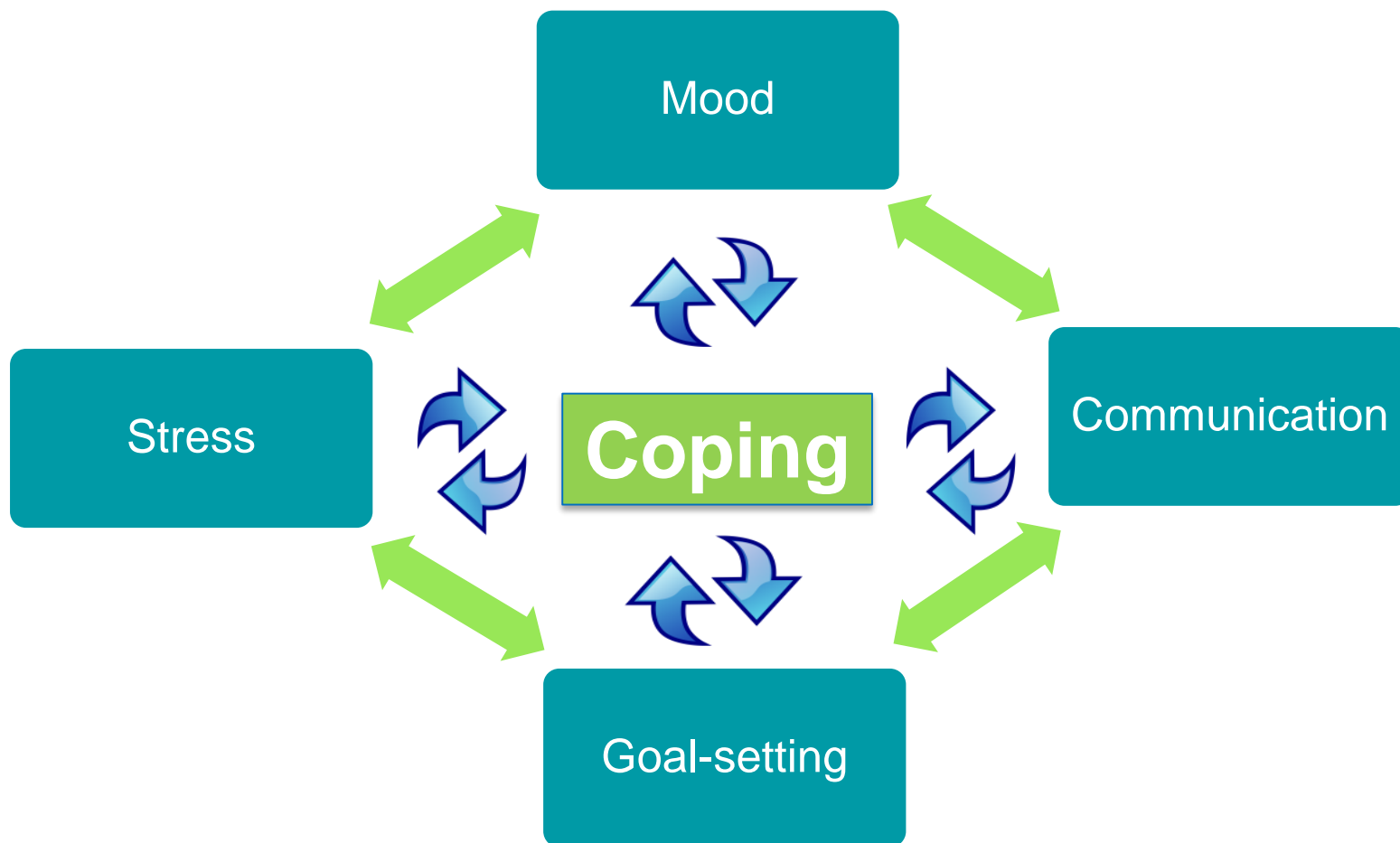
What are your **SMART** goals for health maintenance?



Emotional Well-Being



One Change: Big Benefits!



Coping

- Dealing with challenges that occur way too often
- Ingredients for effective coping:
 - Pursuing a healthy lifestyle/wellness (physical, emotional, mental, spiritual)
 - Balancing the needs of MS with the rest of life
 - Using problem-solving skills
 - Reducing stress and its effects
 - Working on relationships and communication
 - Educating yourself about MS and using resources
 - Resilience - *the capacity to rebound from adversity*

Recognizing Resilient People

- Resourceful and flexible
- Courageous in the face of fear
- Try even when outcome is not guaranteed
- Emphasize strengths, but acknowledge limitations
- Ask for and accept help
- Use a variety of approaches to solving problems
- Stay in the game even when it goes in a new direction
- Learn from experience
- Set “SMART” goals



Managing Stress



- Identify sources of your stress
- Identify how you react to stress and how this affects you physically, mentally, emotionally, and behaviorally
- Ask for feedback from those around you
- Separate your stressors into those you can change and those you're unlikely to change
- Focus on the ones you can change and occur more frequently
- Try a variety of coping strategies

“Stress-Hardy” Individuals



- View stressors as challenges and opportunities
- Focus on the present and what they can change
- Take a more flexible approach
- Actively seek resources and information
- Have a strong support network
- Maintain a sense of hope, optimism, and humor
- Make a healthy lifestyle a priority
- Practice relaxation skills, mindfulness, imagery

Resources on Mindfulness

Books

- Kabat-Zinn Jon. *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain and Illness* (1990).
- Kabat-Zinn J. *Coming to Our Senses: Healing Ourselves and the World Through Mindfulness* (2005)
- Alidina, S. *Mindfulness for Dummies* (2nd Edition, 2015).

CD's/Tapes

- Naparstek, Belleruth. Guided imagery for multiple conditions/topics including stress, sleep, pain, depression and specifically, MS, *A Meditation To Help You With MS* from Health Journeys

More Mindfulness Resources

CD's/Tapes

- Kabat-Zinn, J. Three series of practice CD's, *Guided Mindfulness Meditation* available through www.mindfulnesscds.com.

Websites

- Mind/Body Medical Institute at Massachusetts General Hospital, www.mbmi.org.
- Center for Mindfulness at U of Massachusetts Medical School, www.umassmed.edu/cfm.

Deep Breathing is a Stress Buster



- **4-4-4 breathing exercise**
 - Close your eyes
 - Inhale slowly to the count of 4 and exhale slowly to the count of 4
 - When comfortable with 1 round, try it for 4 rounds once or twice a day
 - Practice before or after meals, on awakening or before bed, and/or when an upsetting thought or emotion occurs

Goals for Stress Management

- “Practice **4-4-4 deep breathing** before I get out of bed in the morning and before I fall asleep at night starting tonight.”
- “Make the phone call I most don’t want to make before I make other calls so I won’t distract myself with worry all day.”

What are your **SMART** goals for stress management?



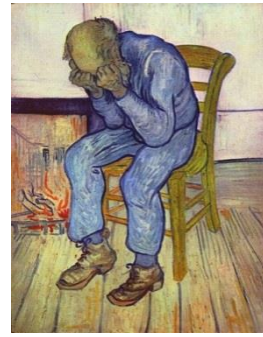
Mood and Emotional Health

- All of us have moods—people with MS and partners
- Moods can be related to MS itself, medications (particularly steroids), and changes in life circumstances
- Mood issues are very common in MS
- People who are depressed/anxious/moody may:
 - Have difficulty taking care of themselves and others
 - Lose time from work
 - Be difficult to live with
 - Have difficulty coping with stress
 - Engage in unhealthy behaviors
 - Not function as well cognitively
 - Be at higher risk of self-harm



The Reality In MS...

- Depression is under-diagnosed; some symptoms overlap with symptoms of MS
- Depression is under-treated; people may not report and doctors may not ask
- Depression can make other symptoms worse (cognition, pain, fatigue,...)
- Depression can be life-threatening
- Regardless of the cause, depression responds well to treatment
 - Psychotherapy + antidepressant medication is the treatment of choice
 - Support group participation is not sufficient treatment



Goals for Mood



- “I’ll put my antidepressant medication in my pillbox, and put the pillbox where I’ll see it every morning.”
- “I’ll make a list of all the activities and people I associate with a better mood and make plans to engage in that activity or contact at least one person in the next week.”

What are your SMART goals for mood?



Diet & Exercise



Diet & Exercise

- Maintaining a healthy weight reduces your risk for other chronic conditions such as high blood pressure, diabetes, and heart disease
- Obesity can worsen MS, and decrease overall quality of life



Diet

- No one specific “MS” diet has been identified, but research is being done.
- Some people with MS see symptom improvement with special diets (such as gluten free, Paleolithic, Swank, or Whals diets)
- In general: follow a heart-healthy diet to optimize overall health
 - Limit sodium, sugar, and processed foods
 - Increase fruit and vegetable intake
 - Choose lean proteins
(chicken, turkey, fish, beans, soy)
 - Choose healthy fats
(nuts, seeds, vegetable oils, oily fish)
 - Consume plenty of fiber
 - Hydrate well



Vitamin D

- We know there is a relationship between vitamin D levels, MS development, and disease progression
- We typically get vitamin D via sunlight and our diets, but we may need additional supplements
- Your vitamin D level can be checked with a simple blood test
 - Normal is 30-100 ng/mL
 - Your MS provider will help identify your personal goal, and give you recommendations for supplement dosage
- Foods high in vitamin D include oily fish, egg yolks, dairy products/juice/cereals that are fortified with vitamin D



Sun



Sardines



Egg yolk



Milk



Cereals



Yogurt



Orange juice



Salmon

Exercise Recommendations

- 30 minutes of aerobic exercise AND strength training twice a week
- Regular exercise improves strength, mobility, fatigue, depression, cognition, and bowel/bladder function
- Modify, Modify, Modify!
- Stay well hydrated and take breaks if needed
- If you aren't sure where to start, work with a physical therapist or fitness professional to get recommendations on exercise type, intensity, and frequency
- If you are heat sensitive, try cooling products and/or activities that are less likely to raise your core temperature (i.e. swimming or Tai Chi)



Goals for Diet & Exercise

- “I will pack a healthy lunch to bring to work instead of ordering take-out at least 3 times a week”
- “At my next neurology appointment I will ask about my Vitamin D level, and take supplements as recommended by my doctor”
- “I will walk for 30 minutes a day on Mondays, Wednesdays, and Fridays.”

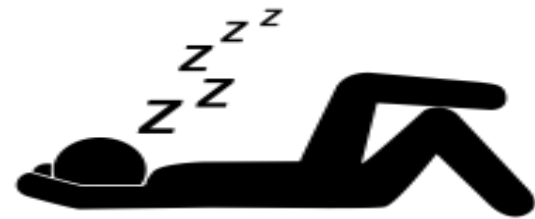
What are your SMART goals for diet and exercise?



Sleep



Sleep



- People with MS are more likely to have sleep disorders such as sleep apnea and RLS
- Impaired sleep can be a result of medications, MS symptoms, and/or mood disorders
- Fatigue can be a warning sign of an underlying sleep disorder
- Talk to your healthcare provider if you have trouble falling/staying asleep or don't feel well-rested during the day
- There are several management techniques to help you get better sleep, including cognitive behavioral therapy, adjusting medication regimens, improving symptoms, over-the-counter treatments, and other medication

When Sleep Is Your Destination

- Maintain a regular time for going to bed and getting up in the morning
- Keep your bedroom cool, dark, and quiet
- Make your 'To Do' list before bed
- Reserve your bedroom for sleep and intimacy
- Avoid exercise, caffeine, smoking, and alcohol before bed
- If you cannot fall asleep within 30 minutes or wake and cannot return to sleep, **GET OUT OF BED** and do something



Goals for Sleep



- “I will go to bed at 10pm and wake up at 7am on weekdays”
- “I will keep a sleep diary for the next two weeks and talk to my neurologist about it at my next appointment”

What are your SMART goals for sleep?



MS Management



Disease Modifying Therapy

- The New Year is a great time to evaluate your medication goals!
- **Over the past year, did you...**

Miss doses of your medication?

Stop medication for any period of time?

Have frequent anxiety about taking your medication?

Experience a lot of side effects?

Struggle to pay for your medication?

- If you answered YES to any of the above talk to your doctor about what you can do as a team to improve things this year



Symptom Control

- You and your neurologist are both MS experts, and taking a team approach is the most effective way to manage symptoms
- What symptoms do you experience most frequently, and how can you incorporate wellness to better control them?



Goals for MS Management

- “By the end of the week I will contact the patient support service for my medication and ask about copay assistance programs”
- “To improve my fatigue I will exercise for 30 minutes 3x per week, avoid caffeine after 12pm, and keep a sleep diary to share with my doctor”
- “I will use my cane if I have to walk more than 200 feet and/or while I am out in crowded areas”

What are your **SMART** goals for MS management?



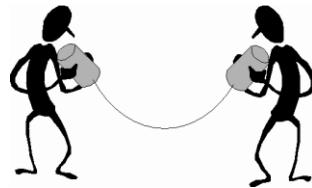


Relationships and Communication

Getting Your Signals Straight

Effective communication includes:

- Accurate and shared information that provides a common language
- Active listening and speaking skills
- Checking out assumptions vs mind reading
- Eye contact and asking questions
- Paying attention to tone and body language
- Clarifying the meaning of emotions
- A safety plan for when emotions escalate



Common Barriers to Communication

- Lack of information- “I don’t know how to talk about this”
- Not making it a priority
- Different coping/communication styles:
 - “I want to know everything about MS and you don’t want to know anything.”
 - “I’m a talker and you’re the silent type.”
 - “I’m a planner and you want to wait and see.”
- Misinterpretations
 - Silence doesn’t necessarily mean not caring
 - Tears don’t necessarily mean stop



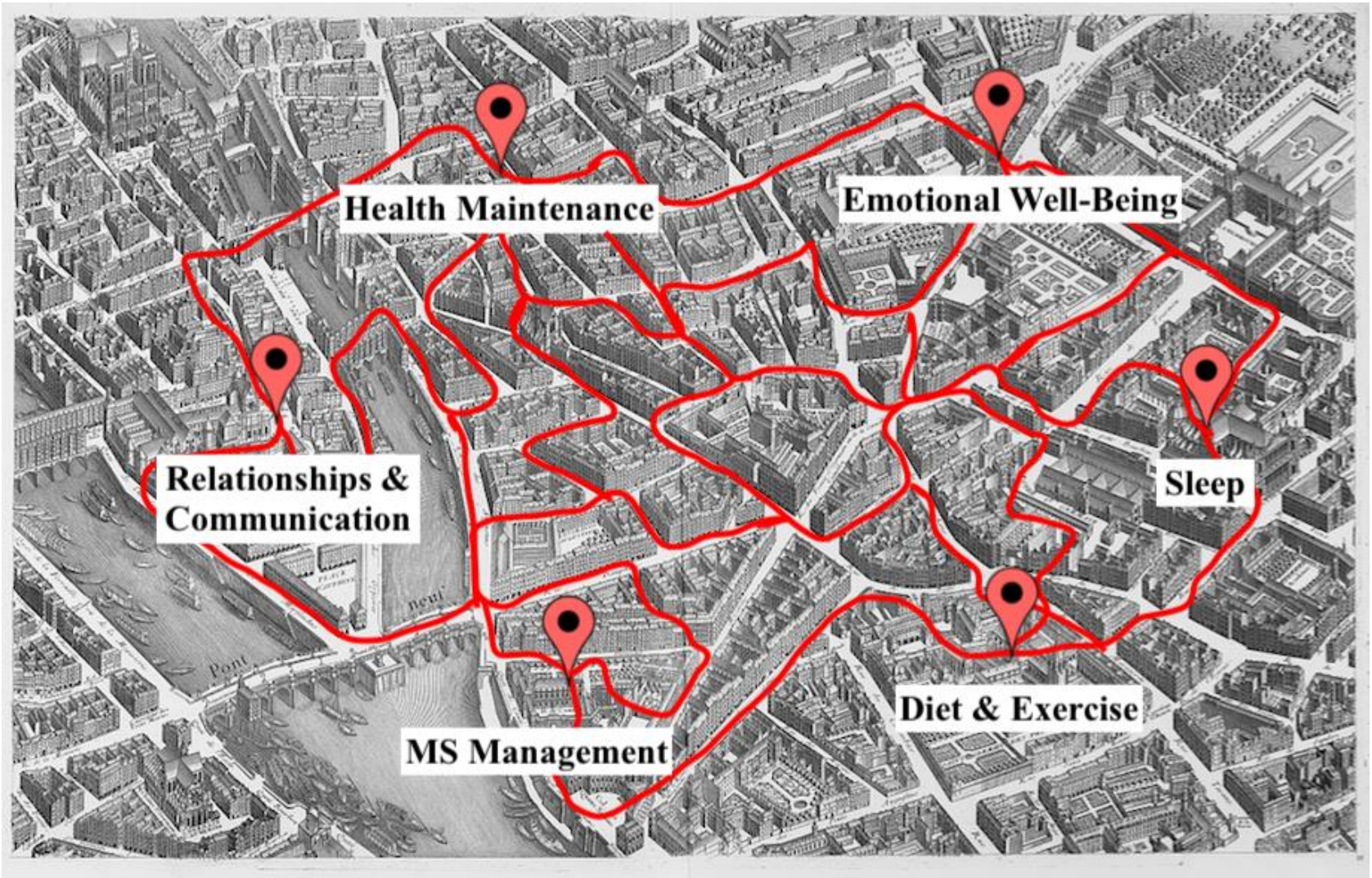
Goals for Communication

- “Set up a regular time to talk with my support partner once a week for a specific amount of time (e.g., 20-30 minutes) preferably not in bed at the end of the day and without TV.”
- “Ask a family member or friend to attend a program on fatigue management so we’ll have a common language. Describe how MS-related fatigue is different from fatigue I had before MS.”

What are your **SMART** goals for communication?



One Change = Big Benefits!



**You have reached
your destination!**



Wellness Resources

- **Wellness Discussion Guide** for people with MS and their healthcare providers—
www.nationalMSSociety.org/WellnessGuide provides links to supporting data and related publications; goal-setting section for each topic.
- The **Living Well with MS** landing page on the NMSS site offers resources on smoking, diet, and sleep in MS.

Questions/Comments



Peggy Crawford, PhD



Stephanie Buxhoeveden, MSCN, MSN, FNP-BC

Questions/Comments

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Our Mission:

People affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever.



Wellness and Lifestyle

Making Treatment & Lifestyle Decisions:
Thinking About Benefits & Risks



Making Treatment & Lifestyle Decisions



Exercise as Part of Everyday Life

Wellness Discussion Guide
for People with MS and Their Healthcare Providers
Integrating Lifestyle and Complementary Strategies into MS Care



Wellness Discussion and Guide



MS CONNECTION NEWSLETTER
WINTER 2012
OHIO VALLEY CHAPTER

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Mood & MS



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Negotiating Reasonable Accommodations January 10, 2017

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