



#### Planning for an Unpredictable Future

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### **SEPTEMBER PROGRAMS**

JUMPSTART –Sept 10 Being CEO of Your Household

COACHING – Sept 15 Keeping Your Life with MS Balanced

> JUMPSTART – Sept 23 Being CFO of Your Household

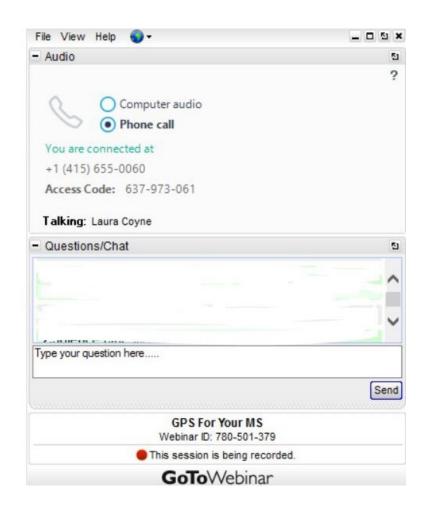
COACHING – Sept 28 Your Questions, Answered: Mapping Out Your Future



#### How to Ask Questions During the Webinar

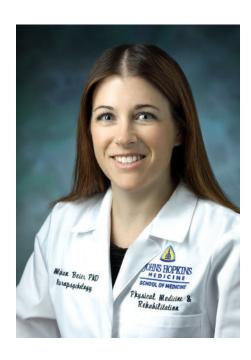
Type in your questions using the **Questions/Chat** box







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# Learning Objectives

Relate how impacts wo care decision

Relate how MS unpredictability impacts work, home, financial, and care decisions

2

Discuss specific strategies to financially plan for a life with MS

3

Describe strategies for maintaining open communication about your financial concerns and goals



Elizabeth is 28 years old.

She was recently diagnosed with MS after an exacerbation that led to hospitalization. To recover, she had to take a 6 week leave from work. She's back to work and doing well.

Her disease modifying medication seems to be working!

She doesn't have any kids.

Can she put off thinking about financial planning, employment options, and disability?



#### Are you...

# Interactive Poll

Working Fulltime Working Part-time

**Chief Home Officer** 

Receiving SSDI/SSI Benefits

Retired



# MS & Employment

- 43-67% leave their job within 12-15 years of diagnosis
- Fatigue is the most common symptom associated with the decision to leave work or reduce employment
- Type of MS, type of job, physical symptoms, and cognition also contribute to change in employment

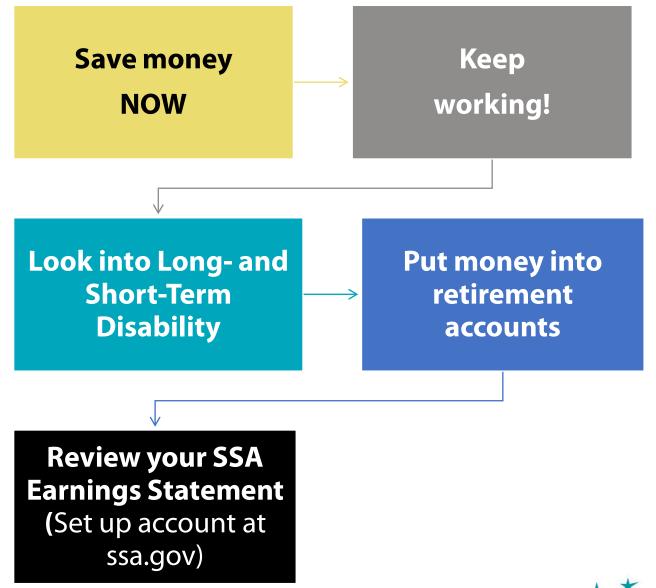


## MS & Employment

- The risk of losing one's job due to MS decreased by 43% when high efficacy DMTs were introduced
- Employment is associated with higher quality of life and better mood
- Education and working with vocational rehabilitation is associated with better outcomes



# Planning for Financial Issues





#### The Decision-Making Spectrum

#### Preplanning

You're in control

Explore all possible options

You can get help and advice

#### Waiting Until You're in Crisis

Very little control

Others deciding for you

Little time to explore options or get advice.



## Interactive Poll

# If you are unable to work, what is /would be your biggest concern?

Financial Pressures

**Lack of Purpose** 

**Outright Boredom** 

Other

(put your answer in the chat box!)



#### **Barriers to Pre-Planning**

#### Vocation = Identity

Feeling like you are losing a part of yourself

#### Feeling Defeated

- "I don't know how to do any other job"
- "I won't make the same salary"

#### My symptoms are well controlled

"I don't need to think about that now"

#### Time

Kids, parents, medical appointments, life



#### **Pre-Planning**

#### Identify Your Values

- What do you love about your job?
- What else is important, meaningful, brings joy?
- Are there ways to use the same values in a different way?

#### Seek Resources:

- SLP, Vocational Rehabilitation
- Look for jobs that recruit people with disabilities/are flexible
  - Example: Chronically Capable wearecapable.org
- See your physicians or your team regularly
  - Report your symptoms
  - Request regular neurological exams
  - Request a neuropsychological exam if you develop cognition issues



Sarah is 54 years old.

She has always received stellar performance reviews and was promoted to head of her department 2 years ago.

Over the last year she started forgetting tasks, missing meetings, and can't seem to get organized. Her boss is noticing and expressing concern.

She's unsure if her challenges relate to the new job, MS, or both.

Her family relies on her income. What should she do?





#### **Accommodations**

#### **Cognitive Accommodations**

Having a private office or allowed noise canceling headphones

#### **Mobility or Physical Accommodations**

- Provided talk to text software
- Office near the bathroom to reduce issues with incontinence

#### Fatigue Accommodations

- Allowed regular breaks (e.g., 15 minutes every 2 hours)
- Working from home to reduce distractions / eliminate commute
- See the Job Accommodations Network for more
  - askJAN.org





Ben is 48 years old.

He started having challenges at work right around his diagnosis 10 years ago.

He did well pre-planning, saving money, and working with his partner to plan for leaving the work force, if needed.

But he loves working.

To help keep his job, he first stepped back to a position with less responsibility but was so fatigued he was sleeping in his car during lunch. He transitioned to part-time. He's still struggling. While his employer still speaks highly of him, they have acknowledged he's not keeping up.

How should Ben Proceed?



## Is it Time to Apply for SSDI? Questions to Ask Yourself.

- Are you able to work full time?
- Are your MS Symptoms preventing full time work?
- Have you noticed a decline in your work performance?
- Has your employer notice a similar decline?
- Are you taking more time off than usual?
- Have you been using FMLA?
- Has your physician mentioned that you consider retiring/quitting?



#### **Definition of Disability**

#### **According to the Social Security Administration:**

- A medical impairment that lasts or is expected to last at least 12 months
- Symptoms and limitations prevent work activity
- MS "Listing": Section 11.09
- Age and Work Skills are considered
  - < 50 years old
  - > 50 years old



# Applying for Social Security Disability Benefits

#### **What to Expect**

- A lot of paperwork
- Between 6 and 24 months

#### **How to Prepare**

- Review your SSA statement
  - ssa.gov
- Gather all medical providers names/addresses
- Call an attorney for a free consultation

#### **Approval Rates**

- Initial level
  - 38%
- Reconsideration Level
  - 14%
- Hearing Level
  - 51%



#### **Working & SSDI**

Working while you have a SSDI application pending



Working after SSDI benefits have been approved



#### **Leaving the Workforce**



Structure your day



**Exercise** your brain



**Exercise** your body



Identify meaningful activities



# Q & A













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# Staying Physically & Emotionally Well this Winter

Wednesday, October 6th at 8pm ET

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