

Webinar Series



Progression Planning: Managing the Common Challenges of Progressive MS

July 9, 2019

Presented by:

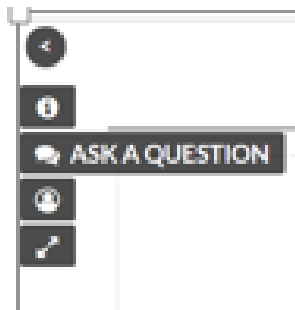


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- This can be found by expanding the second box in your control panel on the left side of your screen.

A screenshot of the 'Ask A Question' interface. At the top, there is a title 'Ask A Question' and a back arrow icon. Below the title is a vertical stack of four icons: a back arrow, an information 'i' icon, a speech bubble icon with the text 'ASK A QUESTION', and a person icon. The 'ASK A QUESTION' button is highlighted. Below the icons is a large empty text box for entering the question. Underneath this box is the instruction: 'To ask a question please type in the box below and click 'Submit':'. Below the instruction is a smaller text input field with the placeholder text 'Type your question here'. At the bottom of this field is a 'SUBMIT' button. At the very bottom of the interface is a circular refresh icon.

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Progression Planning

A Solution and Strategy Focused Approach to the Common Challenges of Progressive MS



Objectives

- Clarify the differences between relapsing-remitting, primary progressive, and secondary progressive MS
- Problem solve strategies and solutions to manage common physical, cognitive, and medical challenges involving disease progression
- Understand and apply the Can Do MS 5 Ps for managing progression

Multiple Sclerosis Classifications

Relapsing MS

- Most common type of MS (85%)
- Characterized by relapses (flares or exacerbations) caused by inflammation in the central nervous system
- Time or steroids may improve symptoms, but some residual disability may remain

Progressive MS

- Thought to be more of a degenerative disease process that damages neurons and axons in the CNS
- Causes a slow, chronic decline in one's function typically without relapses

Progressive MS Basics: SPMS

Secondary Progressive MS:

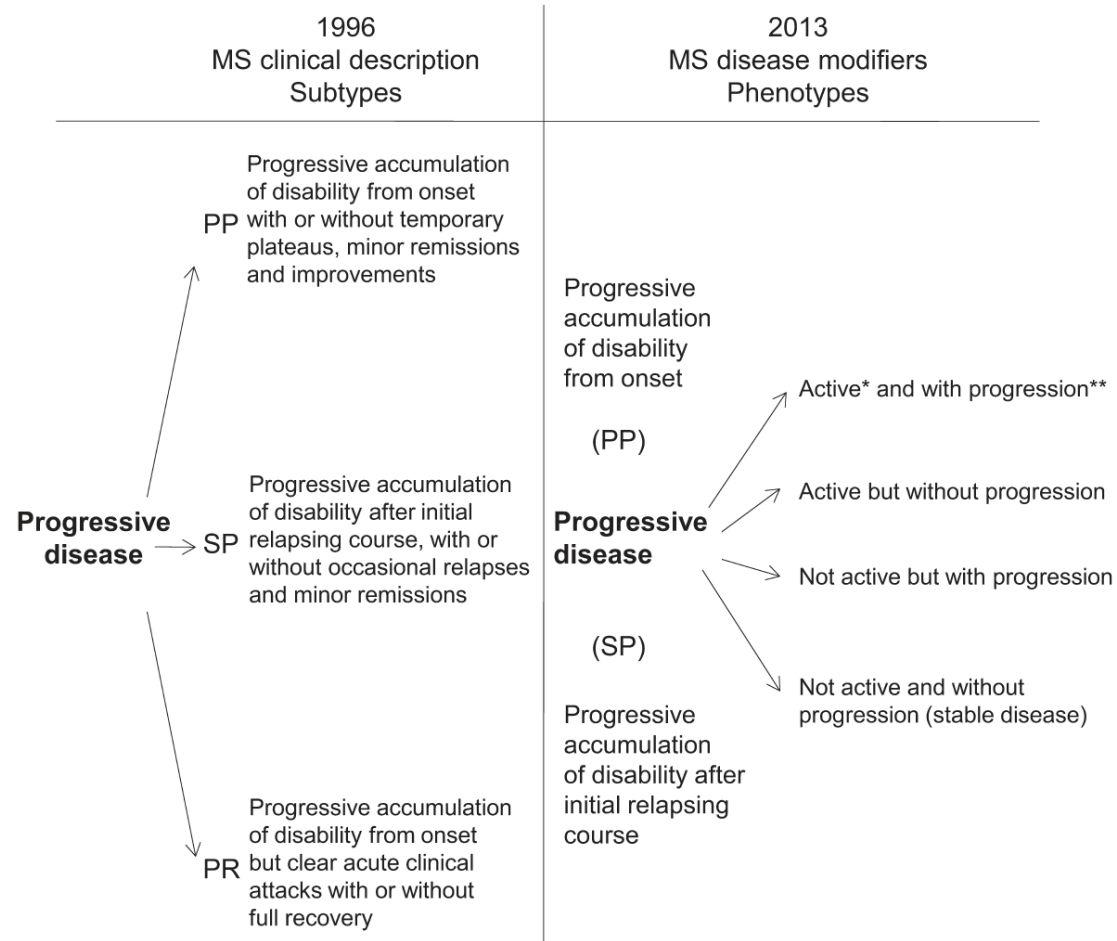
- Without treatment, 50% of those living with Relapsing MS transition to secondary progressive MS within 15-20 years
- In this phase, there is gradual worsening of existing neurological signs and symptoms, with or without occasional relapses
- SPMS is part of MS phenotypes as defined in 2013
- If a person with SPMS is still having relapses, certain disease modifying therapies may be helpful

Progressive MS Basics: PPMS

Primary Progressive MS:

- 2017 McDonald Criteria for PPMS include:
 - One year of disability progression
 - Specific MRI findings and/or findings in CSF
- In 2017, the first medication, Ocrevus (ocrelizumab), was approved to slow effects of PPMS.
 - Ocrevus is not approved for SPMS
- In clinical trials (ORATORIO) this medication showed a 25% slowing of progression.
 - This medication was not shown to improve function in PPMS patients.

Figure 2 The 1996 vs 2013 multiple sclerosis phenotype descriptions for progressive disease



Active = relapse or MRI change

Progression = determined annually by history or objective change on exam

*Activity determined by clinical relapses assessed at least annually and/or MRI activity (contrast-enhancing lesions; new and unequivocally enlarging T2 lesions). **Progression measured by clinical evaluation, assessed at least annually. If assessments are not available, activity and progression are "indeterminate." MS = multiple sclerosis; PP = primary progressive; PR = progressive relapsing; SP = secondary progressive.

Cognition

Sensation

Walking

**Visual
Function**

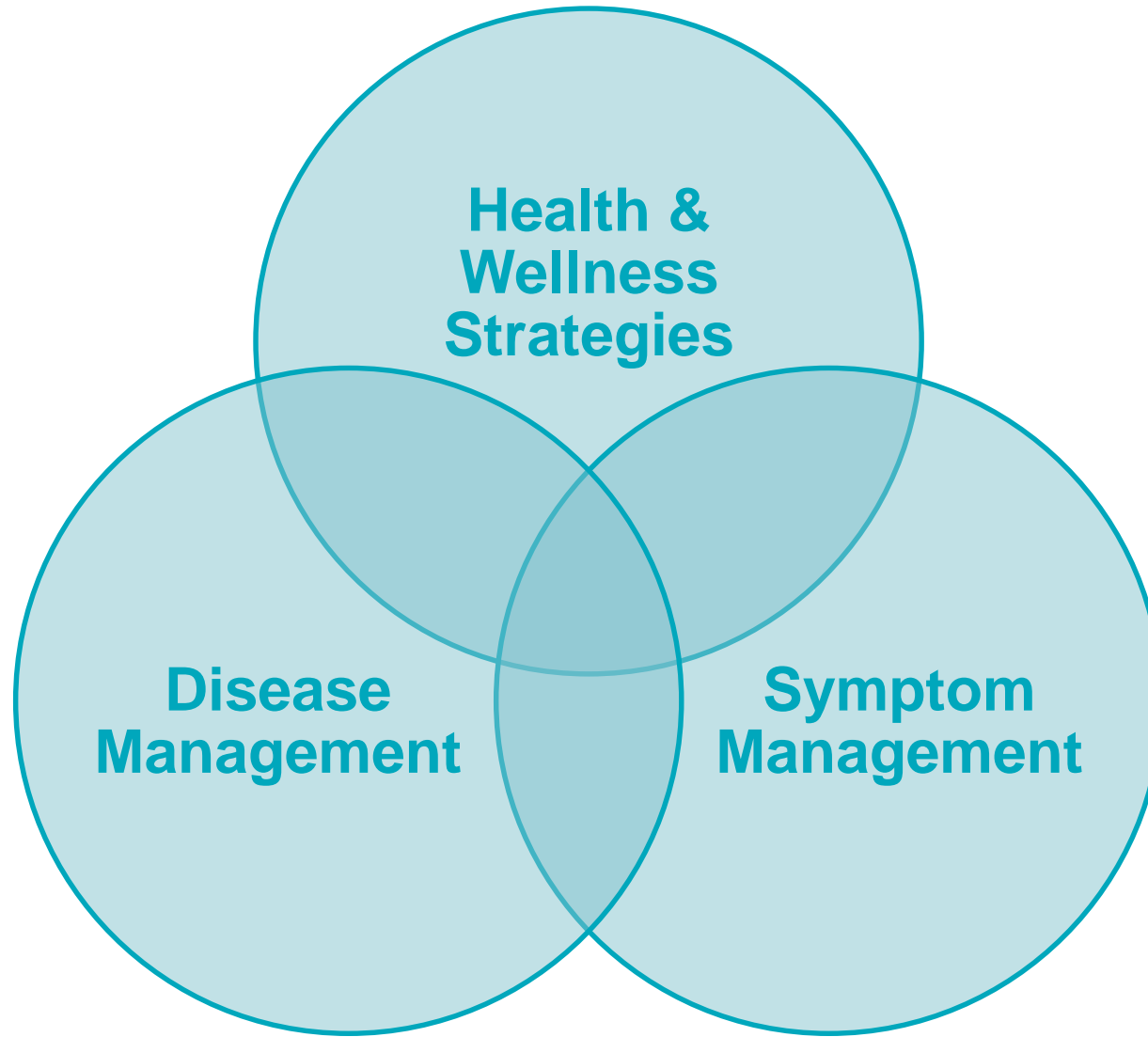
Is this progression?....Over a longer period of time, have you had progression in any of the following symptoms?

Fatigue

Pain

**Bladder or
Bowel Function**

**Balance &
Coordination**



Control What you CAN Control: Taking Charge of Disease Progression

- Ps of Progression
 - Pro-Active
 - Anticipate changes
 - Plan
 - For unpredictability; a plan may reduce anxiety related to potential progression
 - Prioritize
 - Realistic expectations
 - Problem Solve
 - Current disease progression/challenges; menu of options for the unpredictability
 - Professionals who CAN help
 - Monitor changes and intervene

“I keep missing deadlines at work....I am forgetting appointments....I just can’t seem to keep my work organized.”

Progression: Cognition and Employment

- Cognitive changes are common in MS
 - Estimated to affect more than 50-60%
 - Can be related to MS symptoms, or to other issues like medications, sleep, or medical and psychological conditions
 - Can impact:
 - Memory, recall, attention, concentration, speed of thought, complex problem solving
- As an invisible symptom, can be difficult to “prove” or “convince”
 - Cognitive fatigue
- One of the leading reasons to leave the workforce

Can Do To Do:

- Pro-Active
 - Talk to your MS provider as soon as you notice changes
 - Understand ADA
- Plan
 - Daily – Alternative work arrangements, Vocational Rehabilitation
 - Future – Alternative work, Financial planners, FMLA, Disability, Insurance
- Prioritize
 - Obtain baseline cognitive testing; neuropsych testing
 - Make things easier (notes, calendars, alarms, etc)
- Problem Solve
 - Cognitive rehabilitation – remediation and compensation
 - Adaptations and accommodations
- Professionals
 - Mental health professionals, Speech-Language Pathologists, Occupational Therapists, Vocational Rehabilitation Professionals

“Now that my disease has progressed, I have *so many* doctor appointments. This disease is my full time job...I am so anxious.”

Progression: Mood Changes

- Depression and anxiety
 - Depression is one of the most common and treatable symptoms of MS, resulting from brain changes, life changes, and even from medication side effects
 - Characterized by low mood, loss of interest in pleasurable things, suicidal or morbid thoughts, changes appetite, sleep pattern changes, difficulty with thinking and memory, feelings of hopelessness and/or increased irritability
- Can and may occur in tandem
- Can be experienced by not only the person with MS, but also the support partner

Can Do To Do

- Pro-Active
 - Regular screening
 - Make a list of things that bring you joy; make a gratitude list
- Plan
 - Don't hide your symptoms; talk to your support team
 - If you are insured, investigate your mental health benefits
- Prioritize
 - Mood changes deserve the same amount of attention as physical changes
- Problem-Solve
 - Talk therapy, medications
- Professionals
 - Mental Health Professionals; Nurse Practitioners; Neurologists; Clergy

“My wife can no longer walk more than a minute with her walker....I come home to her laying on the floor as she is falling daily....we feel trapped in our home.”

Progression: Walking to Wheelchair

- It is common to either avoid using an assistive device or avoid using the next more “progressive” device
- Unfortunately, satisfying the ego can result in dangerous falls that lead to other medical problems, deconditioning, and worse MS symptoms
- Just because you have one doesn't mean you can't have another
 - Ex: you may choose to use a scooter or wheelchair if you have a lot to do during the day so you have energy to use a walker at night

Can Do To Do:

- Pro-Active
 - Think about how your mobility needs change during an average day
 - Try out a scooter at the grocery store
- Plan
 - Bring up mobility at your MS appointment because mobility evaluations often require a “stand-alone” visit
 - Don’t purchase any device other than a cane without the assistance of a rehab therapist
- Prioritize
 - Safety
 - Adaptations/accommodations=safety=access to life
- Problem Solve
 - Menu of adaptive equipment and exercise options
- Professionals
 - Physical Therapists, Occupational Therapists, Neurologists, Nurse Practitioners, Physiatrists

“My disease is getting worse despite my efforts....I feel hopeless and desperate, I think I am going to go to another country and get stem cells.”

Progression: Disease

- Stem Cells
 - “Research to date suggests that those most likely to benefit are: 50 years or younger, have had MS for 5 or fewer years, have active relapsing-remitting MS but are still walking, and whose disease is not adequately treated by available disease-modifying therapies.” (National MS Society)
 - There are ongoing trials in progressive forms of MS with mesenchymal stem cells
 - For-profit stem cell clinics are not regulated and should be approached with caution
- Cannabis
 - No evidence that cannabis can cure MS
 - Evidence for cannabinoids improving symptoms such as spasticity, neurogenic bladder, neuropathic pain; at the expense of cognition

Progression: Disease

- Nutrition
 - Small studies show improvement in fatigue, sense of well-being with higher quality diets, Wahl's protocol, Mediterranean type diet
 - Suggestion of increased cortical thickness with higher intake of MUFAs
 - No large scale study that shows a certain diet modifies disease BUT lots of studies conclude that plant-based diets improve overall health
- Medication Options
 - Ocrelizumab: PPMS
 - Disease modifying therapies for relapsing forms of MS
 - Disease modifying therapies for active secondary progressive MS

Can Do To Do:

- Pro-Active
 - Do your research on claims; if you can't easily find scientific evidence, there probably isn't any
- Plan
 - Have a discussion with your MS provider about your "why" for a certain type of therapy and consider that opinion
- Prioritize
 - Your life goals, finances, willingness for adverse events including financial loss
- Problem Solve
 - What might be a better choice?
- Professionals
 - Neurologists, Nurse Practitioners

“Since I cannot exercise as much I have gained weight....I now have developed diabetes and sleep apnea, along with this MS mess!”

Progression: Co-Morbid Health Conditions

- Having just one vascular comorbidity increases the likelihood of reaching EDSS of 6 by 6 years
 - High blood pressure, high cholesterol, diabetes, heart disease, stroke, peripheral arterial disease
- Other medical conditions can cause symptoms similar to MS symptoms
 - Thyroid disorders, anemias, vitamin deficiencies, sleep disorders, mood disorders are most common

Can Do To Do:

- Pro-Active
 - Vascular co-morbidities are modifiable with lifestyle interventions and medications thus having positive impact on MS
- Plan
 - Make regular appointments with your primary care provider for screening
- Prioritize
 - Diet: Colorful, plant-based diet
 - Exercise and physical activity: 150 minutes/week
 - Sleep: Practice good sleep hygiene
- Problem Solve
 - Adapt exercise and meal planning/preparation to abilities
- Professionals
 - Primary Care Physicians; Neurologists; Nurse Practitioners; Dietitians; Physical Therapists/Exercise Physiologists

Progression: Medical Management

- See a primary care provider for regular check ups according to recommendations for your age and sex
- Take disease modifying therapy as prescribed
 - The earlier in MS, the better
 - Have regular discussions with your MS provider about whether or not your DMT is appropriate for you
- Follow directions to take care of other medical issues rather than ignore them

Other Thoughts: Progression Preparations

- Avoid avoidance
 - Have honest, open, and regular conversations with your support team about your symptoms
 - Talk to a financial planner
 - Maintain advanced directives, and revisit them regularly
 - Create a will
 - Have FMLA papers filled out for you and your support partner before you need them
 - Create a plan for bad days...who can you call on? Who is your back-up? Would you need childcare? Etc.

Can Do To Do

Proactive	
Plan	
Prioritize	
Problem Solve	
Professionals	

“Find a place for the illness, but keep the illness in its place”

Q & A



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