Your Whole Health, Your Whole Team: Decision-Making and Multiple Sclerosis

March 8, 2016

Presented by:

EMD Serono | Teva Pharmaceuticals | Acorda Therapeutics

Mallinckrodt Pharmaceuticals Autoimmune and Rare Diseases | US Bank
THE POWER TO BE MORE THAN YOUR MS

www.mscando.org | 800-367-3101
How to Ask Questions During the Webinar:

- **Chat Feature** – Type in your questions using the chat box on the lower left hand side of your screen.
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Objectives

• Identify key members of your health care team and understand their roles in helping you manage your symptoms

• Learn tips for making the best use of the time with your health care team

• Establish a framework for making decisions regarding symptom management strategies
Multiple Sclerosis “March Madness”
NCAA March Madness and MS

• NCAA Tournament
  • 68 teams
  • Sweet 16
  • Elite 8
  • Final 4
  • Championship Game

• Multiple Sclerosis
  • Seems like 68 symptoms…
  • Nearly 16 (actually 13) DMTs to choose from…
  • 8 medical appointments/wk. …
  • 4 differing opinions…
  • How to make it to the finals? Achieve Success?
Your MS Team/Your Basketball Team

- Team Captain/”Most Valuable Player” (MVP) – Person with MS
- Co Captain – Primary Care Partner
- Coach – Neurologist
- Assistant Coach – Nurse
- Other Team Members/Players:
  - Mental Health: Psychologist, Social Worker
  - Rehabilitation: Physical Therapist, Occupational Therapist, Speech Pathologist
  - Nutritionist/Registered Dietician
  - Other Physicians: Primary Care; Urologist; Physiatrist
  - Vocational Rehabilitation
Polling Question #1

• Who are the members of your health care team? (Question to gather a sense of what providers participants are currently accessing)
  • Neurologist
  • Nurse
  • Psychologist
  • Social worker
  • Rehabilitation specialist (PT, OT, Speech)
  • Dietitian
  • Urologist

• Other
Many symptoms.....many decisions.....

How do you make the call?

Whom do you call?
My MS can cause all this?!!

- Numbness, tingling
  - Headache
  - Cognitive dysfunction
  - Depression
  - Speech/swallowing problems
  - Breathing problems
- Fatigue
  - Sexual dysfunction
  - Muscle spasms
  - Itching
- Walking difficulty
- Dizziness
  - Vision problems
  - Emotional changes
    - Hearing loss
    - Pain
    - Bladder dysfunction
    - Bowel dysfunction
    - Seizures
    - Tremor

www.blog.mymsaa.org
When trying to explain your Multiple Sclerosis symptom becomes more annoying than the symptom itself...
Communicating with the “Coach,” a.k.a MD

• Your relationship with your doctor requires teamwork
• Your game plan will be built around:
  • Your doctor’s knowledge and expertise
  • Your goals, priorities and preferences
• Treatment decisions will be built around:
  • Your report of symptoms that have appeared, changed, disappeared
  • The doctor’s assessment of your symptoms, neurologic findings on exam, test results
  • Your ability to prioritize the symptoms that are having the greatest impact
• Open communication is essential
  • Even the best clinician cannot read your mind
  • Be prepared with a prioritized list of issues and questions – advocate for yourself!

There’s no room for don’t ask/don’t tell in this partnership!
To help find the right “coach” for you, call the National MS Society at 1-800-344-4867
Meet the Captain and Co-Captain

• Sally and Stan
  • Sally, age 45, has had MS for 15 years
  • She and her husband, Stan, have 2 teenage daughters
  • Recent severe relapse with new symptoms: fatigue, spasticity, difficulty walking, increased numbness, bladder urgency/frequency, and “brain fog” that are affecting activities at home and work
  • Dr. Jones prescribed steroids, which seem to have provided some relief, and discussed treatment options
  • Sally and Stan are concerned with the new symptoms that are impacting Sally’s work and their family life
  • Stan is especially worried and just wants his “wife back”
Polling Question #2

• Which team members would be the most appropriate for Sally and Stan to consult?

  Neurologist
  Nurse
  Psychologist
  Social worker
  Rehabilitation specialist (PT, OT, Speech)
  Nutritionist/Dietitian
  Urologist
First Half: Physician Visit

• Discuss Disease Modifying Therapy
  • Don’t let this dominate the discussion
    • Potential “ball hog”

• Prioritize symptoms
  • Fatigue
  • Spasticity
  • Mood/depression and cognition

• Wellness priorities – physical, emotional, intellectual, spiritual
  • Data supports the value of wellness and exercise in MS

Which play should they execute?
Which team “players” can best help Sally and Stan?
General Exercise Guidelines

**Aerobic:**
- 3-4x/week
- 20 minutes
- Walking, biking, etc.

**Flexibility**
- ROM
- Stretching
- Manual, NMSS
- 3x, 20-30 seconds

**Strength Training**
- 2-3x/week
- 1-3 reps, 8-15 reps
- Bands, weights, body resistance, etc.

**Balance**
- Highly individualized intensity and frequency
- Sitting, standing, walking
First Half: Physical Therapy

• Fatigue
  • 4 Ps play: Planning, Prioritizing, Positioning and Pacing
  • Body temperature – staying cool
  • Appropriate exercise
  • Collaborate with MDs: confounding medical issues, medications

• Spasticity
  • Stretching, positioning, bracing, strengthening, etc.
  • Collaborate with MDs: Botox, Baclofen, etc.

• Walking
  • Safety
  • Exercise
  • Assistive devices
  • Bracing, if appropriate
  • Strategy: Fit for function!

• At the end of PT, Stan mentions that Sally seems really down…..
Mood Changes

- Depression, anxiety and moodiness are common
- While not surprising with a chronic unpredictable illness, mood changes in MS are:
  - More common than in other chronic illnesses
  - Caused by changes in the brain and immune system, as well as daily challenges
- Impact quality of life and make other symptoms (i.e. fatigue, cognition and pain) feel worse
- Deserve the same careful diagnosis and treatment as other MS symptoms (psychologist, psychiatrist, social worker, counselor)
- Are treatable (talk therapy, medication, exercise, stress management)
Timeout Tip #1: Working on Weight Gain

Reduced activity, mood changes and fatigue can all contribute to weight gain.

**Call Your Team!**
- Nutritionist/registered dietician
- Rehabilitation for exercise program
- Emotional/cognitive support
Halftime – Pause/Reflect

• Sally and Stan Update: 3 years later
• Transitioning to secondary progressive MS
• No additional relapses, but gradual worsening
• Sally is concerned with her ability to get to work and function effectively as an insurance agent.
• Bladder challenges causing more isolation and challenges with intimacy

What players from the team should execute the play?
What play should they execute?
Polling question #3

• What would be the most appropriate SMART goal for Sally and Stan?

A. Sally and Stan will complete home modifications, including a stair glide, to better allow Sally to access the family room in the basement, 8 weeks.

B. Sally and Stan will implement 2 organization strategies to help Sally improve her ability to manage family schedules, 8 weeks.

C. Sally and Stan will exercise together a minimum of 2 days per week to address weight challenges, mental health and wellness, as well as mobility, 8 weeks.

D. ALL are SMART goals!
Second Half: Challenges of Secondary Progressive MS (a really tough defense)

• MS management goals
• Rehabilitation goals
• Mood and cognition goals
• Wellness goals

Other team members to recruit?
Cognitive changes
- Are common, affecting up to 65% of people with MS
- Primary reason for early departure from the workforce
- Can impact self-esteem, communication, relationships, daily activities and self-care
- Include slowing of information processing, learning and memory, visual/spatial skills, etc.
- Deserve careful assessment and management with compensatory tools and strategies (neuropsychology, OT, speech/language)
- Can generally be managed in ways that reduce impact at home and at work
Second Half: Nursing +/- Urologist

• Bladder dysfunction
  • Is common, affecting up to 85% of people with MS
  • Embarrassing to discuss, can lead to social isolation
  • Can coexist with sexual dysfunction
  • Can involve failure to store urine (urgency) or failure to empty (hesitancy) or a combination
  • Behavioral strategies: timed or double voids, Kegel exercises, intermittent self-catheterization, avoidance of bladder irritants
• Medications

Fluid restriction may cause constipation and worsen fatigue
Timeout Tip #2

Keep mobile!

• Team members to help
  • Physician/nurse
  • Physical Therapist
  • Exercise physiologist
• Weight control
• Safety is of paramount importance
• Adaptive equipment
Overtime…..Overwhelmed…..Exhausted…..“Too Many Balls in the Air”

• What do you do in those times when it is feeling overwhelming?
• Now is the time to pull together as a team more!!!
• End of game and you are exhausted = when you need your team the most
• Advocate more for yourself and your needs!
Your MS Decision Making Playbook

• Speak up/communicate
• Prioritize
• Teamwork
• “Huddle up” with team during the “hard” times

For referrals to healthcare professionals in your community, contact the National MS Society: 1-800-344-4867

www.mybasketballblackmamba.weebly.com
Your MS Decision Making Playbook

• Ask your healthcare providers for recommendations

• Consult other professional organizations
  • Can Do MS
  • Consortium of MS Centers
  • American Physical Therapy Assoc.
  • American Occupational Therapy Assoc.

• Consider alternative modes of communication/access
  • Email
  • Telehealth

www.mybasketballblackmamba.weebly.com
Polling question #4

• What "player"/discipline will you add to your team?
  Neurologist
  Nurse
  Psychologist
  Social worker
  Rehabilitation specialist (PT, OT, Speech)
  Dietitian
  Urologist
  Other
Thank You!

Questions?
Comments?
Can Do MS Resources

eNEWS
your best life update

Q&A

Can Do Library

Find these resources at www.MSCanDo.org.
National MS Society Resources

http://www.nationalmssociety.org/
Treating-MS/Comprehensive-Care

Making Treatment & Lifestyle Decisions:
Thinking About Benefits & Risks

NORTH AMERICAN EDUCATION PROGRAM
2013
The Complete Guide to Social Security Disability

Employment Series: Part III

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