

# WEBINAR & TELELEARNING SERIES



## MANAGING COMPLEX CARE NEEDS WHENEVER THEY OCCUR: *A TEAM APPROACH*

**August 8, 2017**



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## Objectives:

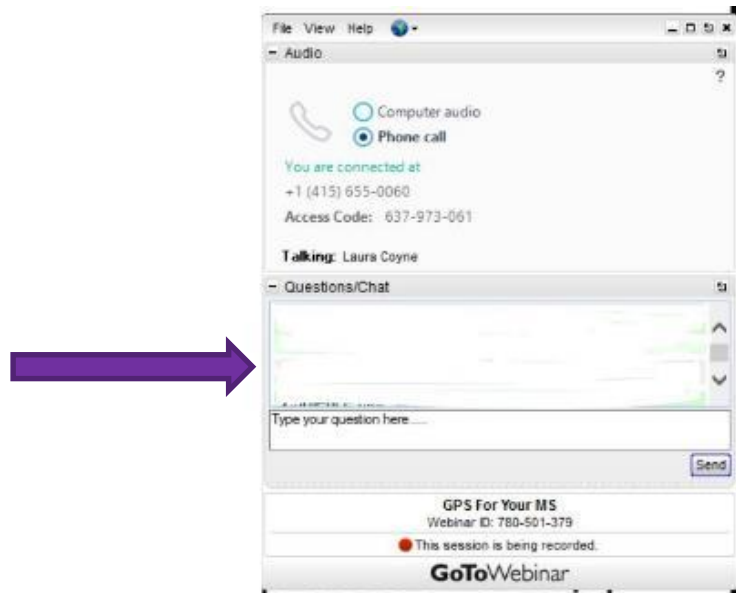
*Participants will:*

- Understand that complex care needs can occur at any stage of the disease process
- Be able to problem solve and prioritize complex needs with their health care team
- Explore helpful resources and strategies for challenging times

# *Be part of the discussion!*

## 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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# Your MS Team



[http://www.ajmc.com/journals/supplement/2013/ace014\\_nov13\\_ms-ce/ace014\\_nov13\\_ms-ce\\_ross](http://www.ajmc.com/journals/supplement/2013/ace014_nov13_ms-ce/ace014_nov13_ms-ce_ross)

# Complex Care Needs: Defined

- Involve one or more worsening symptoms that impact function and quality of life
- Can occur at any disease stage or any age
- Require strategic coordination of care by the appropriate health care providers
- Are unique to each individual and each situation

# Vignette 1: Alice

**“I just love teaching.....I cannot imagine life without a classroom.”**

- Wife, mother of 2 young daughters
- Award-winning 7<sup>th</sup> grade teacher
- Enjoys gardening and watching her daughters’ dance recitals.
- Diagnosed with MS 9 years ago at age 28
- Until this “really bad” relapse, the MS had only a minimal impact on her daily life
- Been on injectable disease-modifying therapy since diagnosis

*Everything is changing now...*

# Alice

- 10 days in hospital, followed by 2 weeks of inpatient rehabilitation because of inability to walk; returned home yesterday.
- 3 new spinal cord lesions on MRI, causing new bladder symptoms, decreased libido, walking and balance problems
- While in rehab, learned that her Body Mass Index (BMI) is high and her vitamin D level is low; wants to lose weight.
- Husband, Rob, an electrical engineer, has taken over most parenting activities and household chores. He feels overwhelmed and incapable of helping Alice.

# Alice

- Starting to walk with a walker, but only slowly and for short distances because of significant spasticity in her left leg and weakness in both legs.
- Extreme fatigue interferes with daily activities – self-care, care of her family, household chores; has had 3 falls since returning home.
- Terrified that she will be unable to return to work, let alone her preferred “active” teaching style.
- Experiencing depression and anxiety, including worries about the impact of her condition on her daughters.

# Complex Care Concerns:

- Disease management
- Management of other health conditions
- Grief/depression/anxiety
- Mobility challenges
- Bladder challenges
- Intimacy issues
- Support partner/family needs

# Can Do To-Do: Nursing

## Assess Treatment Effectiveness

### *Relapse Management*

- How to tell if you are having a relapse
- When to talk to your doctor
- Steroids and rehabilitation

**Should Alice consider switching DMTS?**



# Can Do To-Do: Nursing

## Treat Ongoing Symptoms

### *Bladder Dysfunction*

Medications

Lifestyle management

- Don't restrict fluids, but try just drinking them with meals
- Timed voiding
- Double voiding
- UTI tracker app

# Can Do To-Do: Nursing

## Treat Ongoing Symptoms

### *Fatigue*

- Acute fatigue is common during and after relapses
- Causes: muscle weakness, depression, altered sleep, urinating frequently during the night, medicine side effects
- Check the basics- B12, thyroid, heart disease, anemia, diabetes can be warning signs of fatigue
- Interventions
- Address underlying issues
- Gradually resume daily activities (don't do too much too soon after a relapse)
- Diet (especially after steroids)
- Exercise
- Sleep hygiene
- Avoid overheating
- Rest during the day
- Plan activities for times when you have more energy
- Consider adaptive equipment for weakness

# Can Do To-Do: Nursing

## Treat Ongoing Symptoms

### *Spasticity*

- Medications
- Regular stretching
- Physical therapy

### *Optimize Overall Health*

- Supplement Vitamin D
- Maintain a healthy weight
- Prevent other chronic diseases
- See your primary care provider regularly

# Can Do To-Do: Physical Therapy

- **Impairments:**

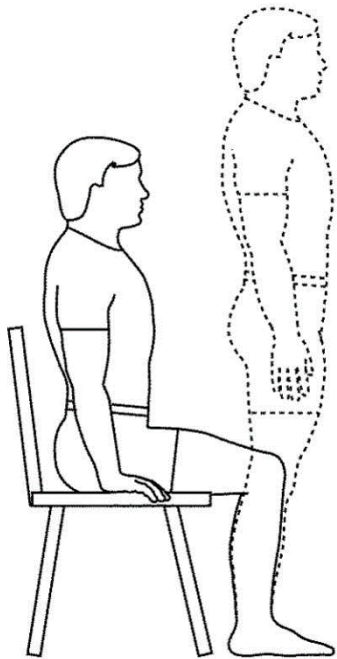
- Walking
- Spasticity
- Weakness
- Falls/Balance Issues
- Fatigue

- **Functional Limitations**

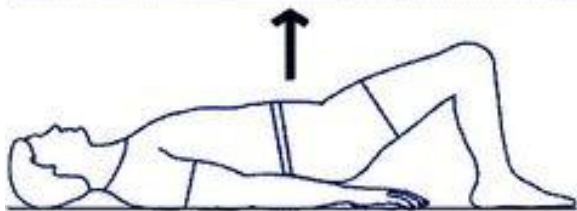
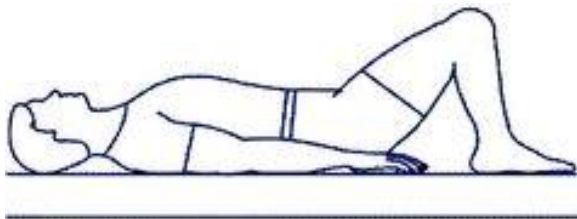
- Walking safely and efficiently in home, community, and eventually school
- Insufficient balance and energy for ADLs
- Adapting an exercise program for weight loss

# Can Do To-Do: Physical Therapy Interventions

- **Exercises**
  - Stretches to address spasticity
    - National MS Society Stretching Resources
  - Progressive, strategic strengthening exercises
  - Balance exercise to minimize falls
    - Problem solving past falls to guide intervention
- **Loss of strength coupled with increased spasticity.....permanency?**
  - How to tell? How to respond?
- **Disease versus deconditioning**



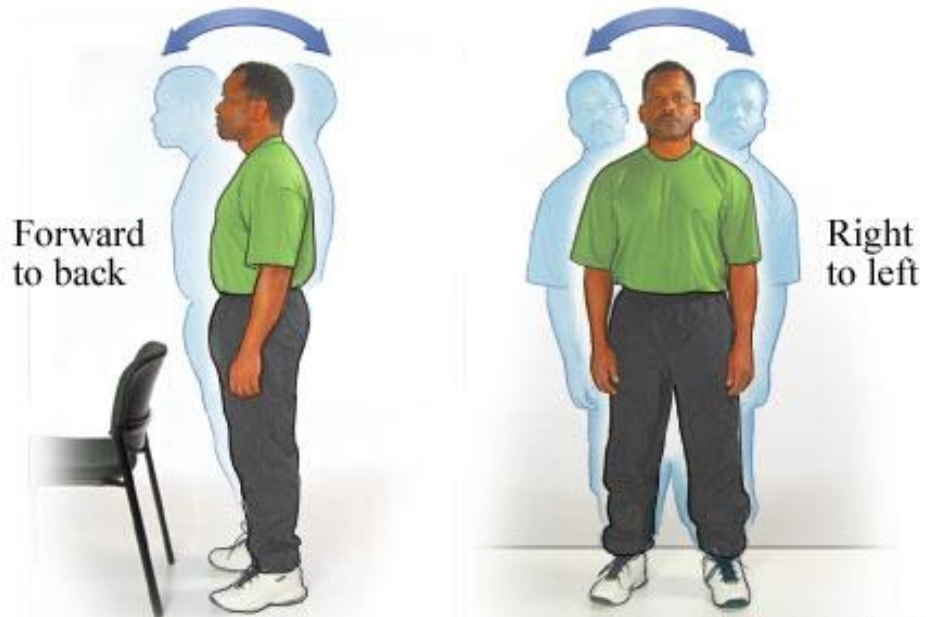
<https://www.orthocarolina.com/news/cat/oc-blog/subcat/fitness-training/detail/osteoporosis-and-exercise>



<https://www.pinterest.com/pin/132011832802501864/>



<http://www.webmd.com/fitness-exercise/marching-in-place-exercise-to-improve-balance>



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<http://www.webmd.com/fitness-exercise/standing-sway-exercises-to-improve-balance>



# Can Do To-Do: Physical Therapy Interventions

- **Assistive Devices**
  - Multiple devices; different situations
  - When to use; when to not
- **Family education**
  - When to help and how to help versus when to empower independence
- **Occupational Therapy**
  - Home safety evaluation; equipment recommendations
  - Energy management strategies
- **Vocational Rehabilitation**

# Can Do To-Do: Psychologist

- Supporting **healthy grieving** over recent changes and losses
- Promoting **effective communication** – with Rob, her daughters, her employer and colleagues, her healthcare team – about feelings, needs, priorities
- Encouraging realistic **planning, problem solving, goal-setting** for herself and with her family
- Promoting a **balanced partnership**, in which Alice and Rob both give and receive care... for each other and themselves



# Vignette 2: John

**“Now that I am retired, I am bored and no good to anybody.”**

- An attorney – forced into retirement at age 62
- Has had MS for 18 years; secondary progressive MS; remains mobile with a power wheelchair; takes a DMT
- Memory problems and slowed information-processing interfered with work.
- Convinced that nothing else could be as engaging or fulfilling as his law practice.
- Wife, Rachel – a family physician – is concerned about his weight gain, smoking, and overall inactivity; John previously enjoyed sports with his sons.

**“I suppose this is my new reality.....”**

# John

- High blood pressure; recently diagnosed with diabetes.
- Concerns about pressure sores because of decreased sensation, reduced mobility and long hours in his wheelchair.
- Constipation, bowel urgency and occasional incontinence.
- Nerve pain that does not respond to over-the counter medications.
- John tends to ignore the problems; Rachel – a family physician – is concerned for his overall health.

# Complex Care Concerns

- Inactivity/weight gain
- Bowel function
- Pain
- Mood and cognition
- Partnership/communication

# Can Do To-Do: Psychology

- Assess for **depression and suicidal thoughts**
- Support the **grieving process** and help John to redefine himself, set new goals, and connect with his strengths
- Encourage **self-care, healthy behaviors**, engagement with healthcare team, reengagement with his community
- Encourage **communication** with Rachel, joint problem-solving and shared activities

# Can Do To Do: Physical Therapy

- **Impairments**

- Skin integrity
- Upper extremity and core strength
- Posture
- Pain

- **Functional Limitations**

- Appropriate positioning and posture within wheelchair
- Exercise for function, weight management, and fun with family

# Can Do To Do: Physical Therapy Interventions

- **Equipment**
  - Dependent lift devices
  - Transfer boards
  - Standing frame
- **Skin care management**
  - Seating needs: cushion; tilt, recline, or standing features
  - Scheduled weightshifting and standing

**CONSULT TEAM BEFORE BUYING**



<http://www.wickedwheelchairs.com.au/standing-frames.html>



[https://www.officesupply.com/cleaning-breakroom/first-safety-security/exam-room-furniture-accessories/bath-seats/deluxe-wood-transfer-boards-with-outs-capacity/p393794.html?ref=pla&product\\_id=393794&adpos=1o5&creative=165102574458&device=c&matchtype=&network=s&gclid=CJWB0dDK\\_9QCFQY0aQodXIoA1w](https://www.officesupply.com/cleaning-breakroom/first-safety-security/exam-room-furniture-accessories/bath-seats/deluxe-wood-transfer-boards-with-outs-capacity/p393794.html?ref=pla&product_id=393794&adpos=1o5&creative=165102574458&device=c&matchtype=&network=s&gclid=CJWB0dDK_9QCFQY0aQodXIoA1w)



<http://www.just-patient-lifters.com/page1.html>



<https://slideboard.wikispaces.com/Slide+Board+Transfer>

# Can Do To Do: Physical Therapy Interventions

- **Exercises**

- *Maximize function*

- Core stability for sitting balance, posture, reaching, pain
    - Upper extremity strength for transfers
    - Lower extremity strength and ROM for transfers
    - Standing for bone density, bowel/bladder, psychological effect, skin integrity, among others!

- **Adaptive sports and online exercise**

- [www.disabledsportsusa.org](http://www.disabledsportsusa.org)
  - [www.msforward.org](http://www.msforward.org)
  - [www.nchpad.org](http://www.nchpad.org)





<http://hpblog.s3.amazonaws.com/blog/wordpress/wp-content/uploads/2013/04/Triceps-dip.jpg>



<http://www.spinalcord.org/resource-center/askus/index.php?pg=kb.page&id=2427>



<http://enables.me/fit-friday-julie-abs-obliques-exercises/>

# Can Do To-Do: Nursing

- **Treat ongoing symptoms**

- *Bowel dysfunction*

- Everyone has a different normal!
- Causes include lack of sensation, dehydration, medication side effects, immobility, and MS lesions
- Interventions
- Increase fluids
- Increase dietary fiber- green leafy veggies, whole grains, take supplements
- Exercise
- Adjust medications that could be causing symptoms

# Can Do To-Do: Nursing

- **Treat ongoing symptoms, cont.**

- *Bowel dysfunction*

- Bowel training- 30min after a meal sit down on the toilet for 20-30 minutes, keep a regular timed schedule
- Use a footstool or the Squatty Potty
- Manual stimulation
- Avoid irritants like caffeine, alcohol, spicy food etc...
- Discuss other medications with your doctor
- Agents used to treat overactive bladder can also help bowel symptoms
- Antispasmodic agents
- Stool softeners
- Imodium as needed

# Can Do To-Do: Nursing

- **Treat ongoing symptoms**

- *Cognitive Issues*

- Increase cognitive reserves by doing challenging your mind daily
- Consider neuropsychiatric testing, cognitive rehab, and medications
- Have family come with you to appointments so you don't forget information
- Stay organized and free your house of unnecessary clutter
- Take your time completing tasks, don't rush through things
- Minimize distractions
- Use a calendar
- Set alarms on your phone
- Consistently keep things in the same place
- If you misplace something, keep it where you first looked for it
- Write down information
- Verbally repeat information you want to remember
- Plan tasks for the time of day when you are most alert
- Sleep hygiene

# Can Do To-Do: Nursing

- **Treat ongoing symptoms**

- *Pain*

- Causes:

- neurogenic pain
      - Spasticity
      - Headaches
      - pressure/skin breakdown from assistive devices

- Treatment

- Address underlying issue(s)
    - Medication
    - Mindfulness/Wellness

- Considering seeing a pain management specialist

# Can Do To-Do: Nursing

- **Treat ongoing symptoms**
  - *Skin Integrity*
    - Regularly check skin for breakdown
    - Keep skin dry
    - Positioning
  - *Optimizing Overall Health*
    - Control blood pressure
    - Quit smoking
    - Prevent other chronic health issues

# Your MS Team



[http://www.ajmc.com/journals/supplement/2013/ace014\\_nov13\\_ms-ce/ace014\\_nov13\\_ms-ce\\_ross](http://www.ajmc.com/journals/supplement/2013/ace014_nov13_ms-ce/ace014_nov13_ms-ce_ross)

**C**omplex Needs  $\neq$  Impossible Needs

**C**omplex Needs = **C**ollaborative  
Problem Solving

You **C***an Do!*



# Additional Resources

- Advocacy organizations
  - National MS Society – [www.nationalMSSociety.org](http://www.nationalMSSociety.org); 800-344-4867 (MS Navigators for information, support, referrals)
  - Multiple Sclerosis Association of America – [www.mymsaa.org](http://www.mymsaa.org); 800-532-7667
  - Multiple Sclerosis Foundation – [www.msfocus.org](http://www.msfocus.org); 888-673-6287
- Article link
- American Physical Therapy Association – [www.apta.org](http://www.apta.org) to find a PT in your area
- HelpPRO Therapist Finder – [www.helppro.com](http://www.helppro.com) to find a mental health professional in your area

***Thank you watching this presentation!***

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<https://www.mscando.org/get-involved>

## ***Questions and Answers***



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# Can Do MS Resources

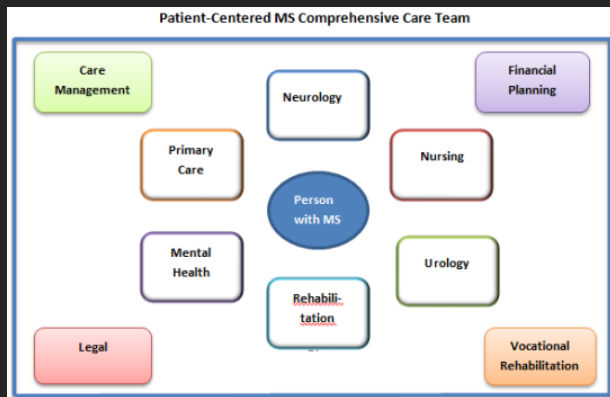
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Q&A

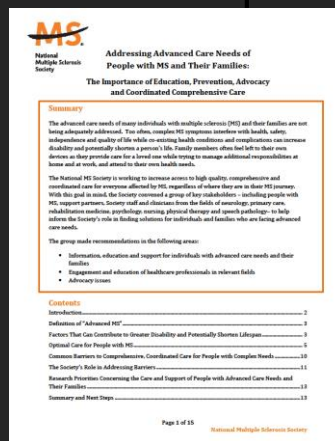
Can Do Library

Find these resources at [www.MSCanDo.org](http://www.MSCanDo.org).

# National MS Society Resources



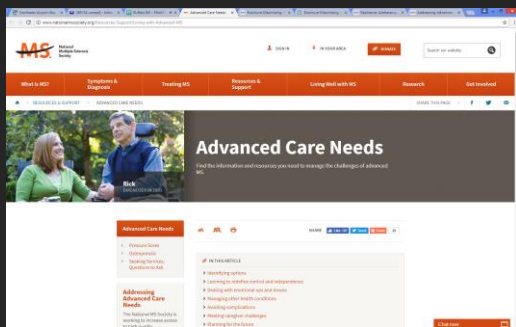
Comprehensive Care



Education, Prevention, Advocacy and Coordinated Comprehensive Care



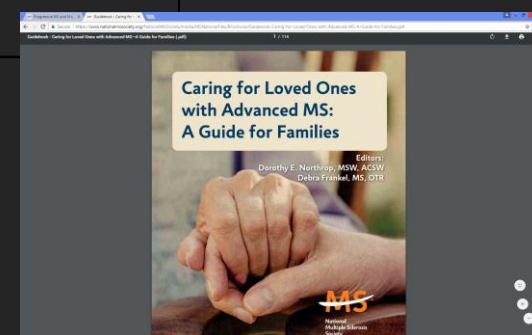
Complex or Advanced Care



Advanced Care Needs



Progressive MS and Major Changes



Caring for Loved Ones with Advanced MS



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September 12, 2017



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