



Home LINKS: Comprehensive care management for people with MS

Dawn Russo, MSW, LCSW, MSSMC

Overview of Presentation

- **Care Management at NMSS**
 - What is MS?
 - Three-tiered model
- **The Comprehensive Approach**
 - Knowing your client
 - Non-medical factors
 - Using resources



Overview of MS

- Chronic disease of Central Nervous System
- Autoimmune disease
- "The body's own defense system attacks myelin, the fatty substance that surrounds and protects the nerve fibers in the central nervous system. The nerve fibers themselves can also be damaged. The damaged myelin forms scar tissue (sclerosis), which gives the disease its name. When any part of the myelin sheath or nerve fiber is damaged or destroyed, nerve impulses traveling to and from the brain and spinal cord are distorted or interrupted, producing the variety of symptoms that can occur."

* <http://www.nationalmssociety.org/about-multiple-sclerosis/what-is-ms/index.aspx>



Overview of MS

- **General Patterns of MS:**
 - Relapsing-Remitting: *approximately 85% of initial diagnoses*
 - Secondary Progressive: *50% of RR switch within 10 yrs*
 - Primary-Progressive: *approximately 10% of initial diagnoses*
 - Progressive-Relapsing: *more rare, approximately 5%*
- **Symptoms and progression vary and include:**
 - fatigue; impaired vision and speech; poor muscle coordination; paralysis; bladder and bowel problems; cognitive dysfunction; tremors and spasticity



Overview of MS

- **Causes**
 - Cause is unknown
 - Virus
 - Genetic
 - Environment
- **Treatments:**
 - Disease modifying drugs
 - 6 DMDs are currently approved
 - 4 injectibles, 2 IV-infusions
 - Visit www.nmss.org to learn more about each DMD
 - Steroid treatments for attacks
 - Symptomatic treatments



Overview of MS

- **Who gets MS**
 - Women more than men
 - Caucasians more than some other groups
 - People living in temperate climates
 - Usually diagnosed between ages of 20-50
- **Incidence**
 - MS affects 400,000 in US
 - In MA and NH 14,000 people
 - Someone diagnosed every hour



Overview of MS

- Why is care management important for people with MS?
 - Younger adults with disabilities lack community support
 - Unpredictability of MS can mean rapid changes
 - Cognitive issues
 - Life Transitions



Overview of National MS Society

- **Mission: To end the devastating effects of MS**
- Founded in 1946
- 51 chapter network
 - Funds research, furthers education, advocacy, programs and services
 - Committed to providing programs and services that help people living with MS to function with highest possible quality of life



Overview of National MS Society

- **Central New England Chapter**
 - Founded in 1951
 - Serves MA & NH
 - Headquarters: Waltham
 - Branches: Wareham MA, Manchester NH
 - Award winning programs and services
 - Cavallo Award



Overview of National MS Society

- **Central New England Chapter**
 - Community Programs Dept
 - Direct Services, Community Programs, Advocacy
 - Development
 - Walk MS, Bike MS, Run, Challenge Walk
 - Help for today, hope for tomorrow



Overview of National MS Society

- **Central New England Chapter**
 - Chapter programs guided by Quality of Life goals and include:
 - Direct Services
 - Information and Referral
 - Financial Assistance in several categories
 - Care management/Home LINKS
 - Peer Support
 - Newsletters
 - Professional education



Overview of National MS Society

- **Central New England Chapter**
- Chapter programs (continued)
 - Community education and support programs
 - Self-help network
 - MS Vacation Week
 - MS Week in Jackson
 - Annual Conference
 - Research, health and wellness programs
 - Newly Diagnosed programs
 - Kids Get MS Too
 - Young Adult Network
 - MS Clinic affiliations



Care Management at NMSS



Overview of National MS Society

- **Care Management is a priority of the National MS Society**
 - NMSS able to respond at all stages of the disease
 - Needs typically increase as disease progresses...
 - Newly Diagnosed –information; coping
 - Relapsing-Remitting – employment; networking, symptom management
 - Progressive MS – housing, benefits, home care
 - However, care management can be provided to anyone at any stage



Care Management at NMSS

- **Model of care management**
 - Three Tiers
 - Tier 1: Information & Referral (I&R)
 - Tier 2: Services Management
 - Tier 3: Care Management
 - Contracted care managers
 - Advisory Committee
 - Chosen model of NMSS



Case Example: Nancy

- **One person's experience with MS and the NMSS**
- **Background:**
 - In 1985, when Nancy was 25 yo she was diagnosed with MS. Nancy worked in Boston, was married, very active in her community and a marathon runner. In 1990, Nancy and her husband welcomed a baby boy into their family. Nancy had supportive parents, who frequently traveled and vacationed on the West Coast. She initially became involved with Chapter as a volunteer. Throughout next 15 years, Nancy attended informational programs that Chapter hosted in the community and engaged others with MS as a peer supporter and support group leader.



Three Tiered Service Delivery Model

- **Information and Referral (Tier I)**
 - Information about MS and referrals to community resources
 - Web-based database with over 4000 resources
 - Over 300 calls per month
 - Denver Information Resource Center (IRC)
 - Why people call
 - Financial Assistance: Symptoms/Treatments; Care Management; Legal services; Home modifications; Chapter Programs
 - Referrals to Doctors: Resources for emotional support, durable medical equipment, independent living and community financial assistance
 - Over 3000 individuals served each year



Case Example: Nancy

- **Tier I**
 - As questions arose, Nancy would contact Chapter to request information or referrals to local providers and programs. Through basic I&R services, the Chapter was able to answer the questions that Nancy and her family had on topics such as:
 - MS,
 - pregnancy,
 - symptom management,
 - exercise,
 - coping,
 - travel options for people with a disability.
 - She also borrowed books from the Lending Library.



Three Tiered Service Delivery Model

- **Tier I – Three more examples**

- Kathy called because she needed a ramp on her home. The Information Specialist gave Kathy the names of contractors, and told Kathy about Chapter's financial assistance program.
- Donna just moved to Massachusetts and needs to find a neurologist. The Information Specialist gave her names of three neurologists in her area from the referral network.
- Joe is considering asking for an accommodation at work, but is unsure how to proceed and looking for guidance. The Information Specialist sent materials about the ADA, NMSS brochures on disclosure and reasonable accommodations.



Three Tiered Service Delivery Model

- **Services Management (Tier II)**

- Intervention by Information Specialist staff beyond an initial telephone call
 - Research
 - Advocacy
 - Necessitated by client's physical, emotional and/or cognitive impairment
- Approx 80 individuals served each year



Case Example: Nancy

- Update...10 years later
- Approximately, 10 years after her diagnosis, Nancy started having some difficulty around her employment. She was finding the commute to and from Boston to be very tiring and impacting her ability to function both at work and at home. Through a personal connection, Nancy found a job working at a local state college. While working at the college, Nancy took advantage of her employee benefits and received a masters degree in social psychology. Nancy used this knowledge and skills to help others with MS who she met through the support group, and developed a peer supporter training program. Eventually though, she found it difficult to keep up with her job and began considering leaving work.



Case Example: Nancy

- **Tier II**

Nancy contacted the Chapter for assistance applying for Social Security benefits. The Chapter Services Staff helped her explore her options for disability benefits. However, Nancy was denied SSDI benefits because her employer, the state college, did not pay into the Social Security Program. Nancy requested and received support through the Legal Referral Network to explore her options. The Chapter also helped Nancy connect with contractors to explore home modifications to increase her safety in the house.



Three Tiered Service Delivery Model

- **Tier II – Two more examples**

- Violet needed help getting to medical appointments. The Information Specialist researched agencies that provide medical escort services, and helped Violet make arrangements for this service. The chapter paid for this service.
- Susan's doctor told her she needed a new wheelchair, but she wasn't sure how to get one. The Information Specialist contacted the doctor for a prescription and called the insurance company to find out if the equipment was covered. The Specialist then arranged a PT evaluation and worked with the vendor to have the wheelchair delivered.



Three Tiered Service Delivery Model

- **Care management services (Tier III)**

- Goal: Connection to resources/programs that will help people remain independent and safe in the community.
- Usually precipitated by change in health status, loss of family or marital support and loss of income
- Short-term, hands-on assistance
- Client-driven care plan guides services



Three Tiered Service Delivery Model

- **Care Management Services (Tier III)**
 - Elements of care management
 - Outreach
 - Referral
 - Initial Screening
 - Home Visit and Comprehensive Assessment
 - Care Plan
 - Service Delivery
 - Service Arrangement
 - Follow up/Monitoring
 - Reassessment
 - Termination of services



Three Tiered Service Delivery Model

- **Indicators - Identifying people in need:**
 - Change in health status or caregiver support
 - Transition
 - Living alone/Isolated/Homebound
 - Inadequate housing or home care
 - Overwhelmed
 - At risk of homelessness
 - At risk of abuse/neglect



Case Example: Nancy

- Update....20 years after diagnosis
- Nancy eventually left work because her MS progressed significantly. Her family modified their home to provide complete accessibility for her. In 2007, several of Nancy's friends contacted the Chapter regarding her situation. Nancy was bedbound and required full-time help with her personal care. Her husband had asked her for a divorce and the stress in the home was affecting the family, including their 17 yo son. Nancy's husband felt her care needs were too great to be handled at home and was suggesting that Nancy should move to a long-term care facility. Her parents, who lived on the west coast but were very involved in her affairs, agreed. Nancy's social network, and specifically her friends with MS, were very upset about this turn of events.



Case Example: Nancy

- **Tier III**
- The Chapter provided care management services to help Nancy and her family explore their options. The care manager connected with the people involved in Nancy's life and care including Nancy, her husband, her father, her close friend who had been arranging her medical care, her medical team, and social workers at potential residences. The care manager gathered information about Nancy's options for care at home, facilities in her area, her rights and shared all the information with Nancy to help her make informed decisions.



Three Tiered Service Delivery Model

- Another Example:
- Norman's MS has progressed, and along with it, cognitive deficits, vision loss and difficulty walking. The care manager met with Norman and helped him complete applications for personal care and homemaker services, arranged transportation services and found adaptive computer software. Now, Norman enjoys better health, improved safety, and a higher quality of life.



Three Tiered Service Delivery Model

- **Demographics – Tier III care management services:**
- Number of clients served to date: 441 (383 in MA, 58 in NH)
- Total "cases" – 487
 - Gender: 73% female, 27% male
 - Average age: 47 (range 16-78 yo)
 - Marital status
 - (40% married; 30% single/widow; 28% divorced/separated)
 - Income: 75% have income of \$25,000/year or less

* Statistics through Feb 2009



Home LINKS Participants

- **Demographics - *Who are we serving:***
What do the statistics mean????
- Eligibility for services
- Life-span issues
- Family dynamics
- collaboration...creativity!



The Comprehensive Approach...

"Where the telescope ends the microscope begins, and who can say which has the wider vision?"

Victor Hugo, *Les Misérables*
French dramatist, novelist, & poet (1802 - 1885)



The Comprehensive Approach

- **Principles of Care Management**
 - Independence
 - Empowerment
 - Collaboration
 - Advocacy
 - Support
 - Education



The Comprehensive Approach

- **Collaboration...It's the Key!!!**

Program Development

- **Who**
 - Stakeholders, creators, funders, provider
 - Home LINKS Advisory Committee
- **Why**
 - Who, what, how, when, where
 - Decisions on directions



The Comprehensive Approach

- **Collaboration...It's the Key!!!**

Service Delivery

- **Who**
 - Care Managers – contract or in-house
 - MS Care Team
 - Independent Living Centers
 - Community Agencies



The Comprehensive Approach

The MS Care Team

- Neurologist
- Neuropsychologist
- Nurse
- Occupational Therapist
- Physical Therapist
- Social Worker
- Care Manager



Collaboration...It's the Key!!!

Service Delivery

- Why
 - Share information
 - Avoid duplication of services
 - Reinforce message to client



The Comprehensive Approach

- The Whole Client, The Whole Situation
 - Consider impact of disease
 - They are more than their disease or disability
 - Non-medical issues impact health
 - Resources...no stone unturned



The Comprehensive Approach

- Who is your client?

Who are you?
How do you describe yourself?



The Comprehensive Approach

Who is your client?



The Comprehensive Approach

- A country music singer
- A race car driver
- A pre-med student
- A graphic designer
- NMSS Ambassador & MS and Me Online Community

• Photos courtesy of www.nmss.org



The Comprehensive Approach

- Who is your client?
 - Roles they have...
 - In family, community, work, background
- Where is your client?
 - Impact of physical surroundings
 - Geographic location, neighborhood, housing
- How do external factors impact your client's situation?



The Comprehensive Approach

- **Factors to consider**
 - Housing
 - Employment
 - Family
 - Social Circle/Community
 - Medical Team
 - Finances
 - Cognitive impairment
 - Safety



The Comprehensive Approach

- **Housing:**
 - Are there stairs? Can client fall and injure self?
 - Is bathroom on different level? Does client limit toileting/bathing?
 - Is home isolated?

 - Are neighbors nearby to check? Can they shovel?
 - Is there management office that can check in? Provide services?

 - Are they at risk of homelessness or eviction/foreclosure?



The Comprehensive Approach

- **Sara**
- Sara was finding it more difficult to climb stairs in her home and walk safely. She was not familiar with community resources and did not have a supportive social network. She could no longer drive and was fearful of using the stove due to decreased sensitivity in her hands.



The Comprehensive Approach

- **Sara**
- Issues to address...
 - **Housing** – CM helped Sara complete and submit applications for accessible housing
 - **Safety** – CM contacted medical team and obtained prescription for walker
 - **Transportation** – CM helped Sara apply for transportation services and learn how to use system
 - **Nutrition** – CM helped arrange for home-delivered meals.
 - **Isolation** – CM connected Sara to local support group and counselor



The Comprehensive Approach

- **If we only looked at medical issues...**
- **Sara might...**
 - Fall and injure herself
 - Become homebound and more isolated and depressed
 - Burn the house down
 - Fail to see doctors
 - Suffer from poor nutrition which could lead to weakness



The Comprehensive Approach

- **Goal of care management services:**
Connection to resources/programs that will help people remain independent and **SAFE** in the community without compromising quality of life.

SAFETY

- Durable medical equipment
- Home modifications
- Occupational Therapy
- Assistive Technology
- Personal Emergency Response Systems (PERS)



The Comprehensive Approach

- **Goal of care management services:**
Connection to resources/programs that will help people remain independent and safe in the community without compromising QUALITY OF LIFE.

SOCIAL SUPPORT

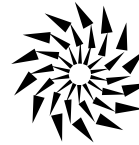
- Support groups
- Peer Support
- Professional counseling services
- Day programs
- Caregiver resources



The Comprehensive Approach

- **Our Challenge...So many needs, so little money!**

- Resource Building
- Community Relationships
- Start at the beginning...
- And then think outside the diagnosis



The Comprehensive Approach

- **Disease specific organizations - examples**
 - Multiple Sclerosis
 - National Multiple Sclerosis Society, www.nationalmssociety.org
 - Multiple Sclerosis Foundation, www.msfacts.org
 - Multiple Sclerosis Association of America, www.msaa.com
 - National Parkinson Foundation, www.northeastparkinsons.com
 - ALS Association, www.alsa.org
 - Arthritis Foundation, www.arthritis.org
 - Lupus Foundation of America, Inc., www.lupus.org



The Comprehensive Approach

- **Prescription Drug Resources**
 - Foundation for Healthy Communities, <http://www.healthynh.com>
 - NORD, www.rarediseases.org
 - Prescription Advantage, www.mass.gov/elders
 - Patient Access Network, www.patientaccessnetwork.org
 - AARP, www.aarp.org/legislative/prescriptiondrugs
 - Drug manufacturers



The Comprehensive Approach

- **More Resources (from large to local)**
 - One Sight Program, www.onesight.org, 1-888-935-4589
 - Catastrophic Illness Fund, www.dhhs.nh.gov/DHHS/BEAS/cip.htm
 - Safelink, www.safelinkwireless.com
 - Helping Our Women, www.helpingourwomen.org



The Comprehensive Approach

- **Accessing Resources**
 - Understanding and respecting eligibility criteria
 - Getting the right documentation
 - Finding the right contacts
 - Engaging the client/family in process
 - Advocacy, advocacy, advocacy: presenting the client's needs/situation
 - "If you can't, do you have any suggestions as to who can?"



Home LINKS

- **What Have We Learned at NMSS**
 - Need for help is there
 - Unique, complex situations
 - Follow through!
 - Resources are limited
 - Skills of care manager are critical to success
 - Assessment, advocacy, persistence, relationship building



Home LINKS...

- **Thank you!!!!**
- **Additional Questions.....**
 - Dawn Russo
 - Dawn.Russo@mam.nmss.org

