

## My Family Has MS

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### Strategies to help families:

- Meet MS-related challenges head on
- Manage the emotional roller coaster
- Build successful coping strategies
- Talk so your partner will listen; listen so your partner will talk\*
- Develop effective care partnerships
- Talk to kids about MS
- Families have rhythm
- MS—The *uninvited guest*
- Shows up when a family is least prepared
- Takes up space in every room of the house
- Is a stranger to everybody
- Doesn't go home
- Disrupts the family's rhythm
- MS-related stresses
- MS is:
  - Chronic
  - Unpredictable
  - Expensive
- MS challenges families with:
  - Change and loss
  - Complex choices
  - MS is a chronic disease
- Most people are diagnosed between 20 and 50.
- Life expectancy is minimally affected.
- A person diagnosed at age 25 is likely to be living with MS for 5 decades.
- To date, we have no cure and no *predictable* means of slowing disease progression.
- MS is an unpredictable disease
- Produces an array of symptoms that
  - Come and go – or come and stay
  - Differ from one person to another
  - May be visible or invisible
  - Interfere with the activities of everyday life.
- MS ⇒ change and loss

- MS may:
  - Impact physical abilities, cognition, emotions
  - Lead to role changes at home and work
  - Alter the way people see themselves and the way other see them
  - Alter interactions with others
  - Impact dreams for the future

In other words...

- MS is an expensive disease
- Direct and indirect costs
- Tangible and intangible costs
  - \$\$\$\$
  - Time
  - Attention
  - Energy
  - Emotions
- May lead to an imbalance in the allocation of these resources among family members
- MS now offers more complex choices
- *Then: "Diagnose & adios"*      Now: Treatment options
- *Then: "Rest & avoid stress"*      Now: Lead a full, productive life
- *Then: "No kids"*      Now: The choice is yours
- Initial family reactions
- Shock—This can't be happening!
- Denial—This isn't happening!
- Fear—What else is going to happen?
- Anger—Why can't you fix what's happening?
- Longer-term reactions
- Grief—a *natural* response to change and loss
- Anxiety—a *natural* response to unpredictability/loss of control
- Resentment—a *natural* response to the unfairness of it all
- Guilt—over letting others down; over angry feelings
- The role of grief in MS
- And the challenge is...
- Family members experience all of these feelings in their own way, in their own time (like an orchestra without a conductor)
- All this can add up to...
- Constant ebb & flow of emotions
- Feeling of "walking on eggshells"

- Additional stress
- The impact on family relationships...
- Communication ↓↓
- Trust and Intimacy ↓↓
- Planning/problem-solving ↓↓
- Conflict/tension ↑↑

⇒ *Disruption of family rhythms*

- Important goals for family members
- Coping individually and as a unit
- Managing resources wisely
- Staying healthy and well
- Planning for the unpredictable
- “Finding a place for the illness while keeping the illness in its place.”
- Something to think about...
- Draw two circles on a piece of paper
- Label one My Own Pie
- Label the other My Family’s Pie
- Ask yourself: “How big is the MS piece...
  - in My Own Pie?”
  - in My Family’s Pie?”
  - “Is MS a bigger piece of either pie than it needs to be?”
- Steps to successful coping
- Information
- Communication
- Shared problem-solving
- Effective planning for today/tomorrow/future
- Sources of reliable information
- MS advocacy organizations
  - National MS Society ([nationalmssociety.org](http://nationalmssociety.org))
  - MS Association of America ([msassociation.org](http://msassociation.org))
  - MS Foundation ([msfocus.org](http://msfocus.org))
  - MS International Federation ([msif.org](http://msif.org))
  - Can Do Multiple Sclerosis ([mscando.org](http://mscando.org))
- Pharmaceutical company websites
- Demos Health ([demosmedpub.com](http://demosmedpub.com))
- Communication is...
- Obstacles to communication
- Denial

- Lack of information
- Conflicting coping styles
- Mutual protectiveness
- Shame or embarrassment
- Lack of time or place
- *Mood changes*
- *Cognitive changes*
- What we know about depression in MS
- Depression differs from normal grieving.
- People with MS are at greater risk than:
  - the general population
  - people with other chronic diseases
- 50+% of people will experience a major depressive episode.
- Depression can impact cognition.
- *Spouses/partners are also at risk.*
- Depression: diagnosis & treatment
- Depression appears to be a symptom of MS as well as a reaction to it.
- Because symptoms of depression can be confused with symptoms of MS ⇒ difficult to diagnose.
- Best Treatment for depression: psychotherapy +  
medication (+ exercise)

*Depression is one of the most treatable symptoms of MS*

- Depression: the implications
- People who are depressed:
  - Carry an additional, painful burden
  - Can't participate actively in their own care
  - Can't plan/problem-solve effectively
  - Are difficult to live with
- What we know about cognition in MS
- 50-60% of persons with MS experience some cognitive symptoms.
- Cognitive changes are a major cause of early departure from the workforce.
- Cognitive changes:
  - can occur at any time
  - are unrelated to level of disability
  - generally progress slowly
- Cognitive functions affected in MS
- Memory - acquisition and retrieval

- Attention/concentration – “working memory”
- Speed of information processing
- Visual/spatial organization
- Abstract reasoning
- Planning, prioritizing, and problem-solving
- Judgment and decision making
- Verbal fluency - word finding
- Obstacles to communication
- Denial
- Lack of information
- Conflicting coping styles
- Mutual protectiveness
- Shame or embarrassment
- Lack of time or place
- Mood changes
- Cognitive changes
- We communicate in many ways
- Words
- Tone of voice
- Facial expressions
- Touch
- Body language
- Behavior
- E-mail, text
- Others?
- Try these tips for talking
- Do’s
  - Make time for talking
  - Acknowledge differences in coping/communication styles
  - Use “I” statements
  - Give the other person time to think and respond
  - Think before you speak
- Don’ts
  - Over generalize
  - Drip with sarcasm
  - Engage in magical *thinking*—*no one can read your mind*
- Others?
- Try these tips for listening

- Do's
  - Listen actively and confirm what you've heard
  - Pay attention to your body language (eye-rolling, smirking, finger-jabbing, doing something else at the same time—like answering your cell phone)
  - Use “ouch” as a short-hand signal
- Don'ts
  - Interrupt
  - Jump to conclusions—if you're not sure what someone is feeling/thinking, *ask*
- Others?
- Challenges for *carepartners*
- Maintaining healthy relationships in the face of significant role changes
  - Spouses
  - Parents of adult children with MS
  - Children of parents with MS
- Retaining outside activities and social relationships
- Staying healthy and rested
- Managing feelings of anger and guilt
- Keeping the rhythm going
  - Communication ✓
  - Mutual respect
  - Mutual support
  - Shared expectations
  - Shared joys and sorrows
  - Managing changes and transitions
  - Interdependence *and* independence

= *A relationship that works*

*for both of you*

- In other words...

Balance

Balance

With each person giving *and* receiving

- Tips for partners with MS
- *You* have MS; but both of you are living with its impact
- Your partner's health and wellness need equal time
  - Rest, exercise, nutrition, stress management, mood
- Both of you need time/space for recreation
- Both of you need to maintain social connections
- More tips for partners with MS

- Plan for the worst while hoping for the best
  - Remember: even the most caring partner can't read your mind
  - Using a mobility aid supports your partner as well as yourself
  - Acknowledge that things take longer than they used to
  - Appreciate your partner's efforts even if...
  - Tips for partners without MS
  - Put on your own oxygen mask first...your health and wellness are important too
    - Self-care ≠ Selfish
  - Acknowledge current/potential losses
    - Your partner's: function, independence, identity, self-esteem...
    - Your own: free time, independence, spontaneity
  - Plan for things taking longer than they used to
  - It's OK to ask your partner to use a mobility aid for some things
  - More tips for partners without MS
  - Don't make assumptions – ask!
  - Hold on to activities that mean a lot to you
  - Watch for signs of being maxed out:
    - You're behaving in ways that you wouldn't want the neighbors to see
    - You're engaging in unhealthy behaviors
  - Pay attention to your own mood
  - Don't just worry about the unpredictable future, *plan for it*
  - You're not alone – reach for the resources
  - A Word about Children's primary concerns
  - Children *of all ages* share common concerns:
    - Is Mom or Dad going to die?
    - Will I catch MS?
    - Did I cause this to happen?
  - Children respond to their parents' moods and the emotional climate in the household; *they may have questions/concerns even when there are no visible symptoms.*
  - How information helps kids
  - Ensures that parents are the source of the news
  - Validates a child's perceptions of what's going on
  - Creates a boundary around children's fears
- Check out *Keep S'Myelin* ([nationalMSSociety.org/KS](http://nationalMSSociety.org/KS))
- How information helps kids
  - Provides reassurance/sense of control
  - Provides a vocabulary for voicing concerns

- Helps children avoid self-blame
- Avoids secrecy and builds trust
- *MS Navigator*  
1-800-344-4867; ContactUsNMSS@nmss.org
  - Information/referral
  - Short-term counseling
  - Self-help groups
  - Social media options
  - Community resources
  - Long-term care strategies
  - Free consultations:
    - Financial planning
    - Insurance questions
    - Employment issues
    - Social Security applications
- Financial assistance
- Scholarships
- Recommended Readings
  - Farrell P. *It's Not All in Your Head: Anxiety, Depression, Mood Swings and Multiple Sclerosis*. Demos Health, 2011.
  - Kalb R (ed.). *Multiple Sclerosis: A Guide for Families* (3<sup>rd</sup> ed.). Demos Health, 2005.
  - Kalb R (ed.). *Multiple Sclerosis: The Questions You Have; The Answers You Need* (5<sup>th</sup> ed.). Demos Health, 2012.
  - Kalb R, Giesser B, Costello, K. *Multiple Sclerosis for Dummies* (2<sup>nd</sup> ed.). Wiley, 2012.