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Living with MS: The Emotional Challenges

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Meet Sam

- He has burning pain in his legs which is worse at night, seems to be less when he walks
- He has painful spasms of his right leg which respond partially to stretch
- He also reports full body spasms that “paralyze” him for up to a day at a time
- His emotional status is directly tied to the severity of his MS sx.

So what can we do for Sam?

- Spasticity
  - Common in MS
    - Increased muscle tension, tightness
    - May interfere with useful movements
    - Phasic spasms: rapid movements of limbs
    - Tonic spasms: tightening of limbs in place
    - Spasms may be painful
    - Treat when it gets in the way of function
    - SPASTICITY DOES NOT EQUAL WEAKNESS

MS related pain

- Common problem, 30% of patients
- Various types:
  - neck and back muscular pain
  - facial pain (‘trigeminal neuralgia’)
  - limb pain (often burning, band-like)
  - Pain due to secondary problems (e.g. hip disease due to steroids)

Treatments...

- Physical measures, biofeedback
- Anti-cholinergics
- Alpha blockers
- Muscle relaxants
- Intermittent catheterization

Another patient, Nina...

- Nina is 26, works full time, and was just diagnosed with MS. She is on copolymer 20mg sc daily, tolerating it well. Her main problem is severe, distressing fatigue. She comes home after work, flops onto the sofa, and drags herself to bed a couple of hours later. What are we to do?

Fatigue in MS

- Very common symptom of MS
- Part of the disorder
- May limit activity
- Not due to depression, sleep disorder, or medications (but these must be considered)
- “Like having a virus all the time”.

Fatigue management...

- Exercise
- Energy conservation
- Avoiding heavy meals
- Amantidine (Symmetrel)
- Provigil
- methylphenidate (Ritalin, Adderal, Concerta)

Meet Sarah

- 31 years old, married, mother of 2 small children
- FT labor and delivery nurse from Pittsburgh, PA
- Diagnosed with R/R MS

- 6 months after the birth of her 2nd child, she lost vision in her left eye
- 2 months later, she developed numbness R>L from the waist down

- Sarah is a FT nurse, mother and wife
- She has fatigue on a daily basis that is severe.
- Because people can not see her disease, the expectations are that she produce/act like a healthy individual.
- To cope she works the night shift and uses the maintenance closet to escape and take a quick nap. She has been caught twice and will lose her job the next time.
- This causes significant anxiety and feelings of frustration
- Racing heart, rhuminating negative thoughts and feelings of hopelessness

Mental Health and MS

- MH professionals are in a unique position to offer support to patients and family members affected by MS.
  - Disease-related education
  - Diagnosis and treatment of emotional and cognitive problems
  - Adjustment to the disease
  - Mood changes
  - Fatigue management
  - Cognitive and memory problems
  - Functional disability
  - Relationships-socially and romantically
  - Family and parenting skills
  - Pain management
  - Support of the unpredictable nature of the disease
  - Support for individual's efforts to remain productive as long as they are able
  - Helping individuals and family members access available resources

Interdisciplinary MH

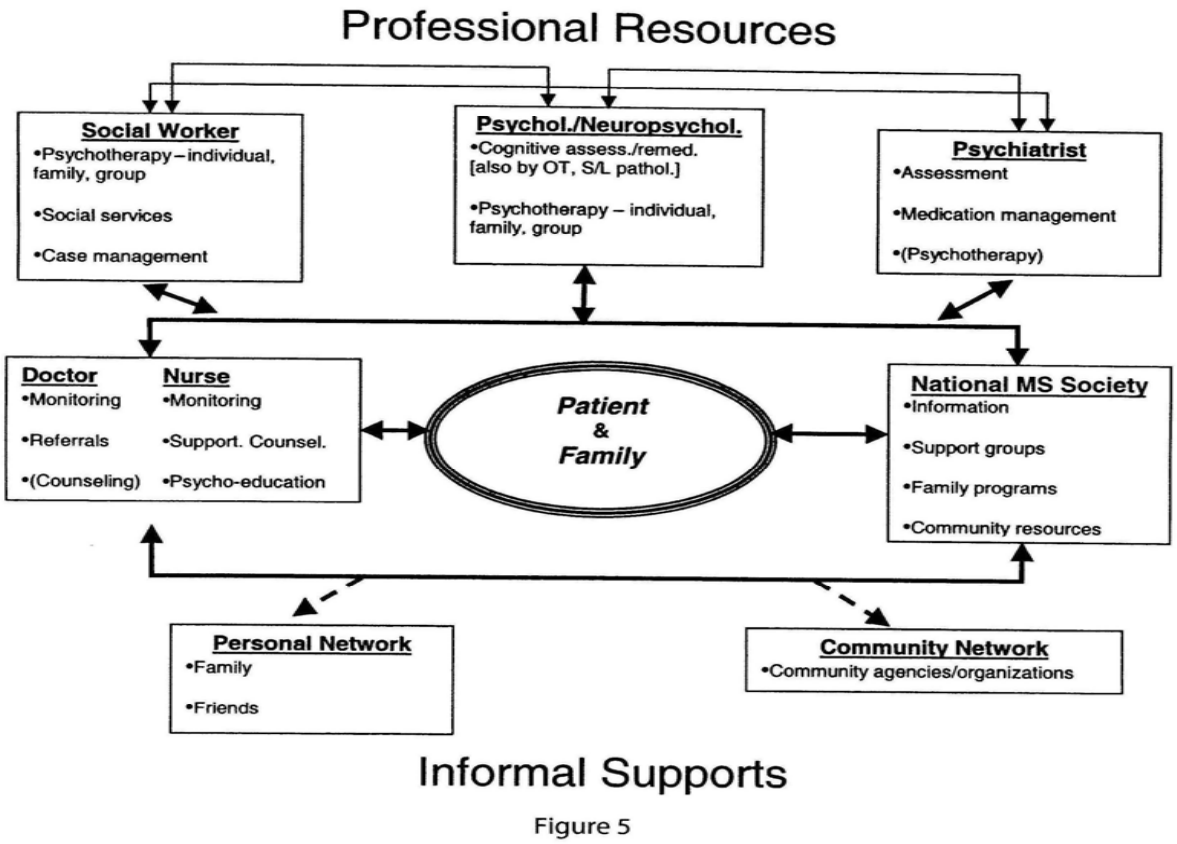


Figure 5

Psychosocial Support

MS Disease Challenges

- Dealing with the “invisible symptoms”
  - “But you look so good, nothing can be that wrong”
- Making difficult treatment decisions
  - Tysabri
- Making disclosure decisions
  - New relationships, employer, children, etc
- Dealing with the reaction of others
  - Employer, family, friends
- Identifying and communicating limitations and needs
  - Asking for help; deciding to withdraw or not join
- Planning for uncertainty
  - Financial and estate planning, disability insurance policy, SSDI

Emotions and MS

- Individuals with MS experience a range of emotions over the course of the disease
- No two individuals or family members react to the disease in the same way, or face the same challenges.
- Their emotions are related to many things:
  - Stresses and challenges created by this chronic, unpredictable illness
  - Symptoms of MS itself
  - Family members reactions

- Proposed:
  A sense of fear combined with a perception of lack of control is the Common Factor, by which an unknown process progresses to a self-sustaining chronic fear and disability

Long- Term Reactions to MS

- **Grief**: a unique type of sadness that is a normal reaction to change or loss.
  - Important 1st step in coping
  - Pain eases with time, and pt is able to begin making + adaptations to new change
  - Grief cycle and adaptation continues to repeat self whenever significant change or loss occurs
- **Anxiety**: response to unpredictability
  - Learning how to live with the unpredictable nature of MS and the ups and downs associated with MS is a challenge
- **Anger**: a common response to the disease and the associated loses and potential disability.
  - Learning how to manage anger and express in productive ways that do not disrupt relationships.
  - Healthy anger can fuel productive creativity
- **Guilt**: feeling of letting someone down due to the interference of the disease.
  - worry over not contributing to the family financials; others taking on more responsibility bc of their inability; not giving as much attention to children or loved ones; feeling like they should be trying harder to fight the disease.

Long-Term Reactions to MS (cont)

- ***Eventually progressing to **Adaptation**:
  - Realizing that even though life will change, pts can learn to adapt and still have a good life
  - Recognizing that identity changes, but a new one will emerge→ we chose whether it will be a positive or negative identity
  - The emotions are normal, but pt can only stay stuck for a short period of time before MS takes over their life.
  - Pts did not chose to have this disease, but they do→ what can they do with the mind/body/spirit.

How to Manage Another's Emotions

1. The above reactions can occur at any time
2. Acknowledge and normalize the emotional reaction
3. Early identification of a psychological condition is imperative. Treatment outcomes are much higher when a psychological condition is treated in the beginning stages.
4. Understand the connection between the above reactions, depression/anxiety and the disease. It is important to treat a psychological condition because a patient will do better physically and emotionally
    1. More on this next

- Utilize Basic Listening Skills :
  - Take 5 minutes to have an emotional interchange
  - Turn to the person, look at them and STOP WHAT YOU ARE DOING
  - Allow silence and tears- avoid your own discomfort by jumping in and rescuing.
  - Encourage an emotional response- “It sounds as if you are saying you are scared, sad, etc.” Nod your head occasionally.
  - Reflect and Paraphrase-
    - “I hear you saying…,” “It sounds like you were….”
    - “It sounds like you were saying…”
    - Summarize responses
  - If able/comfortable show affection is a way of connecting.
  - Watch your body language- do you tense up with an emotional response?
    - uncross your arms
    - sit facing the person
    - soft, warm facial expressions
  - Normalize the emotional experience
  - Encourage the person to continue with cues such as “uhhuu, really, tell me more”
  - Defer judgment

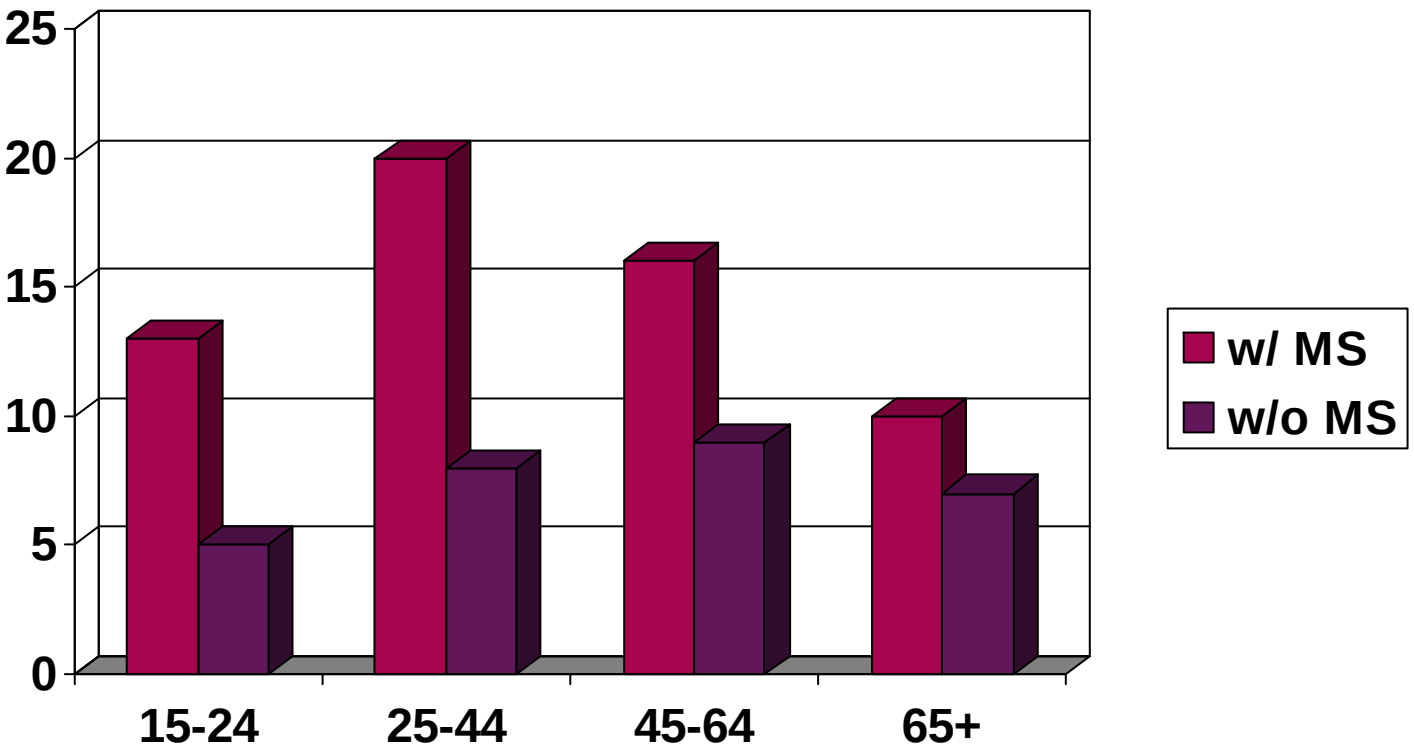
Depression

- According to WHO- depression is the largest cause of disability in USA
- Depression defined:
  - A part of the definition of depression is “change in function.”
  - Several weeks of continuous sx
  - Some sx parallel MS: fatigue, cognitive impairment
  - At least 5 sx, one of which is depression or loss of interest
  - Must interfere with functioning
  - Not associated with bereavement
  - Irritability not in DSM criteria, but in MS population this is a sx
  - Suicidal ideation is a sx of depression

Depression in MS: Facts

- Depression differs from normal grieving
- More common in females than males, but strength of depression greater in males.
- Stressful life event is one of the strongest predictors of developing a depression
- Individuals with MS are at greater risk than the general population
- 50% of people will experience a depression at some point over the course of the disease (3-4x as high)
  - General population is 2.3-6%
  - Other chronic conditions (e.g., Rheum arthr.) 15%
    - MS pts more prevalent than other chronic conditions that are just as disabling
  - Mood disorder due to GMC
  - Drug Induced Mood Disorder (with disease modifying agents, narcotics, benzos)
- Suicide rate is 7.5x higher than in the general population.

Affective Disorder Prevalence, by Age, Group & MS Status



Possible Causes of Depression in the MS Population

- Disease activity (esp. onset and exacerbation)
- Neuropathologic changes in areas of brain related to affective states
- Neuroendocrine or psychoimmunologic changes
- Reaction to life changes
  - As QOL decreases, depression increases
- Side-effects of medications (esp. steroids, disease modifying therapies, narcotics, benzos)

Suicidality in MS

Does asking a patient about suicide increase their risk of making an attempt?

A) True
B) False

Suicidality and MS

Females are more likely to commit suicide than males?

A) True

B) False

Suicidality in MS

- As the stigma of Mental Illness declines, many myths are disputed.
- Males are more likely than females to complete suicide, they chose more lethal means. Females attempt more often
- As patients directly and non-defensively about suicide intent
- Asking will not increase their chances of attempting

Suicidality in MS

- Suicide rate is 7.5x higher in MS than GP
  - Highest in the first yr after dx; likely due to unknown
  - Starts to decline after individuals reach 40yo
  - Hopelessness→ best predictor of suicidality

Sadovnick et al (1991); Bronnum-Hansen et al (2005)

Depression and MS: Dx and Tx

- In addition to common depressive sx; pts with MS also display: anger, worry, discouragement, irritability- which are not classified in DSM-IV
- Depression may be a sx of MS as well as a reaction to it.
- Sx of depression can be synonymous with sx of MS- especially fatigue
- Best Treatment for depression:
  - Combination therapy including psychotherapy, exercise, and at times medications.
  - 10 Minute Tread Study

Treatment of Depression

- Combination therapy:
  - CBT, acceptance therapy, Behavioral therapy, couples/family therapy
    - Identify patterns of thinking and behavior that have changed with depression
    - Work on cognitive distortions (catastrophizing, overgeneralizing, etc.)
    - Skewed negative perception
  - psychopharmacology
- Few randomized, double blind controlled studies
  - Schiffer and Windman (1990)
  - Scott et al (1995)

At the Mellen Center we evaluate other comorbid factors when deciding on antidepressant therapy (See table). This helps guide the selection of antidepressants.

Medication:	Population to consider in:	Use Caution:
SSRIs	Any MS	If on other serotonergic meds
SNRIs	Any MS; pts with migraine or neuropathy	If on other serotonergic meds
TCAs (eg amitryptiline, nortryptiline)	Sleep disruption. Neuropathic pain. nocturia	Cognitively impaired, diabetic, cardiac, urinary retention
duloxetine	Neuropathic pain	
bupropion	Smokers wishing to quit	Risk for seizure. Not 1st line, not useful for anxiety component

Implications of Depression

- People who are depressed:
  - Carry an additional, painful burden
  - Can not participate actively in their treatment decisions
  - Can not problem solve effectively
  - Are difficult to have relationships with
- **Depression is one of the most common but treatable symptoms of MS!**

Other Emotional Challenges

- Anxiety
  - 55% lifetime prevalence
  - Mood and Anxiety disorders always go together; 2/3 of Anxiety disorders also have Mood
  - In next rendition of DSM will not be a dx separation
  - GAD, Panic D/O, OCD
  - Look closely for substance abuse, esp benzo and EtOh
- Mood Swings
  - Anger, irritability, dysphoria→ come and go rapidly as rxn to stress and/or result of MS-related changes in the brain
- Bipolar Disorder
  - Lifetime prevalence in MS of 15%, 10x the rate in GP
- Anger
- Pseudobulbar affect
  - Pathological laughing and/or crying at inappropriate circumstances, unrelated to mood
  - Likely caused by lesions in the limbic sx
  - 10% of MS patients
- Relational difficulties
  - Part of depression and of MS

Relationship Challenges

- Family members go through their own grief/adjustment reaction, at their own time
- Maintaining a healthy relationship in the face of significant role changes
  - Spouse→ caregiver/nurse
  - Child→ parent (*resources for children of parents with MS attached)
  - Home maker → FT work
- Continuing outside activities and social relationships in spite of partners limitations
- Staying healthy and rested
- Managing feelings of guilt and anger

Impact of MS on the Family

- MS is a chronic disease, most families will be living with the effects for several decades
- MS is a drain on important resources:
  - Time, energy, house help, child help, finances
- MS can necessitate role changes w/i the family
- MS can disrupt the family's everyday patterns
- Each family member will emotionally handle MS differently

Impact on Family (cont)

- Feeling of “walking on egg shells,” due to mood swings
- Additional stress
- Decreased communication
- Decreased trust
- Decreased intimacy
- Decreased problem solving
- Increased conflict and tension

Just as the individual with MS needs to redefine him/herself in the context of limitations of the disease, so does the family member

****Goal of MH provider is to help the family communicate effectively and to re-develop their identity by adapting to the disease****

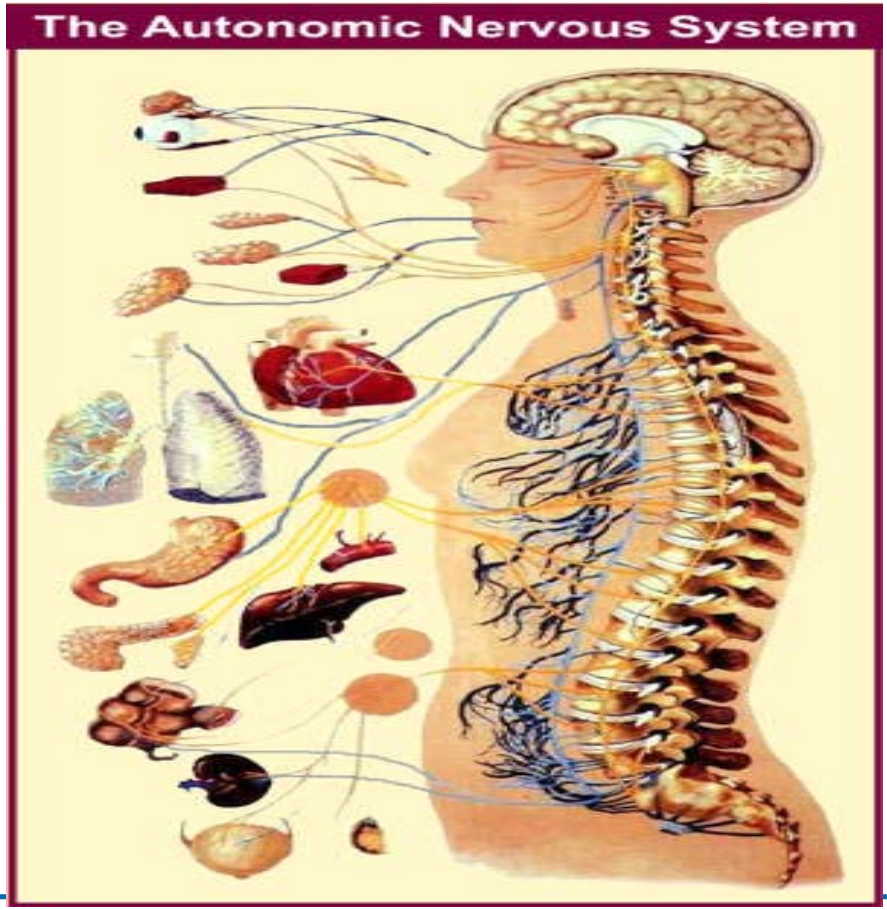
Abuse/neglect

- Common in MS population
  - Regardless of age, race, gender, SES
- Most common forms:
  - Emotional, physical, neglect, exploitation/theft
- Abuse/neglect often go unreported for fear of retaliation or being put in a nursing home
  - Advocate for your patients
  - Cuyahoga County Adult Protective Services
    - (216) 420-6700
    - 60+ mandatory reporting; 18+ voluntary

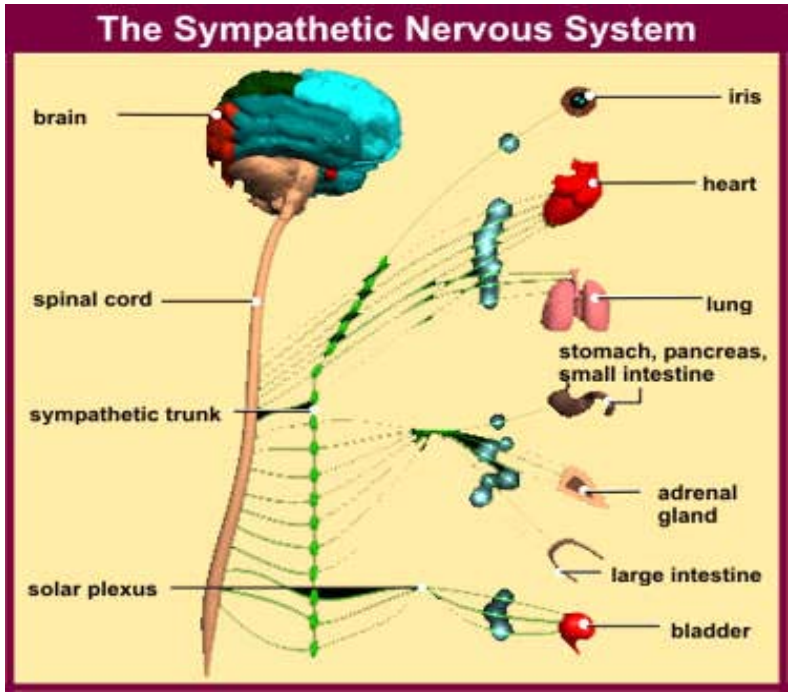
Coping/Adapting

- Support
- Connection
- Sense of Purpose/Meaning
- Pulling on Positives→ what CAN DO
- Sense of humor
- Spirituality
- Openness

The Autonomic Nervous System



Sympathetic Nervous System



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- Goal in psychology is to help mediate the activated SNS by:
  - understanding the mind/body connection,
  - identifying distorted thoughts and associated emotions
  - teaching skills to shut down the fight or flight response

- *Did You Know?*
- **Did You Know? Psychotherapy Changes the Brain!**
  By Dr. Nate Tomcik

- A large body of research supports the efficacy of psychotherapy to treat a wide range of mental health related problems. Until recently, however, the mechanism by which those changes occur have been somewhat of a mystery.
- neuroimaging technology now allows us to see further into the brain than ever before. To date there are over 20 studies showing significant changes in the brain following successful treatment with psychotherapy for depression, anxiety and borderline personality disorder.
- studies show differential changes in the brain following successful treatment with psychotherapy vs. successful treatment with medication, suggesting different pathways may be involved which may ultimately explain why the most effective treatments usually result from a combination of psychotherapy and medication.
- Future directions in neuroimaging research may help psychologists better understand the biological processes that makes therapy effective and develop specific treatment approaches that are informed by the neural structures involved to more efficiently target specific conditions (i.e. "top-down" vs. "bottom-up" change).

- Selected References:
- Beutel ME, Stark R, Pan H, et al. Changes of brain activation pre- post short-term psychodynamic inpatient psychotherapy: an fMRI study of panic disorder patients. *Psychiatry Res*. 2010;184:96-104.
- Gabbard GO. A neurobiologically informed perspective on psychotherapy. *Br J Psychiatry*.2000;177:117-122.
- Goldapple K, Segal Z, Garson C, et al. Modulation of cortical-limbic pathways in major depression: treatment-specific effects of cognitive behavior therapy. *Arch Gen Psychiatry*. 2004;61:34-41.

Summary

- MS in unexpected
- Grief and acceptance model are healthy; and there are no pre-determined stages of adjustment
- Family members share the impact
- **Adaptation** is more realistic than **acceptance**

Resources

- Multiple Sclerosis: A Model of Psychosocial Support (Kalb, R.)
- National MS Society
  - Offers resources for the MS healthcare professional
    - Continuing education programs
    - Website for healthcare providers (www.nationalmssociety.org/PRC.asp)
    - Offers information about insurance concerns and development of long-term care programs for pts with MS
    - Collaborates with Americans Committee for Treatment and Research in MS (ACTRIMS)

Resources (cont)

- National MS Society
  - Offers resources for the MS patient and Family
    - Support groups
    - Psychoeducational programs and materials
    - Resources→ accommodation devices, rides to med apts.
    - Social gatherings
    - Financial support
- National MS Society
  - www.nationalmssociety.org
  - 1-800-344-4867
- Ohio Buckeye Chapter of NMSS
  - www.MSohiobuckeye.org
  - 1-800-667-7131

Resources (cont)

- Well Spouse Foundation:
  - offers emotional support network for significant other's of chronically ill partners.
  - Advocacy for home health and long-term care, peer support and newsletters
  - www.wellspouse.org
  - 1-800-838-0879

Recommended Reading for Patients and Families

- *Multiple Sclerosis: A Guide for Families*; Kalb (ed)
- *Multiple Sclerosis: The Questions You Have, The Answers You Need*; Kalb (ed)
- *Multiple Sclerosis: A Guide for the Newly Diagnosed*; Holland, Murry, Reingold
- *The First Year: Multiple Sclerosis, An Essential Guide for the Newly Diagnosed*; Blackstone

Recommended Reading for Children of Parents with MS

- *Someone You Know has MS: A Book for Families* (ages 6-12)
- *Keep S'myelin*- a newsletter for children (ages 5-12) who have a family member with MS
- *MS Journey Club*- a 2 day program for people with MS and their children (ages 5-12)
- *When a Parent has MS: A Teenager's Guide*

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