

Webinar Series



Landing on Your Feet When Your World is Turned Upside Down

Tuesday, January 14, 2020

Presented by:

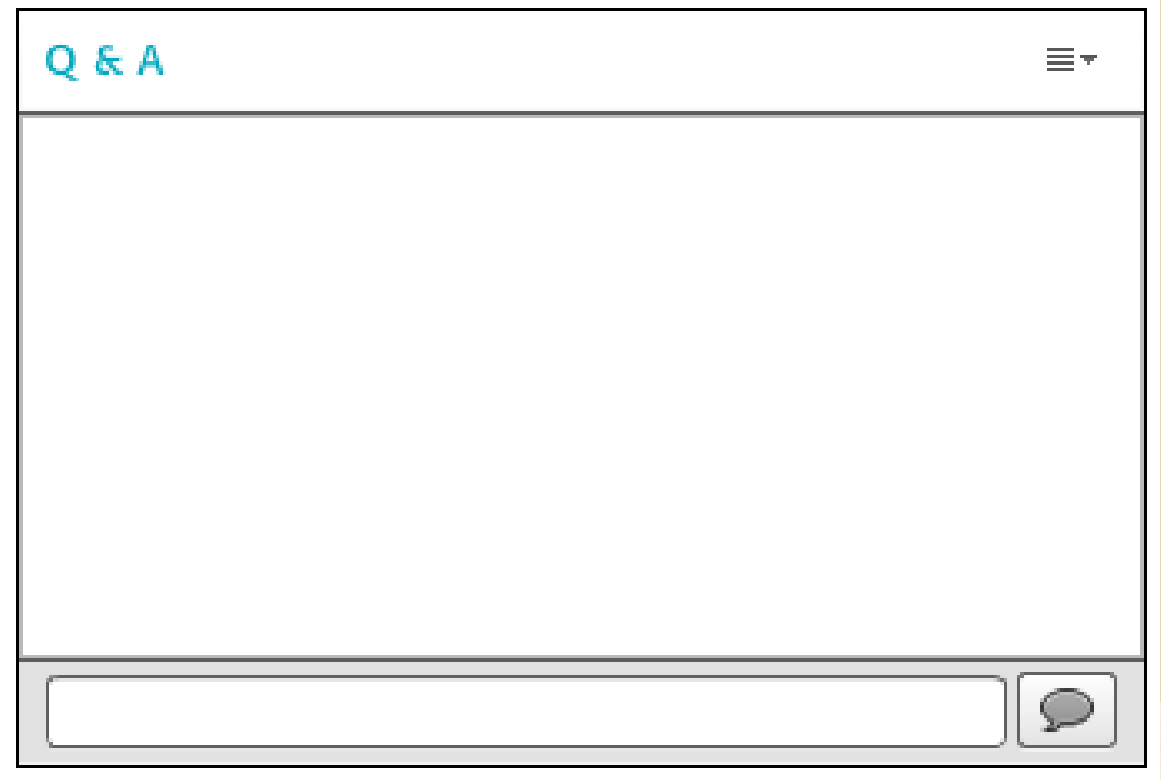
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How to Ask Questions During the Webinar:

- Type in your question in the Q & A pod



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Webinar Learning Objectives

People with MS and Support Partners will learn:

- How change is part of everyday life
 - Changes we strive for
 - Changes we try to avoid
- How change offers challenges *and* opportunities
- How MS involves change and loss
 - The role of healthy grieving
 - **The difference between *acceptance* and *adaptation***
 - The role spirituality can play in staying grounded
 - Helpful strategies for coping and adaptation





Polling Question

Which areas of wellness are important to you (check all that apply)?

- a) Emotional Wellbeing
- b) Cognitive Well-Being
- c) Spirituality

Change Is Part of Our Daily Lives

Changes we strive for:

- Growing up
- Getting educated
- Finding a partner
- Having children
- Buying a house
- Buying a bigger house
- Winning the lottery

Changes we try to avoid:

- Aging
- Major losses
- Job; spouse; friend
- Major gains
- Weight; debts
- Getting sick
- Getting injured

Any Change Can Be Challenging

Positive change

(job promotion/new child)

- Personal gain/growth
- Mastery
- Pride



- Stress
- Anxiety

Negative change

(diagnosis of MS/job loss)

- Anxiety
- Stress



- Personal growth/gain
- Mastery
- Pride

Changes Alter Perceptions

How we perceives ourselves

- Self-image
- Self-concept
- Self-confidence

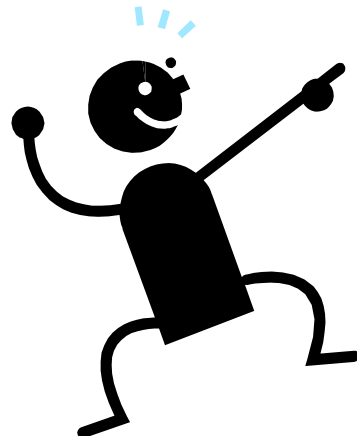
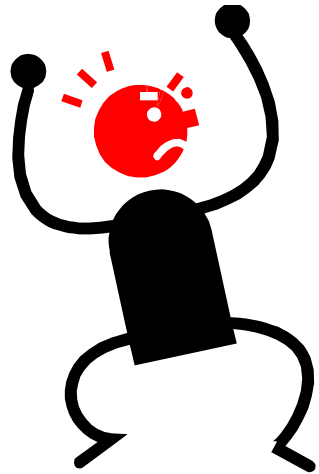
How others perceive us

- Appearance
- Actions
- Attitudes
- Abilities



Changes Alter Feelings

- Our feelings about ourselves
- Our feelings about the world around us
- Others' feelings about us



Life With MS Is A Life With Change(s)

MS-Related Changes:

- Are unpredictable and often frightening
- Often involve loss (function; control)
- Often require changes in daily life
- May threaten sense of self and connection with the world and other people
- May interfere with independence
- Always offer opportunities for creativity, mastery, growth

MS-Related Changes Can Impact Personal Roles And Quality Of Life...

...for people with MS & Support Partners

- **Self-Image** – person with a chronic illness (support partner)
- **Symptoms** – physical and/or cognitive changes may interfere with abilities
- **Changed abilities** – may interfere with activities at home and work
- **Reduced activities** – may alter key roles and the balance in a partnership

Building Resilience in the Face of Change and Loss

So what are some strategies for landing on one's feet when these changes occur?

How does navigating these changes help one build/strengthen the resilience to keep growing and adapting?

Each Point of Impact Offer Opportunities for People with MS and Support Partners

Chronic Illness



Education

Symptoms



**Medication
Management and
Rehabilitation**

Abilities



Activities



Assistive Technology

Life roles



Communication

Steps along the way

So – what are the steps from impact...

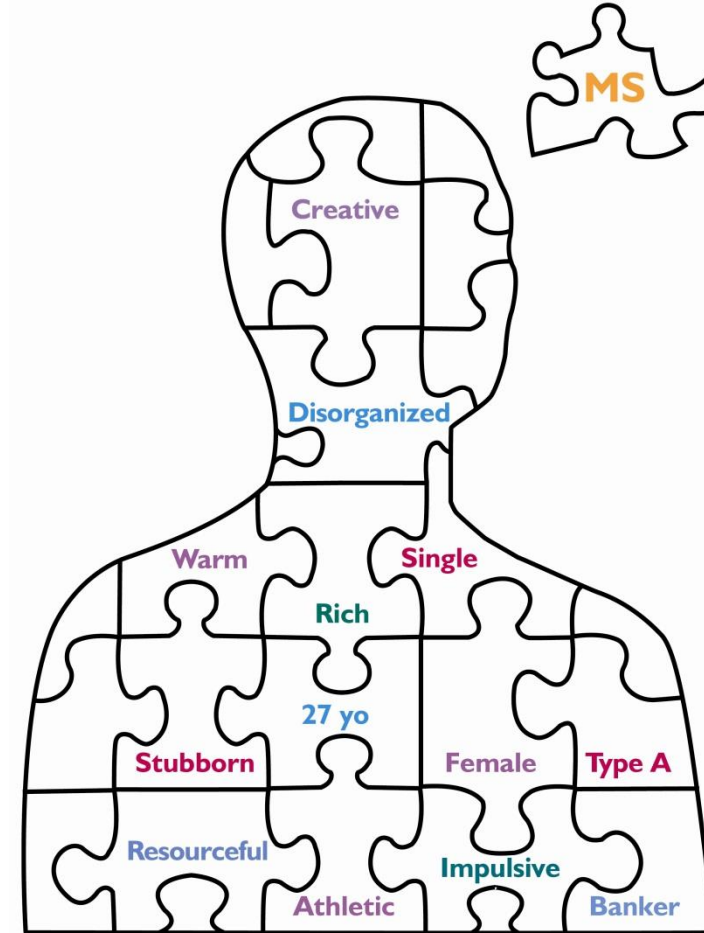
... to growth and opportunity?

Adapting to MS-Related Changes is a Process

- Common initial reactions:
 - Shock, disbelief, anxiety, anger, **grief**
- Acknowledgement
 - Recognition that a change has taken place
- Adaptation
 - Problem-focused coping
- Personal growth
 - Mastery, pride, confidence, personal discoveries, connection to your spiritual self/community

STEP 1:

Grief is a Normal Reaction to Loss



Kalb, 2008

Grief triggers a search for deeper meaning...

Why me? Why this? Why now?

Many religious traditions propose helpful answers. But if the answer is “you’ve done something to deserve it,” you are wise to keep searching.

Seeking answers to spiritual questions: Thinking outside the box:

Spirituality is a sense of connection to something more, something encompassing, or what one author* calls “jumping out of yourself.” It does not require belief in the God of your family’s tradition and may, instead, begin with a connection to nature, to art, to music, to athleticism, to beauty.

*Landis Vance, A Most Clarifying Battle (2017))

Spirituality

Spirituality can sustain you through times of crisis and loss. It can enlarge your worldview and increase your compassion for yourself and others.

There is no formula, but we will describe some ways to develop it.

Developing Spirituality

- Acknowledge your losses and disappointments to someone who will not try to fix you or blame you
- Make a habit of noticing things that warm your heart
 - A colorful sunset, a good meal, a piece of music, a painting, a pet, a poem, a flower...
 - Study and record them if you can
 - Say “thank you” for them



Adopt a Spiritual Practice

- Sit still and alone for 10 minutes in a place where you feel peaceful
- Create or color a mandala
- Walk a labyrinth or do a simulated labyrinth on paper
- Meditate
 - Recordings on topics including anxiety, insomnia, pain, gratitude
 - Belleruth Naperstak has good ones, including for MS
 - Nature sounds like rain, ocean waves, or soothing music
 - Try phone apps such as Insight Timer, Calm or Headspace



Adopt a Spiritual Practice (cont.)

- Pray
 - Wordless focus on icon or photo
 - Written prayers or poems
 - Prayer beads or chants
- Play a musical instrument
- Write in a journal



Share Your Spiritual Self With Like-Minded Others

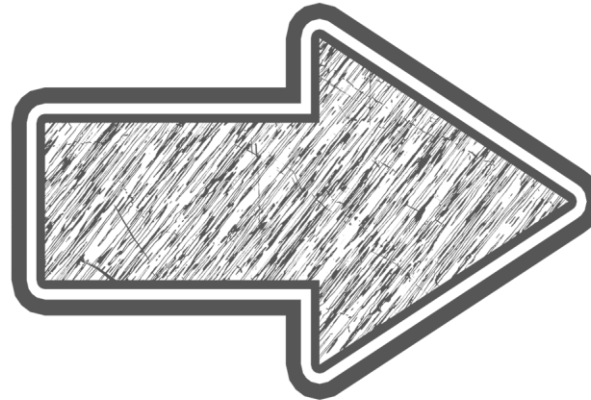
- Join a new faith community or commit to better attendance
- Try a meditation or study group, a centering prayer group, a 12-step meeting
- Meet one-on-one with a faith leader or spiritual guide

STEP 2:

Acceptance or Adaptation?

Acceptance

- This is step 1
- Step 2 is moving toward adaptation (don't get stuck here!)



Adaptation

- Active
- Creative
- Energizing
- Solution-focused
- Growth-promoting
- Confidence-building

Adaptation Has Several Components

- Focusing on “battles” you can win rather than a “war” that can’t be won (yet)
- Capitalizing on your strengths/past successes
- Building your team
- Identifying attitudes that get in your way
- Identifying helpful tools and resources
- Taking care of the whole you – attending to your overall Wellness
- Enjoying new-found interests/abilities
- Asking for help when you need it
- Finding your spiritual core

And more...



Paying Attention to Your Mood and Cognition

Depression and cognitive changes were described as a feature of MS as early as 1877 in Charcot's case reports



Why Mood Issues Are So Important

- All of us have them – people with MS and partners
- People who are depressed, anxious, moody:
 - May not function as well cognitively
 - May have difficulty taking care of themselves and others
 - May lose time from work
 - May be very irritable
 - May be difficult to live with
- Anxiety also interferes with function, self-esteem, communication
- Mood can be affected by medications — particularly steroids

What We Know About Depression in MS

- Major depression is common in MS (and in support partners as well)
- Depression in MS probably has multiple causes (neurologic, immune, psychosocial)
- Factors causing depression may differ from one person to another
- Diagnosis and treatment should take individual differences into account
- Depression can interfere with cognitive function

Regardless of the cause, depression is depression and responds well to treatment

What We Know About Cognition In MS

Cognitive changes:

- Occur in 65%+ of people
- Are unrelated to level of physical disability
- Are a primary cause of early departure from the workforce
- Generally progress slowly
- Are best managed with compensatory strategies
- May benefit from DMTs, brain stimulation/activity, exercise

Why Cognitive Changes Are So Important

Cognitive changes can:

- Threaten a person's sense of self, self-esteem and self-confidence
- Impact planning, problem-solving and adaptive coping
- Affect interactions with others
 - Alter communication
 - Interfere with daily activities
 - Impact other people's perceptions
 - Affect the balance in a partnership

Action Items

- Report significant mood changes to your healthcare provider
- Take a look at how cognitive changes might be affecting your coping efforts
- Make up your mind that it's OK to do things a little differently than in the past – tools and strategies can help you compensate
- Although abilities may not improve, function can be enhanced
- Compensation is key—e.g., many memory problems can be solved with better organization
- Consistency is essential
- Keep the mind active and stimulated – stay engaged!
- Consider adopting a spiritual practice

STEP 3:

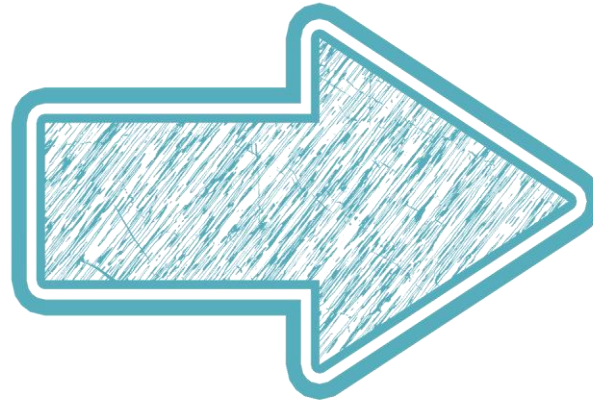
The Goal Of Adaptation

**To find a place for the illness
while keeping the illness in its place**

(Gonzalez et al, 1989)

Adaptation & Spirituality

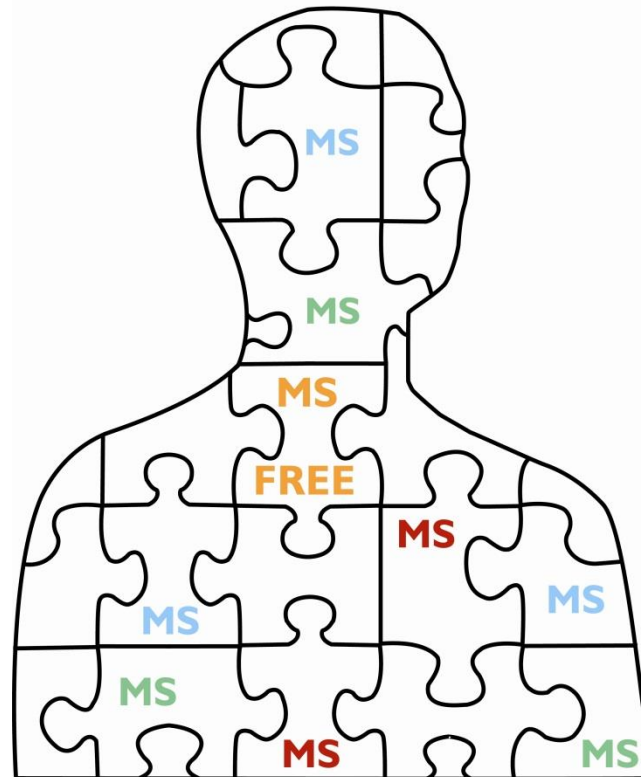
Crisis



**Creative
Connections**

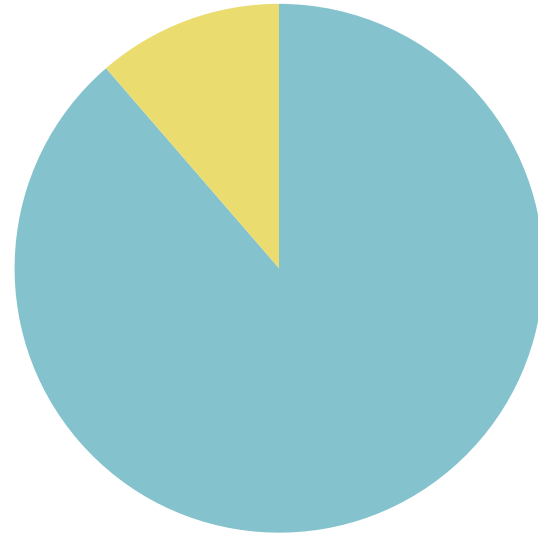
If It Feels As Though MS Is Taking Over

Look for your MS-Free Zone



Here's A Question To Ask Yourself

How "big" is MS in my life?



Q & A



Programs



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Webinar Series



Achieving Emotional Wellness

Tuesday, February 11, 2020

Presented by:

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