

**The Bumpy Road of MS: Adjusting to your new normal and maintaining health & well-being**

# OVERVIEW

- Shock & awe: Responding to a diagnosis of MS
- Stages of grief
- Adjustment factors
- Emotional disturbances in MS
- Your best self: How to flourish despite your MS

# RESPONSE TO A MS DIAGNOSIS



# DIAGNOSIS: MS



- Common initial reactions
  - Will I be in a wheelchair?
  - Am I going to die from MS? Go blind?
  - What does this mean for my family? My work?
  - Am I going to be totally dependent on others?
- An emotional trauma – can lead to denial
- Fear – due to the uncertainty of the illness
- A relief
  - Finally! a name to what you have been experiencing. “I’m not crazy”

# QUALITATIVE STUDY ON PATIENTS' REACTIONS TO DIAGNOSIS

- Identification of 4 themes:



**Knowledge  
Deficit**

**Concealing  
the Disease**

**Emotional  
Reactions**

**Religiosity**

# REACTIONS TO DIAGNOSIS

- Most patients were completely unfamiliar with MS  
Information seeking

*“When I found out that I had MS I didn’t know it at all. I bought and read some books about MS. I attended MS societies meetings and seminars. I also searched on the Internet.” (man, aged 27 years)*



**Knowledge  
Deficit**

# REACTIONS TO DIAGNOSIS

- Most had false perceptions about MS  
Mostly due to inadequate information and generally negative public attitudes towards MS

*“When I knew that I had MS I thought that I was going to die within 6 months. I had a stupid view about the disease. It was just paralysis and death in my mind like other people.”* (woman, aged 38 years)



**Knowledge  
Deficit**

# QUALITATIVE STUDY ON PATIENTS' REACTIONS TO DIAGNOSIS

- Identification of 4 themes:



**Knowledge Deficit**

**Concealing the Disease**

**Emotional Reactions**

**Religiosity**



# REACTIONS TO DIAGNOSIS

- Most hid their illness due to lack of awareness and widespread misperceptions of MS
- Disgusted by reactions such as pity or rejection

*“I hid my disease from others because they did not have enough information about MS. In addition, if they knew, they might show inappropriate pity or reduce their contact with me. It was frustrating for me.” (man, aged 24 years)*

Concealing  
the Disease

# REACTIONS TO DIAGNOSIS

- Another reason for concealing disease was fear of job termination or unemployment

*“I might be dismissed from work if my coworkers or my boss knew that I have MS. Actually, it would be a disaster, as I am in the midst of highly expensive treatments.” (man, aged 40 years)*

Concealing  
the Disease

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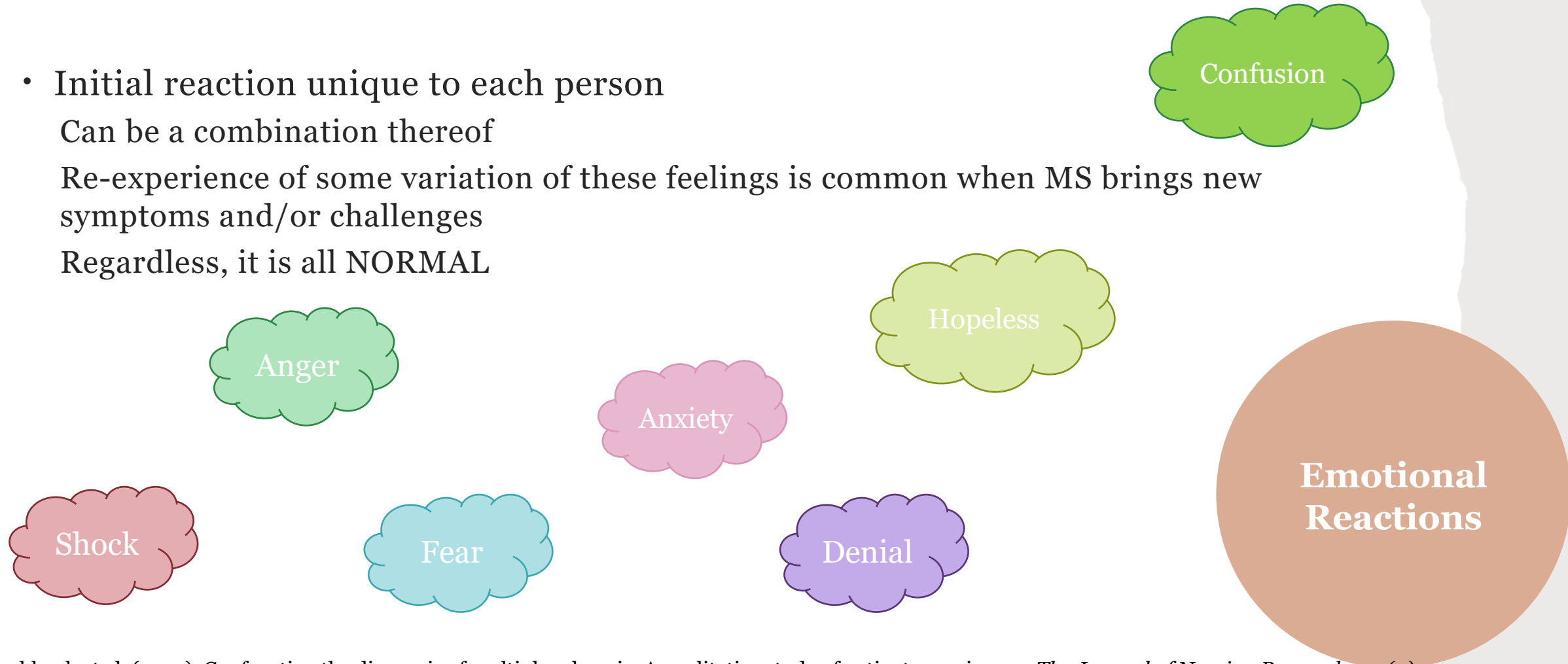
# REACTIONS TO DIAGNOSIS

- Initial reaction unique to each person

Can be a combination thereof

Re-experience of some variation of these feelings is common when MS brings new symptoms and/or challenges

Regardless, it is all NORMAL



# REACTIONS TO DIAGNOSIS



## Shock

*“When I found out that my disease is MS, I was shocked. I walked for several hours on the streets without purpose or destination.” (man, aged 34 years)*

*“When the doctor told me: ‘Unfortunately you are suffering from multiple sclerosis.’ I took the MRI paper from him angrily and told him ‘You are wrong.’ I didn’t let anyone talk to me about the disease. For a few weeks I denied everything.” (woman, aged 33 years)*



## Anger



## Emotional Reactions

# REACTIONS TO DIAGNOSIS

## Fear

*“I said, what if my hands and feet become paralyzed? What if I wake up in the morning and am blind? I was so afraid and apprehensive because I had heard these things about MS. My ignorance and that of my family made the situation worse.” (woman, aged 34 years)*

*“My fear and anxiety for the future was doubled due to knowing nothing about the disease.” (woman, aged 35 years)*

## Anxiety

## Emotional Reactions

# REACTIONS TO DIAGNOSIS



## Denial

*“After the diagnosis of MS, I went to several doctors because I didn’t believe that I had MS and, at that time, I vigorously denied my disease.” (man, aged 32 years)*

*“When I heard the name of the disease I was confused because it’s somehow a new disease and has various medications and alternatives.” (man, aged 48 years)*



## Confusion



## Emotional Reactions

# REACTIONS TO DIAGNOSIS

Hopeless

*“When I found out that I had MS, I was crushed. Oh my God! What will happen? Everything seemed at an end for me. For a few months, I had no hope for survival.” (woman, aged 42 years)*

*“I cried every day in private and confined myself to the house. I feel the same now too. When I think of my disease, my tears fall. I’m always in a bad mood and cry all the time. I prefer to be alone.” (woman, aged 45 years)*

Emotional  
Reactions



# QUALITATIVE STUDY ON PATIENTS' REACTIONS TO DIAGNOSIS

- Identification of 4 themes:



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# REACTIONS TO DIAGNOSIS

- Most reported that when they found themselves alone with a refractory disease, they put their trust in G-d
- Reading and listening to prayer was mentioned as an effective way to gain peace and calm and acceptance of MS
- Individuals who use their faith gained a sense of hope through seeing the purpose and benefit of their MS (Soundy et al, 2012)



**Religiosity**

# REACTIONS TO DIAGNOSIS

*“Being diagnosed with MS caused me to become closer to God. Therefore, I know the disease as God’s grace. Since I’ve been sick, I have surrendered completely to God, and I can feel the presence of God every moment and everywhere.” (man, aged 39 years)*

*“I trust in God and accept this disease as God’s will and a blessing, so I can accept it and manage it.” (woman, aged 38 years)*

*“I read prayers, I read Ziarat Ashura, I listen to Komeil prayers on the TV. Through these actions I am able to manage my disease during difficult times.” (woman, aged 45 years)*



**Religiosity**

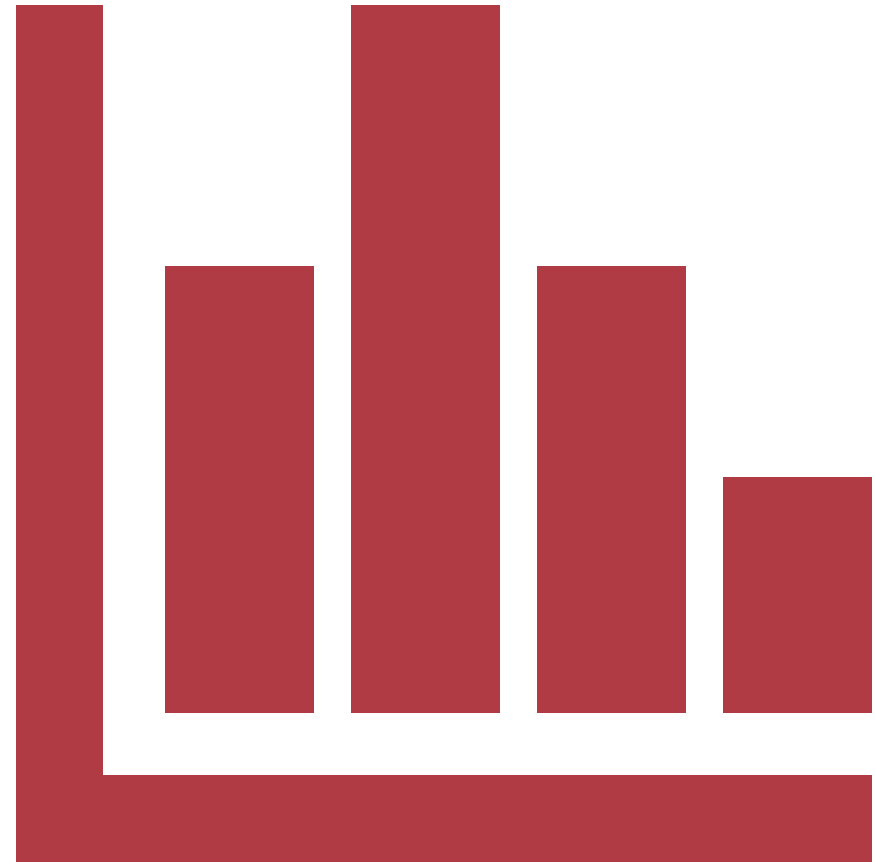
# FOOD FOR THOUGHT: WHAT RESONATED WITH YOU?

Do these feelings and thoughts sound familiar?

How has your knowledge or perspective of MS changed?  
Or not changed?

What has been most helpful?

# POLL ONE



## TAKE AWAY MESSAGE



- There is no right wrong reaction, all feelings are normal
- Feelings can fluctuate and resurface over time
- Seeking and gaining appropriate knowledge of MS is important (Knowledge is power, but too much, too soon can also be detrimental)
- Educating others about MS and your experience early on may be difficult, but worth it in the end.

# TAKE AWAY MESSAGE



- Putting faith in something outside yourself is helpful and important to recognize the things you have control over and the things you do not.
- Acceptance of MS is difficult but is the ultimate goal.
- Some find meaning, purpose, or benefit from MS. They are not just Pollyannas.

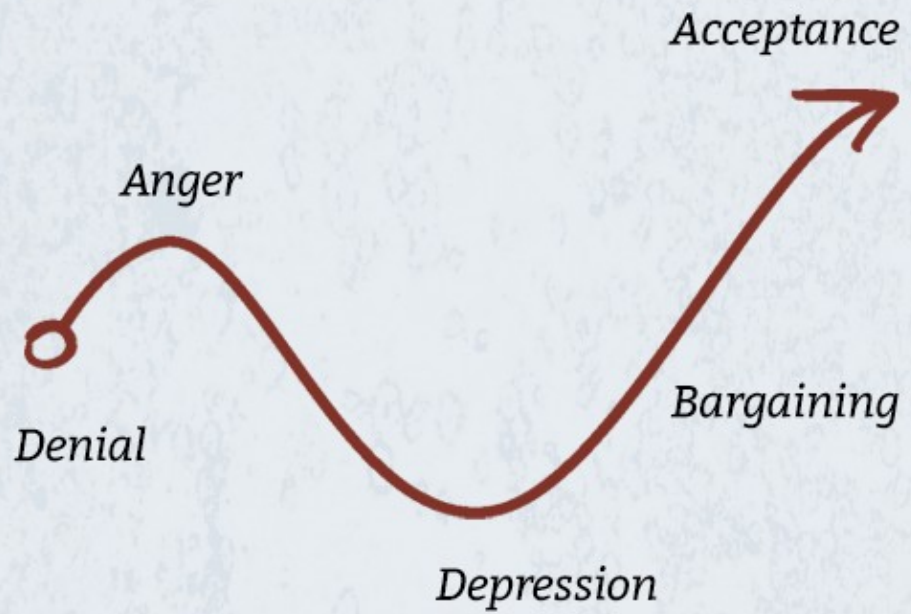


# STAGES OF GRIEF

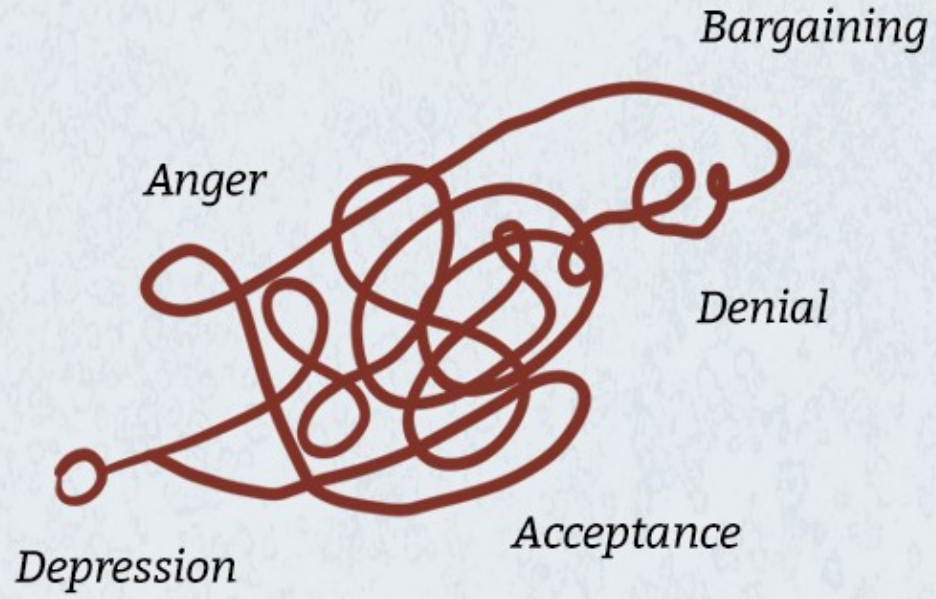


# Stages of Grief

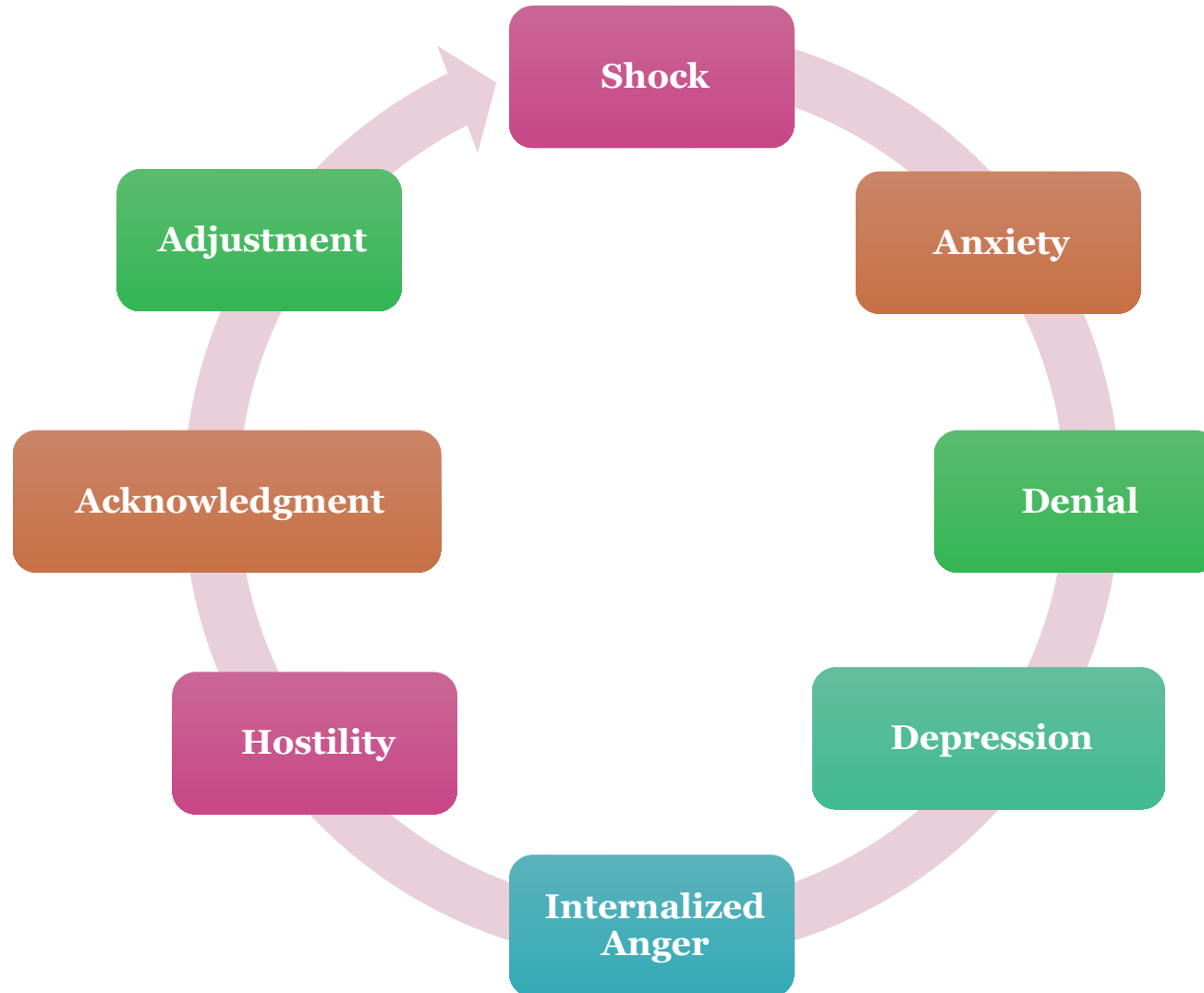
The experience you expected:



The experience you got:



# ADJUSTMENT TO MS- FROM 5 TO 8 STAGES



# ONE WOMAN'S EXPERIENCE WITH GRIEF

## Denial

- I can't have MS because I can still walk
- I am just tired because I am a working mom

## Anger

- Why didn't I go to the doctor for the parathesia back in 2001 (diagnosed in 2013)

## Bargaining

- If I just eat an anti-inflammatory diet, it'll go away
- If I can just get through this relapse, I'll be able to go back to normal living

## Depression

- I don't want to get out of bed, and that has nothing to do with my pain or spasticity
- Everyone thinks I'm lazy because I sleep all the time. Maybe I am.

## Acceptance

- My life isn't over, it's just taking a different path
- What can I do about it? I can focus on what I can do, for one thing

# THE SIXTH STAGE: FINDING MEANING



- Dr. David Kessler published a book in 2019 titled, “ Finding Meaning,” which describes the “phoenix rising from the ashes” once you move past the Acceptance stage.

# ONE WOMAN'S EXPERIENCE WITH GRIEF

## Finding Meaning

- I can write about my MS using my voice and a life's worth of communications skills in order to help others
- I can practice self-care now in a way that makes me slow down and enjoy my life in the moment
- I can see how MS has made me a better person: It's gifted me perspective, a sense of humor, and self-knowledge I didn't possess before

# SENSE-MAKING OR FINDING MEANING



- Assumptive Worlds Theory (Janoff-Bulman, 1992) proposes that individuals hold assumptions about the world:

The world is benevolent

The world is meaningful

I am worthy

- Provides a sense of invulnerability, order, and predictability

# SENSE-MAKING OR FINDING MEANING

- Following a traumatic event, these assumptions can be shattered → sense of meaningless (“*What is it all for?*”).
- Involves finding reasons or explanations for what has happened
- MS diagnosis is a trigger to rebuild one’s sense of purpose, order, and self-worth (Taylor, 1983)
- Through building new worldviews, a person can experience personal growth and develop new values, priorities, and self-awareness



# BENEFIT FINDING



- The process of deriving growth from adversity; typically follows sense-making or finding meaning
- Includes
  - Personal growth
  - Strengthening of relationships
  - Change in life's priorities and personal goals



# OUTCOMES ASSOCIATED WITH SENSE MAKING IN MS

- Study examined sense making among 296 individuals with MS living in Australia  
81% Female; 67% Relapsing-remitting; Mean age = 49.33; Years since diagnosis = 10.56
- Participants completed assessments of their sense-making and adjustment at Time 1 and their sense-making, meaningfulness, and adjustment a year later
- Sense Making defined as:
  - Redefined Life Purposed
  - Spiritual Perspective
  - Causal Attributions
  - Changed Values and Priorities
  - Acceptance
  - Luck

# OUTCOMES ASSOCIATED WITH SENSE MAKING IN MS

\* p < .05, \*\*p > .01

	Life Satisfaction	Positive States of Mind	Anxiety	Depression	Caregiver Rating
Redefined Life Purpose	.41**	.37**	-.17**	-.36**	-.28**
Spiritual Perspective	.07	.04	.06	.04	-.12
Causal Attribution	.01	.10	-.02	.02	-.04
Changed Values & Priorities	.04	-.03	.12*	.05	-.03
Acceptance	.38**	.41**	-.36**	-.41**	-.40**
Luck	-.05	-.13*	.04	.12	.05

# OUTCOMES ASSOCIATED WITH BENEFIT FINDING IN MS

- Study examined benefit-finding (BF) among 381 individuals with MS living in Australia  
77% Female; 73% Relapsing-remitting; Mean age = 47.77; Mean months since diagnosis = 117.24
- BF defined as:
  - Personal Growth
  - Family Relations Growth
- Individuals with relapsing-remitting MS found to have higher Personal Growth than those with progressive MS
- Time since symptom onset was positively correlated with Personal Growth

# OUTCOMES ASSOCIATED WITH BENEFIT FINDING IN MS

	Subjective Health	Global Distress	Negative Affect	Positive Affect	Dyadic Adjustment	Life Satisfaction
Personal Growth	-.01	-.01	-.04	.23****	.06	.12**
Family Relations Growth	-.06	-.08	-.13**	.22****	.34****	.20****

\*\* p < .01, \*\*\*\* p > .0001

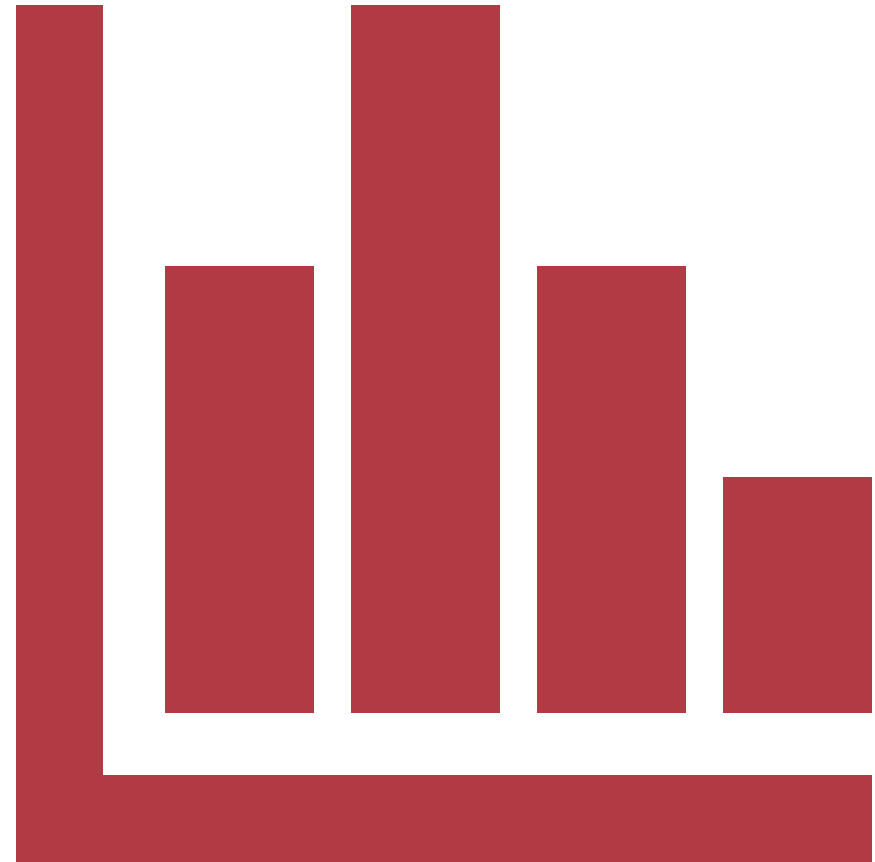
## FOOD FOR THOUGHT:

HAS YOUR MS  
BROUGHT NEW  
MEANING, PURPOSE,  
OR BENEFIT?



- How did you make sense of your MS?
- Did you find more meaning in things? A renewed way of seeing things?
- Have your priorities shifted?
- Have your relationships changed for the better?

# POLL TWO



# ADJUSTING TO ONE'S MS



# FACTORS ASSOCIATED WITH ADJUSTMENT TO MS



- Dennison et al. (2009) review of the literature
- Comprised of 72 studies examining the psychological factors associated with adjustment to MS
- Divided these factors into eight broad categories



# EIGHT DOMAINS:

Stress and  
coping

Social support  
& interactions  
with others

Cognitive  
models of  
psychopathology

Illness and  
symptom  
cognitions

Perceptions of  
control and  
self-efficacy

Positive  
psychology

Health  
behaviors

Miscellaneous  
factors

# STRESS & COPING

- Perceived stress → Depression, anxiety, psychopathology, mood, life satisfaction and psychological well-being, QOL, distress, and social adjustment.
- Emotion-focused coping (e.g., Wishful thinking, escape-avoidance coping) → Worse adjustment.
- Problem-focused coping, seeking social support, and more adaptive emotion-focused coping (e.g., positive reappraisal) → Better adjustment.  
Latter has weaker relationships



## SOCIAL SUPPORT & INTERACTIONS WITH OTHERS

- High perceived support → Better adjustment
- Over-solicitous or critical responses from significant others not beneficial to adjustment.

# COGNITIVE MODELS OF PSYCHOPATHOLOGY

- Cognitive distortions (e.g., catastrophizing, overgeneralization, selective abstraction), learned helplessness, and self-efficacy explored by Shnek et al.
- Learned helplessness the greatest predictor
- Negative attributional style with stable and global attributions → Depression

# ILLNESS & SYMPTOM COGNITIONS

- Jopson & Moss-Morris (2003) found the following illness representations to be related to worse adjustment:

Tendency to attribute a wide range of symptoms to MS

Beliefs of lack of personal control over the illness

Perceptions of severe illness consequences

Representations of a cyclical illness timeline

Believing MS was caused by psychological factors

A lack of a coherent understanding of MS

# ILLNESS & SYMPTOM COGNITIONS

- Illness uncertainty (Mishel, 1988) includes perceptions of ambiguity, complexity, deficiencies in information, and unpredictability regarding the disease, relationships, and future.
- High uncertainty → Worse adjustment.

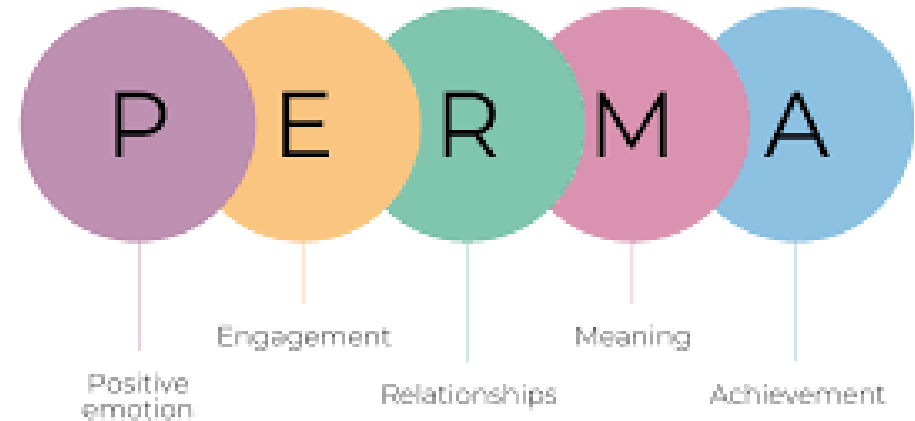
# PERCEPTIONS OF CONTROL & SELF- EFFICACY



- General locus of control (LOC) – Found that individuals with high internal LOC had lower depression and distress, more positive mood, and more life happiness.
- Health-specific aspects of self-efficacy associated with better adjustment.

# POSITIVE PSYCHOLOGY

- Optimism → Lower depression, less anxiety, less negative affect and more positive affect, and better physical, social, and psychological adjustment.
- Low hope → Increased depression (and vice versa)
- Benefit finding → Positive adjustment





# HEALTH BEHAVIORS

- Engagement in health behaviors → Better adjustment in terms of marital relationships and QOL.
- One study showed that continuation of exercise behavior over time predicted continued enhanced QOL.
- High levels of perceived barriers to health behaviors → Worse QOL.

# CONCLUSIONS

## SUCCESSFUL ADJUSTMENT

- **Cognitive Factors**

- **Coping - Positive Re-appraisal**

- Perceived control over generic life events

- Self-efficacy regarding MS management

- Optimism/Hope/Benefit Finding

- General self-efficacy

- Acceptance of illness

- Spirituality

- **Behavioral factors**

- **Coping - Problem-focused or seeking social support**

- Health behaviors

- **Social/Environ. Factors**

- **High perceived social support**

- Positive relationships/interactions

## ADJUSTMENT DIFFICULTIES

- **Cognitive Factors**

- **High perceived stress**

- **Coping - Wishful thinking or avoidance**

- **Illness uncertainty**

- Appraisal of MS as threat

- Dysfunctional cognitions

- Helplessness

- Perceived barriers to health behaviors

- Unhelpful illness/symptom representations

- Unhelpful beliefs about pain

- **Behavioral Factors:**

- **Coping through avoidance**

- Unhelpful responses to symptoms



EMOTIONAL  
DISTURBANCES IN MS

# DEPRESSION IN MS

- Grief is more transient, but depression is more stable and remains longer  
Poor adjustment or failure to accept & cope with MS → sustained depression
- Depression is much higher in MS than among healthy controls and individuals with similar illnesses.
- Incidence of lifetime depression is 50%.
- Greater suicide risk (2-7x).
- Considered to be a combination of biological and psychological contributors.



# PREDICTORS OF DEPRESSION IN MS

## Biological factors:

- Temporal and frontal lobe brain lesions
- Greater involvement of brain versus cervical cord

## Psychosocial factors:

- Perceived stress and social support
- Use of emotion or avoidant focused coping
- Greatest in first 10 years of the illness

# ANXIETY IN MS



- Much less studied in MS
- Lifetime prevalence around 35%
- More prominent in the earlier stages of illness
- Female > Male
- Comorbid with depression
- Associated with engagement in negative health behaviors, greater levels of stress, and suicidal ideation



LIVING WELL  
WITH MS

# HOW TO LIVE WELL WITH MS



- Allow yourself to experience your emotions  
Emotions are fleeting, even negative ones and they serve a purpose
- Acknowledge that things are rough
- On the flipside, recognize the good things are when you are happy  
Consider starting a gratitude journal



# HOW TO LIVE WELL WITH MS



- Don't compare yourself to others
- Build and maintain your social network, including others living with MS
- Find healthy and productive means of coping
- Accept limitations and work to your strengths

# HOW TO LIVE WELL WITH MS



- Engage in self-care
- Find a doctor that you trust and can communicate openly with
- Stay cognitively, physically, and socially active
- Know when enough is enough and don't overdo it  
Banking energy

# GRATITUDE



- Construed as a trait as well as an emotional state
- People high on trait gratitude appreciate the benefits give by others to oneself, value simple pleasures, and experience a sense of abundance.
- Well appreciated that gratitude is a significant predictor of life satisfaction
- Gratitude may also serve as a mechanism of resilience

# GRATITUDE



- In MS, has been shown that gratitude is a predictor of quality of life even when taking into account objective and perceived cognitive functioning, fatigue, depression and years of education.
- Exercises:
  - Three Good Things
  - Say “Thank you” regularly
  - Step back daily and appreciate what you have
  - Look for others’ good deeds

FOOD FOR THOUGHT:

WHAT ARE YOU  
GRATEFUL FOR?



- What you did (or can do) and less on what you did not (or cannot do)
- Family & friends
- Support from others with MS
- Available healthcare and resources

THANK YOU  
QUESTIONS &  
DISCUSSION



## RESOURCES – RESEARCH CITATIONS

- Fallahi-Khoshknab et al. (2014). Confronting the diagnosis of multiple sclerosis: A qualitative study of patient experiences. *The Journal of Nursing Research*, 20 (4)
- Antonak & Livneh (1995). Psychosocial adaptation to disability and its investigation among persons with multiple sclerosis. *Soc.Sci.Med*, 40(8)
- Dennison, et al. (2009). A review of psychological correlates of adjustment in patients with multiple sclerosis. *Clin Psychol Rev*, 29 (2).
- Pakenham (2008). Making sense of illness or disability: The nature of sense making in multiple sclerosis (MS). *Journal of Health Psychology*, 52 (4)
- Pakenham (2005). Benefit finding in multiple sclerosis and associations with positive and negative outcomes. *Health Psychology*, 24(2)
- <https://multiplesclerosisnewstoday.com/news-posts/2020/04/14/diagnosis-stages-grief-need-know-acceptance/>

# RESOURCES – REFERENCED WEBPAGES & OTHER HELPFUL SITES

- <https://multiplesclerosisnewstoday.com/news-posts/2020/04/14/diagnosis-stages-grief-need-know-acceptance/>
- <https://www.verywellhealth.com/living-with-multiple-sclerosis-2440580>
- <https://www.everydayhealth.com/columns/trevis-gleason-life-with-multiple-sclerosis/>
- <https://www.nationalmssociety.org/Get-Involved/Stay-Informed/RealTalk-MS-Podcast>
- <https://www.nationalmssociety.org/Resources-Support>
- <https://mymsaa.org/>