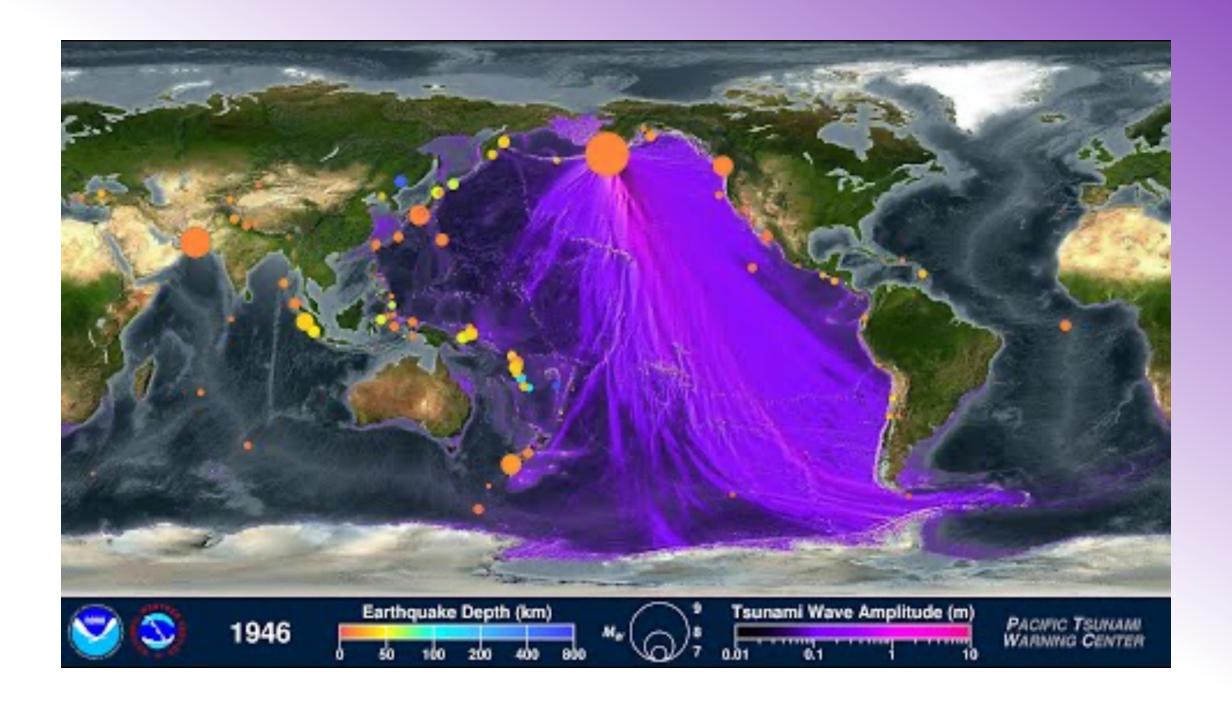
# Resilience in MS: Navigating the Unexpected

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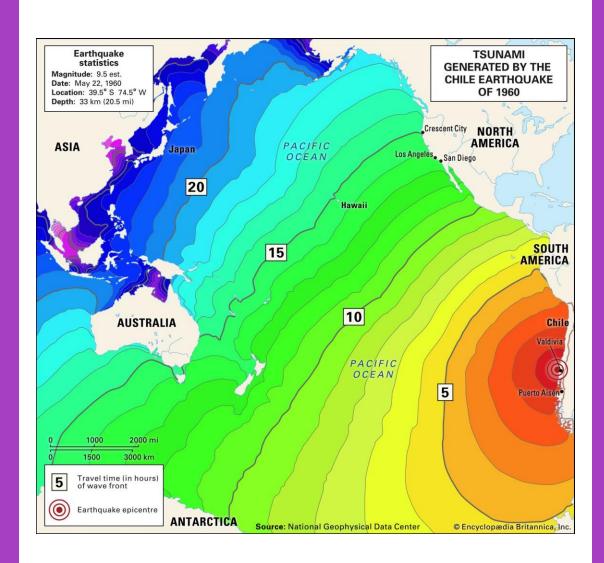












# Engineering

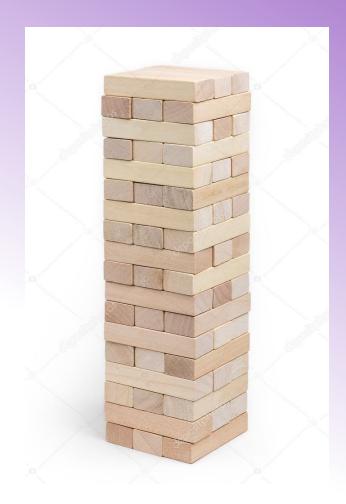
Create a flexible foundation

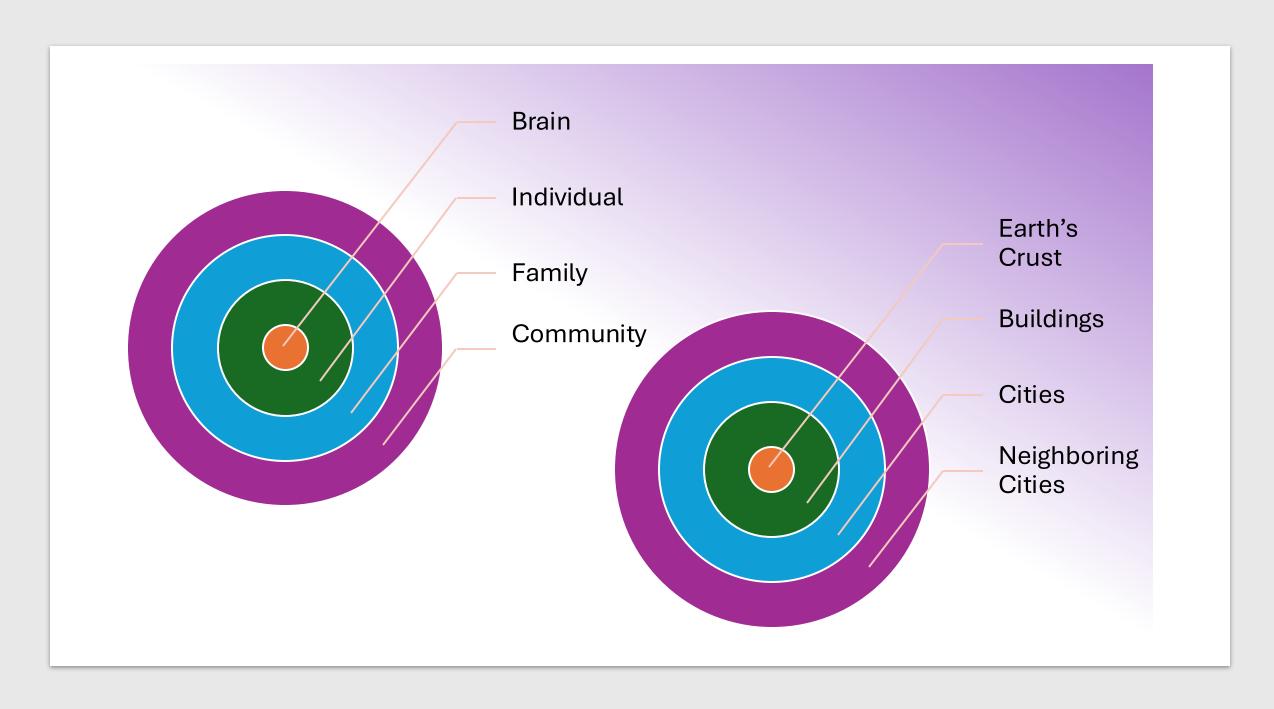


 Counter forces with "damping" (Shock absorbers on a car)

Shield buildings from vibrations

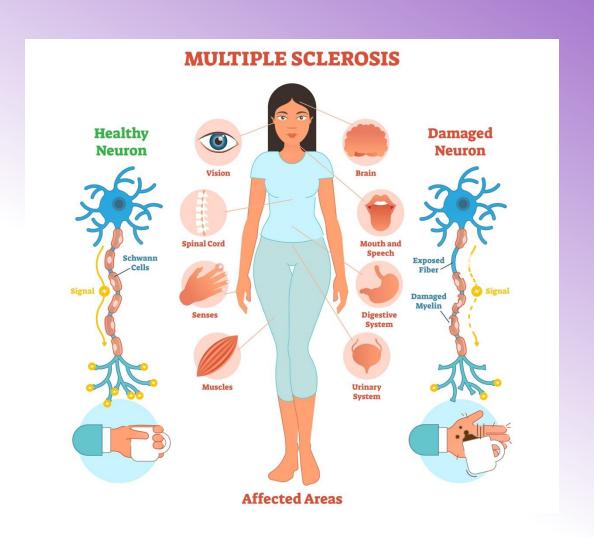
Reinforce the building's structure





# Managing the Unpredictable

- Walking & mobility
- Talking
- Breathing
- Thinking
- Vision
- Fatigue
- Pain
- Sensory changes



# Managing the Unpredictable

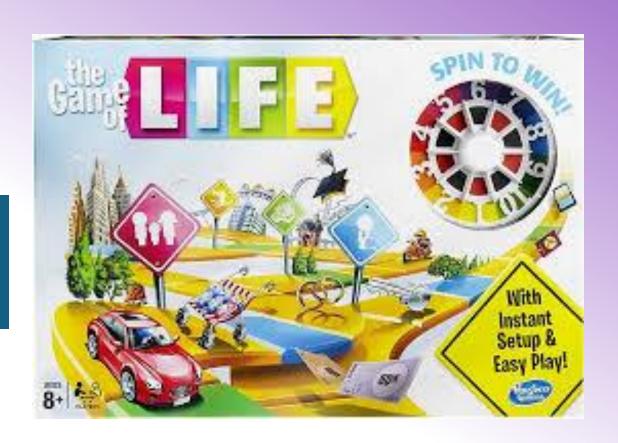
- Sexual dysfunction
- Cognition
  - Memory
  - Language
  - Attention
- Personality
- Mood



## The Game of Life

Transitions and change

Learning to modify expectations and adapt to circumstances



## Childhood & Adolescence

- Cognitive Development
- Behavior
- Schooling
  - Learning problems
  - IEPs
- Being social
- Growing independence
- Learning to drive
- Feeling different/ stigma



## Adulthood

- College
- Work/ career goals
- Relationships
- Family/ children
- Aging
- Transition to physical and cognitive changes



# MENTAL HEALTH

- 50% of people with MS experience depression over the course of their life
- 3-10x higher than the general population
- 36% of people with MS experience anxiety



## Depression

Sadness or low mood

Loss of interest in things (anhedonia)

Changes in appetite or weight (increase or decrease)

Insomnia or excessive sleeping (hypersomnia)

Restlessness or slowed movements

Fatigue or loss of energy

Feelings of worthlessness or excessive guilt

Difficulty concentrating, making decisions, or remembering things

Thoughts of death or suicide

Irritability or anger

Physical symptoms (headaches, digestive problems, or chronic pain)

# Anxiety

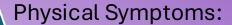
#### **Behavioral Symptoms:**

- Avoidance of situations that trigger anxiety
- Seeking reassurance from others
- Difficulty sleeping or staying asleep (insomnia)
- Performing rituals or repetitive behaviors (compulsions)



#### **Emotional Symptoms:**

- Feelings of fear or panic
- Restlessness or irritability
- Anticipating the worst or feeling like something bad will happen
- Feeling overwhelmed or out of control



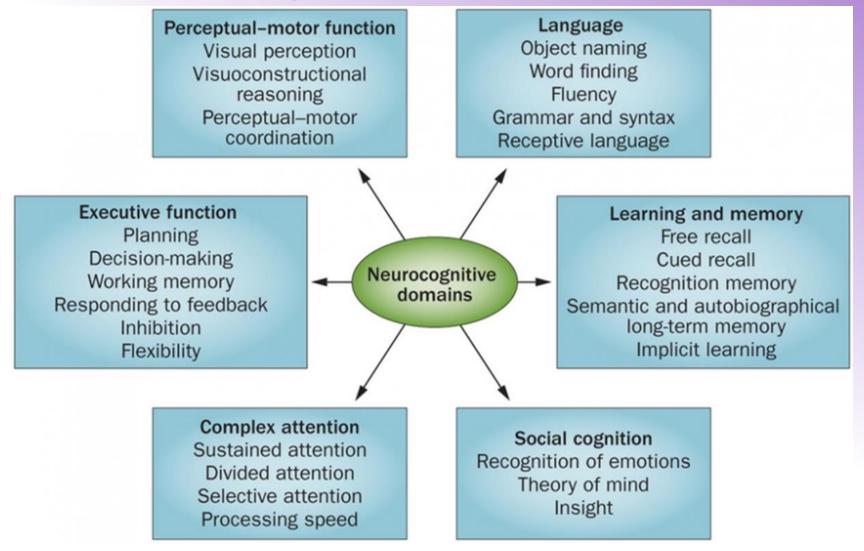
- Rapid heart rate (palpitations)
- Sweating
- Trembling or shaking
- Shortness of breath or feelings of being smothered
- Feeling dizzy, lightheaded, or faint
- Chills or hot flashes



#### Cognitive Symptoms:

- Excessive worry or apprehension
- Difficulty concentrating or mind going blank
- Racing thoughts or feeling keyed up or on edge
- Intrusive thoughts or concerns

# Cognitive Challenges in MS



# Things that Affect Cognition

- Disease status
- Depression
- Anxiety
- Sleep
- Fatigue
- Medications
- Other medical concerns
- Normal changes



# How Cognition (and Mood) Affects Life

- Work & school stress
- Financial concerns
- Family obligations
- Forgetting appointments
- Becoming less social
- Driving
- Independence
- Physical abilities
- Fear about the future







# Caring for Your Body, Brain, and Soul



# Manage stress & care for your emotions

Exercise

Yoga

Meditation/ Mindfulness

Relaxation techniques (e.g., diaphragmatic breathing, progressive muscle relaxation, visualization, etc.)



# Involve yourself with others and don't isolate

Support and peer groups

Schedule routine social plans (or phone calls) with family and friends

Join a book club or other group

Join a local community center or church

Go online (but cautiously)

# Caring for Your Body, Brain, and Soul



#### Prioritize quality sleep

Treat sleep apnea
Establish a consistent schedule & routine
Limit daytime naps
Limit caffeine & exercise late in the day
Manage stress



# Avoid/ limit toxins (alcohol, tobacco, drugs)

Aim for moderate consumption

Talk to your doctor/ therapist

Devise a plan for reducing/eliminating

Join AA, NA, or other support groups

# Find a Mental Health "Engineer"

#### **Psychotherapy**

- Cognitive Behavioral Therapy (CBT)
- Psychodynamic Therapy
- Interpersonal Therapy (IPT)
- Mindfulness-based
   Therapies

#### **Medications**

- Antidepressants
- Antipsychotics
- Mood stabilizers
- Anxiolytics (anti-anxiety meds)

# **Smartphone Applications**

Clarity:
CBT Self Help Journal

Headspace:

Meditation

Calm:

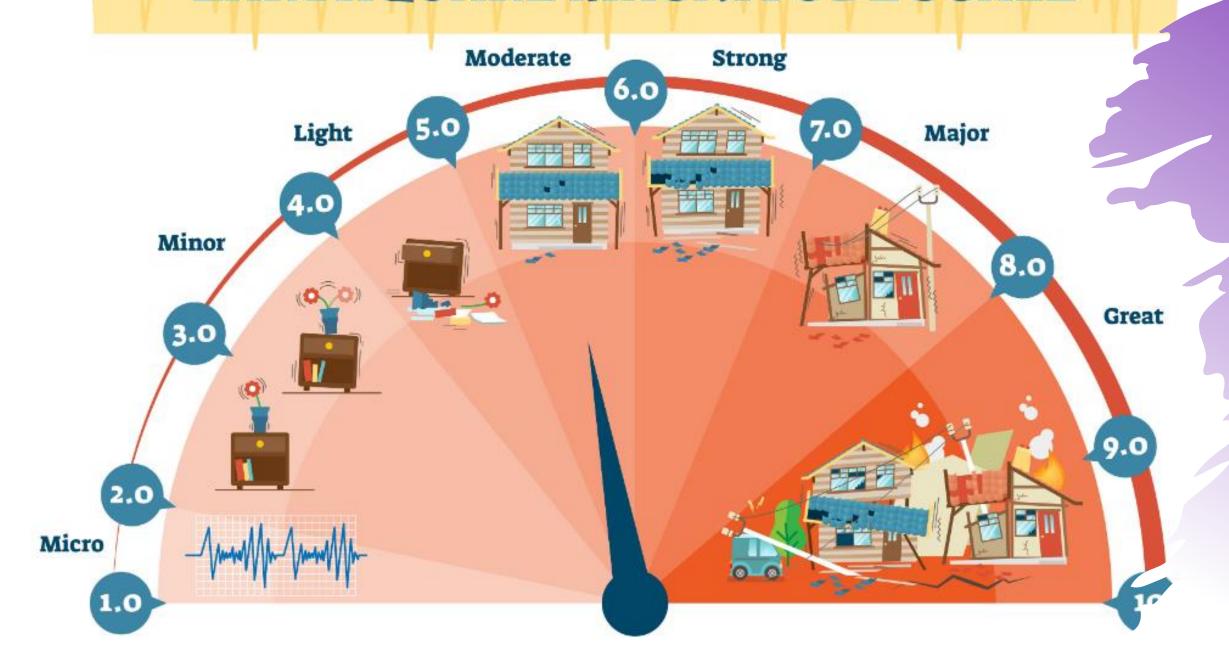
Relaxation and stressreduction







## EARTHQUAKE MAGNITUDE SCALE



# Fatigue

- Rest
- Take naps
- Exercise
- Avoid heat
  - Jacuzzis
- Conserve Energy
  - Activity Pacing
- Plan your Schedule
  - Work and rest

- Reorganize family schedules and duties
- Set realistic goals
- Do not over commit
  - Learn to say no

## Coping with Cognitive Challenges

- Restorative Training
  - Remediate deficits in step-by-step, hierarchical model ("bottom-up")
  - Incorporate several skills at once ("top-down")
- Compensatory Training
  - Does not restore impaired cognitive skill
  - Teaches compensatory strategies (e.g., using memory journal, calendar/organizer, creating "To-do" lists, etc.)
- Environmental Manipulation
  - Facilitation of changes to a person's life that make a cognitive deficit less important (e.g., reliance on others for transportation needs, labeling/maintaining "central location" for important items such as keys, wallets, phones, etc.)

# CogSMART

Cognitive Symptom Management and Rehabilitation Therapy

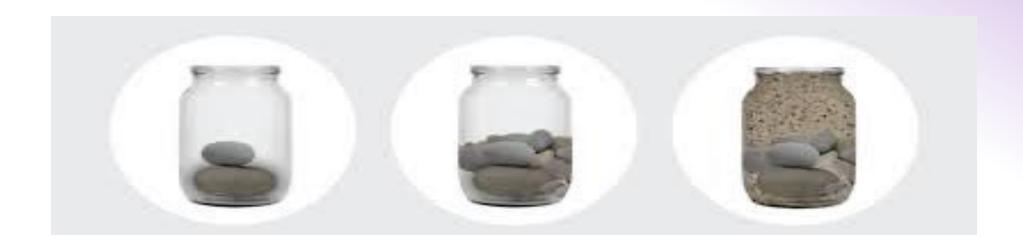
- Compensatory cognitive training to help improve skills in:
  - Prospective memory (remembering to do things)
  - Attention
  - Learning/memory
  - Executive functioning (problem-solving, planning, organization, and cognitive flexibility)

# 2 Main Theories of CogSmart

- Cognitive compensation.
  - By working around impairments (similar to using a cane to support a weak leg), we can take advantage of an individual's cognitive strengths, use different strategies, and use different brain areas to perform cognitivelydemanding tasks.
- Habit learning.
  - Habits good or bad are hard to break because they are particularly resistant to forgetting.

# Organizing your time & prioritizing the important things

- 80:20 we spend 80% of our time doing 20% of the tasks in our lives that are least important to us, and we often do easiest tasks first because we can cross them off a list
- The goal is to reverse this pattern schedule chunks of time to work toward your most important life goals without interruption
- Metaphor: filling a bucket with large rocks, then pebbles, then sand, then water



#### **Time Management Matrix**

	Immediate/Deadline	Not Immediate/No Deadline
Important	Large Rocks/Pebbles	Large Rocks/Pebbles:
	Emergencies	Health/Exercise
	Important appointments	Prevention
	Important deadlines	Important relationships
	Pressing problems	Planning
	(car dies, roof is leaking)	Recreation and self-care
Not As	Sand:	Water:
Important	Interruptions	Some chores
	Phone is ringing	Some mail, phone messages,
	Someone is knocking on door	or meetings
	Popular activities (TV shows,	Unimportant relationships
	shopping)	Trivia, busywork, time wasters

The goal is to move toward spending most of our time in the Important/Not Immediate quadrant. These are the large rocks/pebbles.

If you spend more time on planning and prevention, you will not need to spend as much time in the Important/Immediate quadrant.

What are <u>your</u> big rocks, pebbles, sand, and water? How do they fit into your time management matrix?

## Activity

- Think of 5 things you need or want to do, and categorize them according to how important they are in your notebook
- Examples:
  - Laundry
  - Grocery shopping
  - Washing face
  - Visiting a friend
  - Cleaning house
  - Taking a shower
  - Paying a bill
- Rationale: to help with organizing tasks

#### TO DO

High Priority (today or tomorrow)	Medium Priority (within a week or so)	Low Priority (within a month or so)

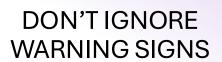
## Tips & Tricks

- Stay organized
  - Make a "Home" for your most important personal items (e.g., your calendar, keys, wallet, and cell phone)
  - Have a weekly planning session to plan tasks for the week ahead
  - Establish routines
- Write things down
  - Carry a notebook (physical or virtual) and/or calendar with you every day
    - Enter all the upcoming doctor appointments or other activities
    - Check it regularly
  - Use to-do lists

## (More) Tips & Tricks

- Avoid multi-tasking. Try completing one project before starting another.
- Prioritize those tasks that must be completed in a timelier fashion. Save less pressing tasks for a later date.
- Avoid divided attention tasks (focus on one thing at a time).
- Try to minimize distractions when doing work (e.g., do not listen to music, do not check email or texts while working on projects).
- Use noise-cancelling headphones to reduce impact of auditory distractions and improve focus.
- Take notes during meetings with supervisors, coworkers, and/or doctors to stay engaged and record action items to be completed after meetings.
- Emphasize efficient time management. Set aside 30 minutes at the beginning of the week to plan and record work and activities.
- Set aside consistent time for cognitive work (e.g., patient charting, checking over his work or evaluating task completion). Do such tasks at the same time each day/week. Check off accomplishments daily.







REMAIN FLEXIBLE



USE SAFETY NETS OR SHOCK ABSORBERS

# Lessons Learned



SHIELD YOURSELF (WHEN POSSIBLE)



**FIND BALANCE** 



STRENGTHEN YOUR CORE



# RESILIENCE

#### Resilience











Adaptability:

adjusting to changes and setbacks, finding new ways to move forward. Positive
Thinking:
maintaining a
hopeful outlook
and seeing
beyond the
immediate
challenges.

Emotional
Regulation:
managing
strong emotions
and maintaining
a balanced
perspective.

Social Support:
building strong
relationships
and support
networks can
bolster
resilience.

ProblemSolving Skills:
tackle
challenges
more effectively.







# Thank You!