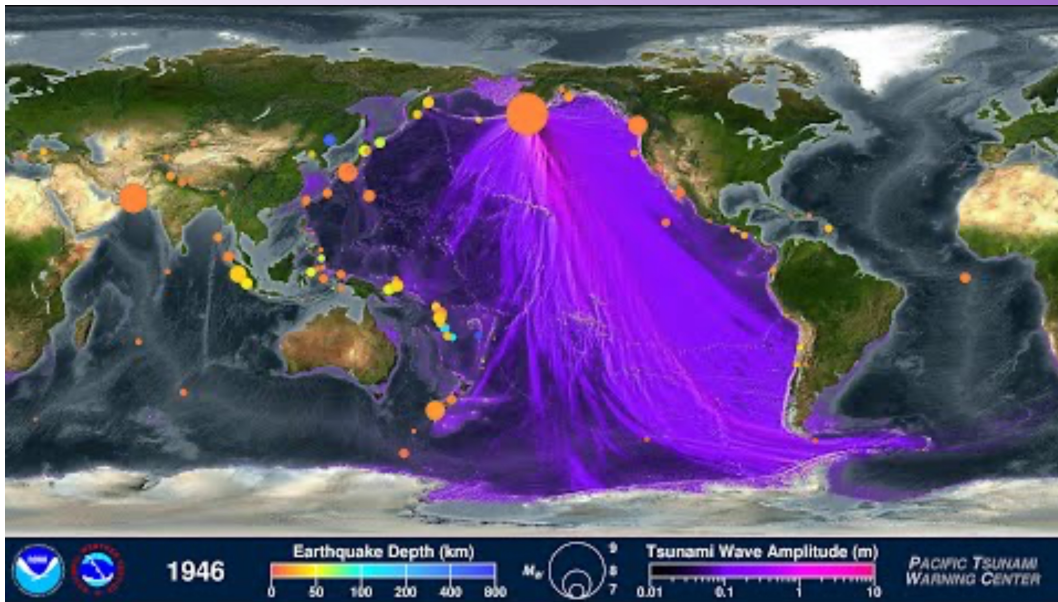


Resilience in MS: Navigating the Unexpected

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This animation shows every recorded earthquake in sequence as they occurred from 1901-2020.

The earthquake centers first appear as flashes then remain as colored circles before shrinking

The size of each circle represents the earthquake's magnitude while the color represents its depth within the earth.

This animation also highlights significant tsunamis generated by some of these earthquakes – in purple.



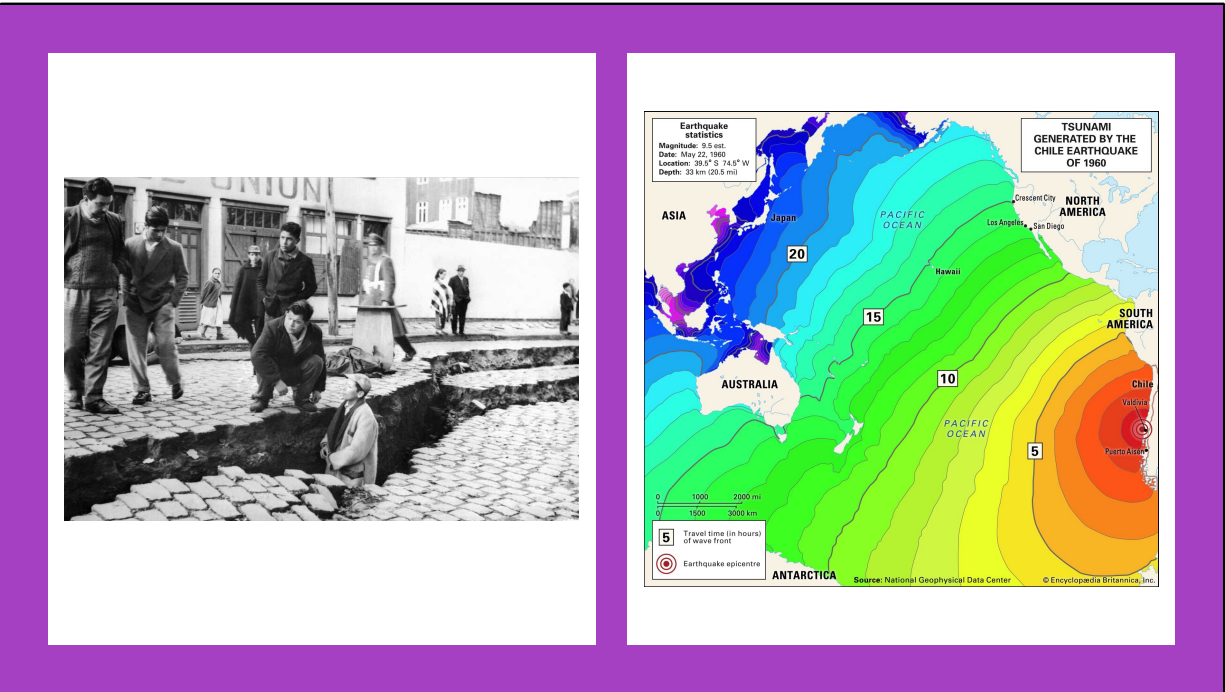
For a moment I'd like you to imagine that this map of the world is like a map of your brain.

There are certain regions that are clearly more vulnerable than others.

There are also regions that are more "dense" in terms of the population or functions housed there.

Memory, language – critical functions and any disruption has a huge impact on us

So too, the impact of an earthquake on a rural town is going to be quite different than densely populated urban center.



On May 22, 1960 a 9.5 magnitude earthquake, the largest earthquake ever instrumentally recorded, occurred off the coast of southern Chile.

The ground shook so hard that people knocked off their feet — unable to stand for about 10 minutes as the earth heaved.

The whole country stretched during this earthquake, and the coast moved toward the west, increasing the area of the country of Chile by an area equal to about 1,500 football fields.

Unfortunately, this earthquake generated a tsunami that was destructive not only along the coast of Chile, but also across the Pacific.

12 hours after the shaking stopped, a tsunami smashed into Hawaii.
 12 hours later, another tsunami smashed into Japan.

Various estimates of the total number of fatalities from the earthquake and tsunamis have been published, ranging between 1,000 and 6,000 killed.

In addition to the tsunami, landslides, a flood, and a volcanic eruption occurred

In spite of the tsunami warning system in place in the Hawaiian Islands, there were numerous fatalities and injuries in Hilo. It appears many of those killed or injured thought the siren was a preliminary warning that would be followed by a second evacuation signal, instead of understanding that it was a signal to evacuate immediately without further notice. Others apparently chose not to evacuate immediately because they did not take the alert seriously after experiencing little or no damage in their experience with previous alerts.

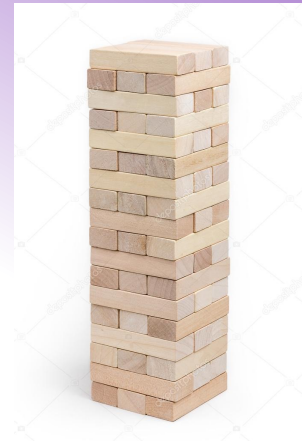
This past summer A magnitude 7.4 earthquake struck northern Chile near its border with Argentina. Despite remarkable size, it was NOT considered a major intensity earthquake. There were some minor shocks to infrastructure but no immediate reports of injuries or major damage.

Why??

Engineering

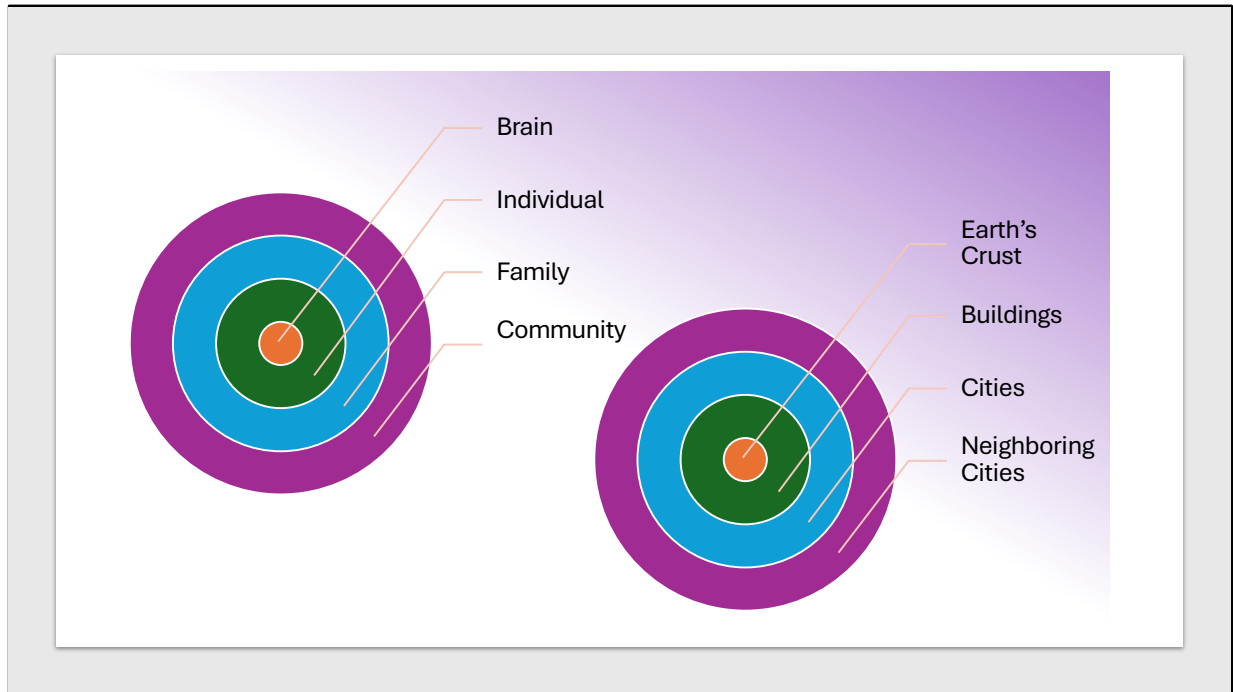


- Create a flexible foundation
- Counter forces with “damping”
(Shock absorbers on a car)
- Shield buildings from vibrations
- Reinforce the building’s structure



Over the past few decades, engineers have introduced new designs and [building materials](#) to better equip buildings to withstand earthquakes.

- 1) When the base moves, the structure stays steady
- 2) Shock absorbers reduce the shockwaves’ magnitude and help reduce pressure on the building**
- 3) Rather than just counteracting forces, researchers are experimenting with ways buildings can deflect and reroute the energy from earthquakes altogether
- 4) Now – I am not going to pretend to be an engineer and explain these concepts to you, so instead I’m going to use a different analogy.



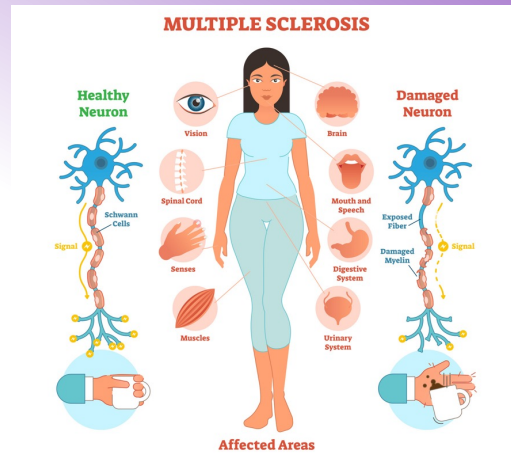
Instead I'm going to start talking about the brain and the impact of MS.

MS affects many people at once

You, family, friends, caregivers, employers

Managing the Unpredictable

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



Multiple sclerosis is an unpredictable disease of the central nervous system. The central nervous system includes the brain, spinal cord and optic nerves. This system controls everything we do.

MS disrupts the flow of information within the brain, and between the brain and body.

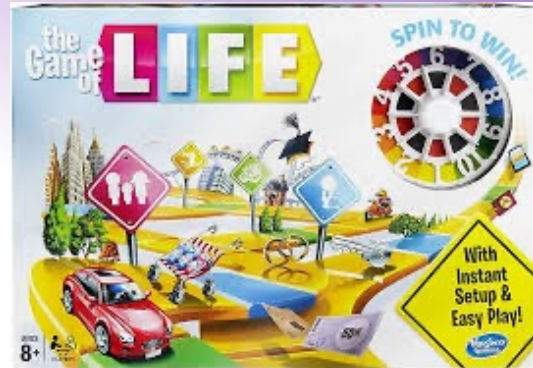
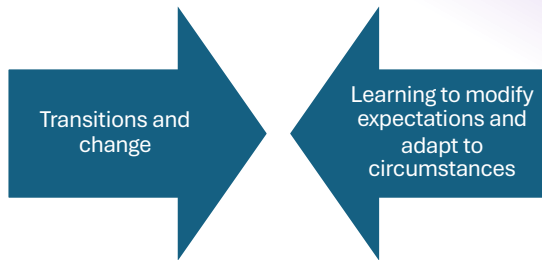
An individual's experience with MS may change from day to day and year to year. Symptoms can be severe or mild, short-lived or enduring. Symptoms also vary from person to person and can include:

Managing the Unpredictable

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



The Game of Life



According to the National Earthquake Information Center, there are about 20,000 earthquakes around the world each year, or about 55 per day. However, the frequency of earthquakes varies by magnitude:

- Magnitude 2 and smaller: Occur several hundred times a day
 - Major earthquakes: Greater than magnitude 7, happen more than once per month
 - Great earthquakes: Magnitude 8 and higher, occur about once a year
- I can't tell you exactly how many MS flares you will have. But I can tell you there will be many stressors throughout the course of your life – whether related to your MS or not.

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



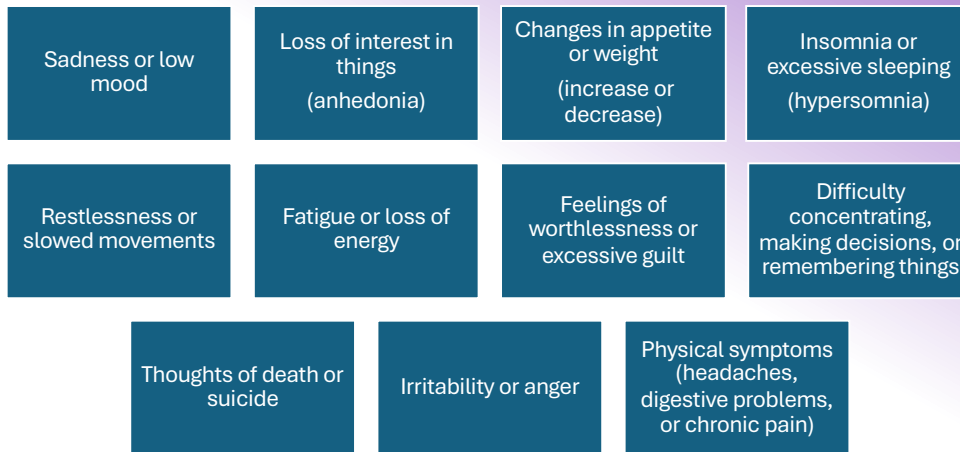
MENTAL HEALTH

- 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

An illustration featuring a red brain with a blue stethoscope around it. A red heart is positioned above the brain, and the stethoscope's chest piece is at the bottom. The entire graphic is surrounded by stylized red flowers and green leaves on thin stems, set against a light beige background with small red and green dots. The text 'MENTAL HEALTH' is written in a bold, dark blue, sans-serif font at the top of the illustration.

Quality of Life: Mental health issues in MS significantly affect overall quality of life. For instance, individuals with both MS and depression or anxiety tend to report lower satisfaction with life, increased social isolation, and greater impairment in daily functioning compared to those without these conditions.

Depression



It's important to note that the severity and combination of these symptoms can vary widely among individuals experiencing depression. If you or someone you know is experiencing several of these symptoms persistently for more than two weeks, it's advisable to seek professional help from a healthcare provider or mental health specialist.

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)

Physical Symptoms:

- 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

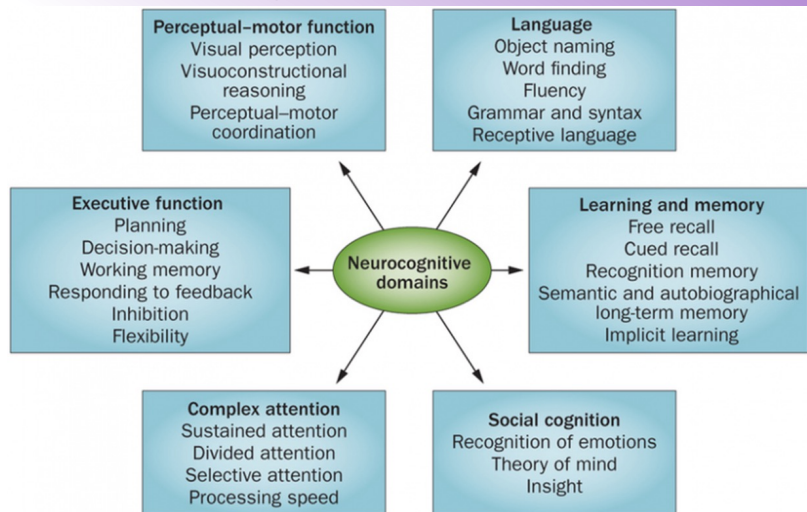
Emotional Symptoms:

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

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



Approximately 50%

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







Change our mindset
Change our behaviors

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)

Lifestyle Changes: Incorporating healthy lifestyle habits such as regular exercise, balanced diet, adequate sleep, and stress management techniques can significantly support mental health.

Support Groups and Peer Support: Participating in support groups or receiving peer support from individuals who have similar experiences can be beneficial for emotional support and practical advice.

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)

•Sometimes mood may need professional attention

•**Cognitive Behavioral Therapy (CBT)**: Focuses on changing patterns of thinking and behavior that contribute to the patient's problems.

•**Psychodynamic Therapy**: Explores unconscious processes and past experiences to understand current behavior and feelings.

•**Interpersonal Therapy (IPT)**: Focuses on improving communication and relationship patterns.

•**Mindfulness-Based Therapies**: Incorporate mindfulness practices to help manage emotions and reduce stress.

•**Antidepressants**: Used to treat depression, anxiety disorders, and sometimes other conditions like OCD or PTSD.

•**Antipsychotics**: Primarily used to treat schizophrenia and bipolar disorder, but may also be prescribed for severe depression or other conditions.

•**Mood Stabilizers**: Commonly used in the treatment of bipolar disorder to stabilize mood swings.

•**Anxiolytics (Anti-Anxiety Medications)**: Used to treat anxiety disorders, often in the short term.

•**Complementary Therapies:** Some people find benefit from complementary therapies such as yoga, acupuncture, art therapy, or music therapy as adjuncts to traditional treatments.

Smartphone Applications

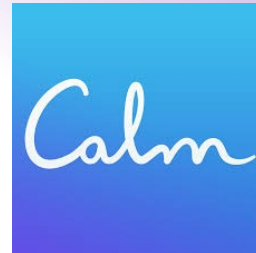
Clarity:
CBT Self Help Journal

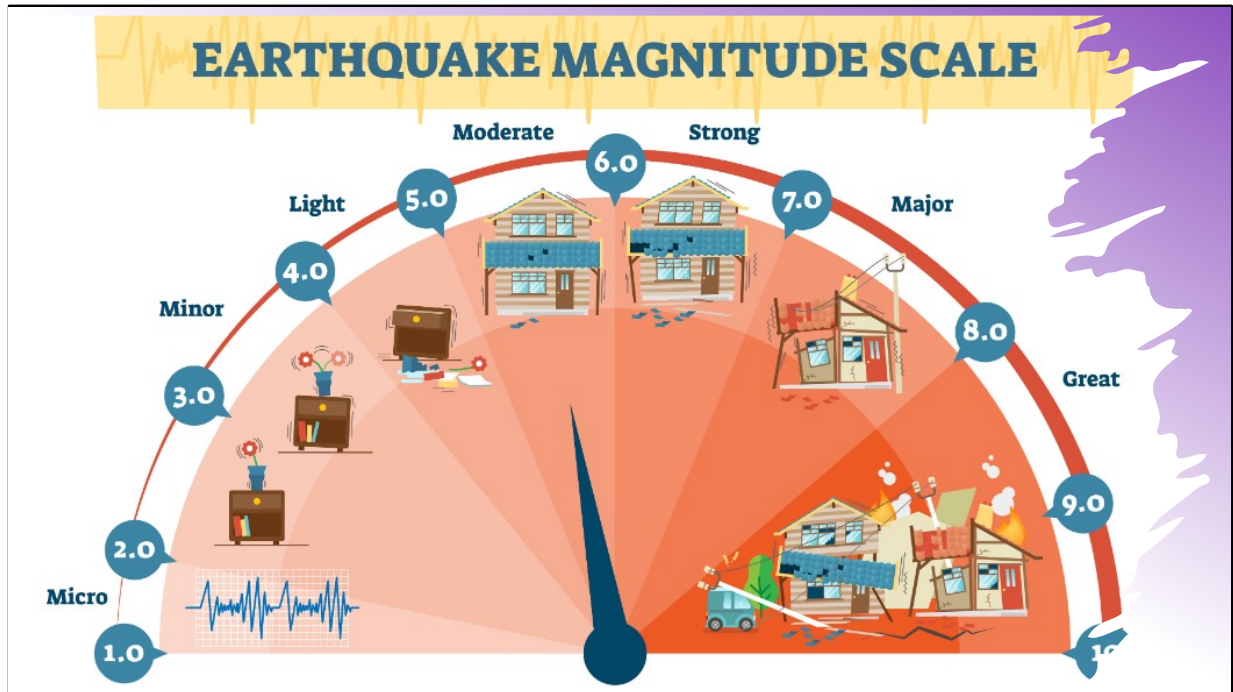


Headspace:
Meditation



Calm:
Relaxation and stress-
reduction





So how do you know when you need more help?

Let's go back to earthquakes

Just like there is a magnitude to any of life's many curveballs/stressors, there is also a magnitude to earthquakes.

The way we measure this is the Richter Scale. And with time, we as humans have learned that not every great quake needs to result in this level of destruction. We can do things to strengthen our souls and minds to protect and manage damage.

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

Fatigue is the most common reason for people with MS to go on disability

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 cognitively-demanding 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



The lesser items will fit in. This is like filling your bucket with large rocks first, then filling the rest in with pebbles, then sand, then water.

Time Management Matrix

	Immediate/Deadline	Not Immediate/No Deadline
Important	<u>Large Rocks/Pebbles</u> Emergencies Important appointments Important deadlines Pressing problems (car dies, roof is leaking)	<u>Large Rocks/Pebbles:</u> Health/Exercise Prevention Important relationships Planning Recreation and self-care
Not As Important	<u>Sand:</u> Interruptions Phone is ringing Someone is knocking on door Popular activities (TV shows, shopping)	<u>Water:</u> Some chores Some mail, phone messages, or meetings Unimportant relationships 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 your big rocks, pebbles, sand, and water? How do they fit into your time management matrix?

DR

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)

AG

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.

Lessons Learned



DON'T IGNORE
WARNING SIGNS



REMAIN FLEXIBLE



USE SAFETY NETS OR
SHOCK ABSORBERS



SHIELD YOURSELF
(WHEN POSSIBLE)



FIND BALANCE



STRENGTHEN YOUR
CORE



RESILIENCE

Resilience is the ability to adapt and bounce back from adversity, trauma, tragedy, threats, or significant sources of stress.

It involves being able to cope with life's challenges and setbacks, as well as to recover and even grow stronger from difficult experiences.

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.



Problem-Solving Skills:
tackle challenges more effectively.

Resilience is not just about bouncing back to where you were before facing adversity; it often involves personal growth and transformation.

It's a skill that can be developed and strengthened over time through various strategies, including self-care, seeking support from others, maintaining a positive mindset, and learning from setbacks.



Resilience is this: Chile in 1960 vs. 2024

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Thank You!
