



The Mind-Body Connection in Rare Neuroimmune Conditions: Exploring the relationship between mental health, fatigue, and cognition

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Acknowledgments

Patients and families impacted by rare diseases





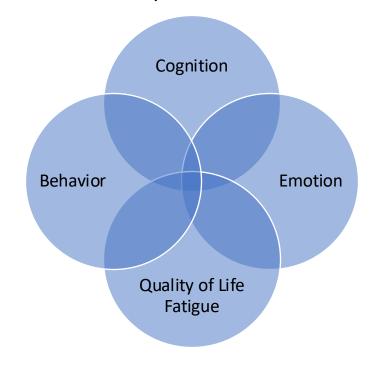
children'shealth?

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Role of Neuropsychology

Science of human behavior as it relates to central nervous system function







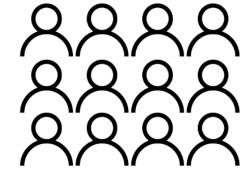




Neuropsychologists as Clinician and Researcher

- Clinical individual evaluation
 - Focus on one person
 - Understand how multiple factors impact daily life
 - Tailored evaluation and recommendations
- Research evaluating groups
 - Diagnostic groups
 - Age range
 - Test hypotheses at the group level







Role of Neuropsychology

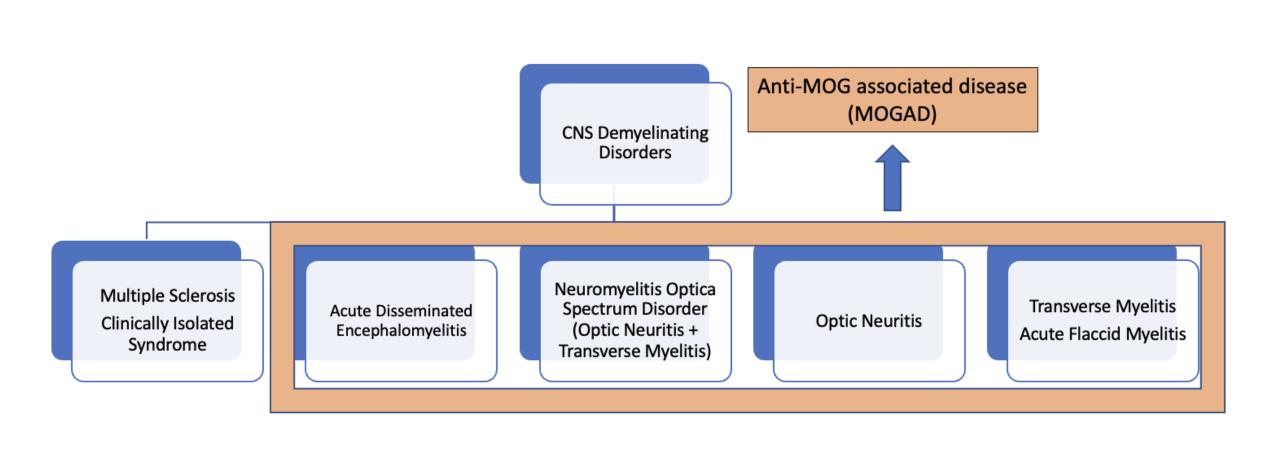
Clinical Care

- Consultation
- Neuropsychology Screening Evaluation
- Comprehensive Neuropsychological Evaluation
- Transition Planning

Research

Education and Clinical Training

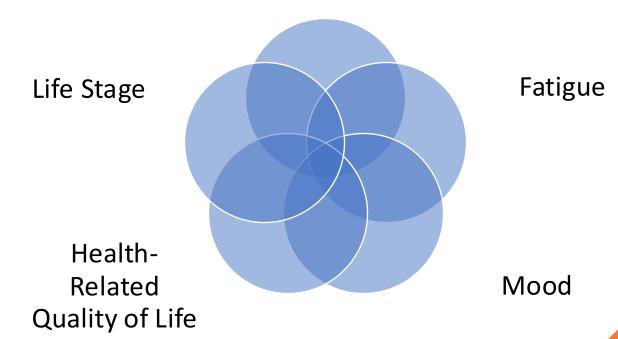
Administrative Leadership



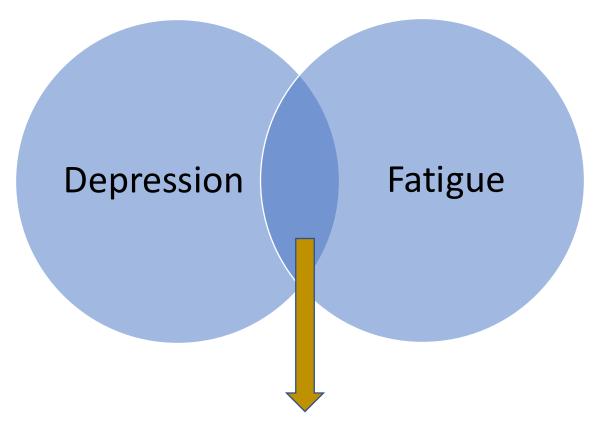
Common and Overlapping Areas We Address

Cognition

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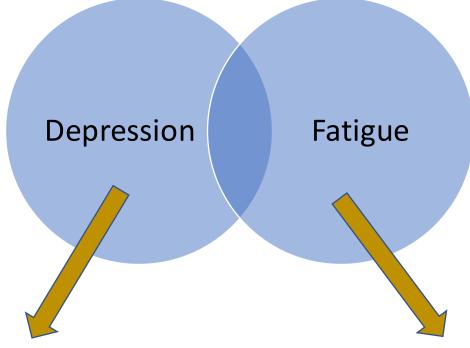


Overlapping symptoms: How can you tell the difference?



Changes in sleep, motor slowing, loss of energy, diminished engagement in activities, diminished cognitive skills (concentration, etc.)

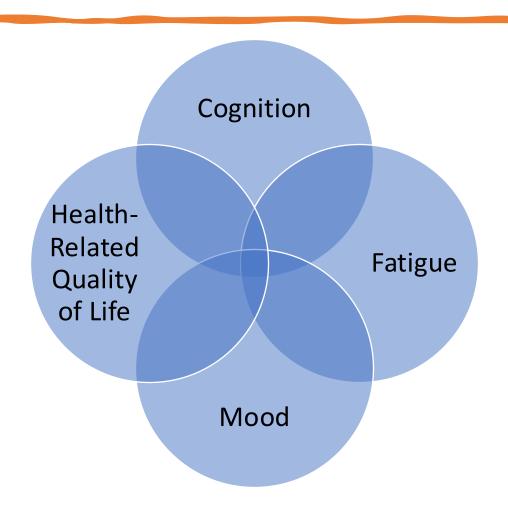
Overlapping symptoms: How can you tell the difference?



Depressed mood
Feeling sad, empty, hopeless
Weight changes
Motor agitation
Feelings of worthlessness, guilt
Recurrent thoughts of death and dying

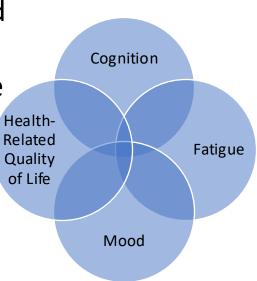
Feeling <u>tired</u> leads to reduced engagement in activities Feeling physically weak

Research suggests that cognition, mood, and fatigue are interrelated and that by treating one problem, you may also be treating another.



Summary

- Rare neuroimmune disorders may be associated with changes in thinking, energy levels, mood, and quality of life.
 - Not all are impacted the same way
 - No one-size-fits-all approach to intervention
- Research may offer clues about areas for targeted intervention
 - Ex: Cognitive problems are associated with greater fatigue and depression symptoms.
- There are many opportunities for intervention, and these must be tailored and prioritized to meet individual needs.
 - What is the most distressing?
 - What symptoms interfere the most with daily life?





What is Mental Health?

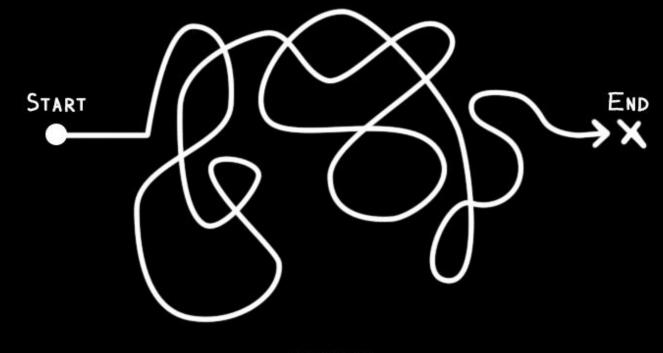


- General state of psychological well being
- How we cope and manage stress, relate to others, and make choices
- Related to how we think, feel, and act
- Part of being human
- Important at every stage of life
- One important aspect of health and linked to physical health
- Like physical health, something we need to take care of each day

HOW LIFE IS SUPPOSED TO GO

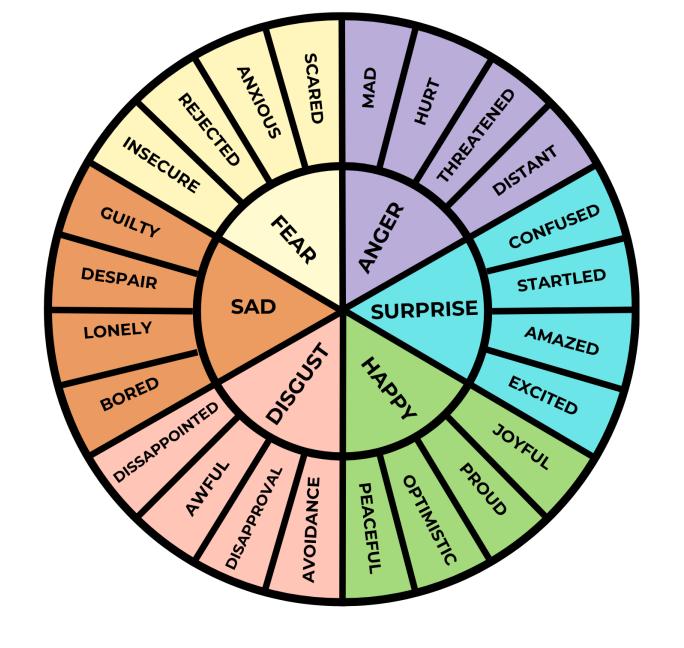


HOW LIFE ACTUALLY GOES



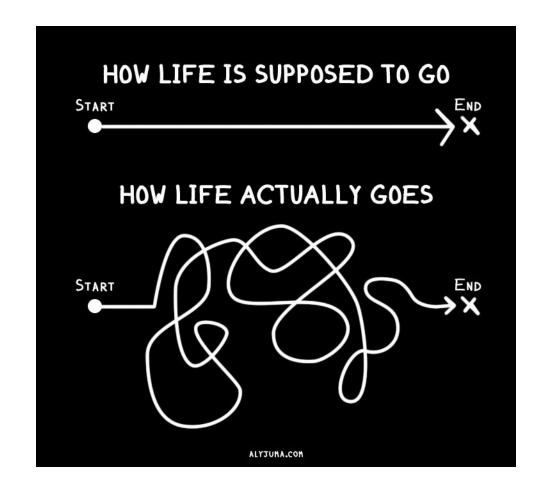
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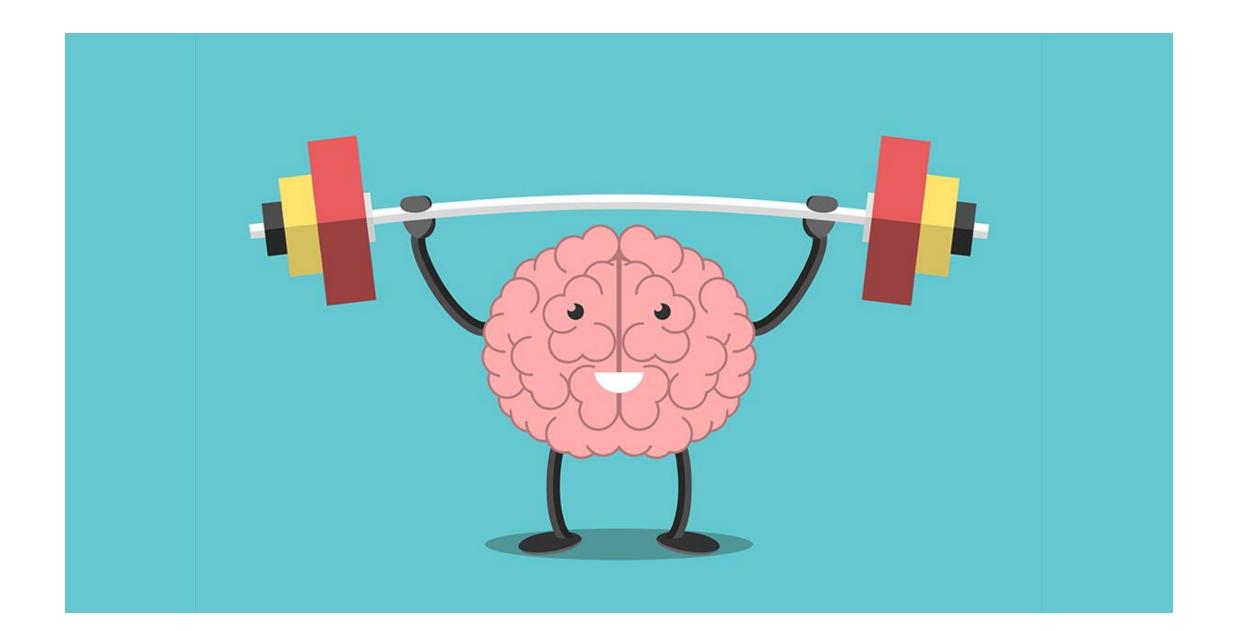












Ideas for promoting mental health!

Be curious about your feelings and what they are teaching you

Tune into how your body feels

Nurture healthy relationships

Ask yourself,
"what might help
right now?"

Take a break

Breathe

Drink a glass of water

Talk to a trusted person

Journal: Write down three nice things about yourself

Go outside

Name three things you are thankful for

Exercise

Get a good night's sleep

Engage in a favorite hobby

Meditation

Listen to music

Hang out with a pet

Watch a funny video





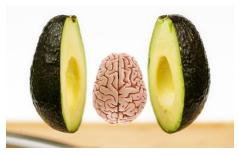
















Stronger together



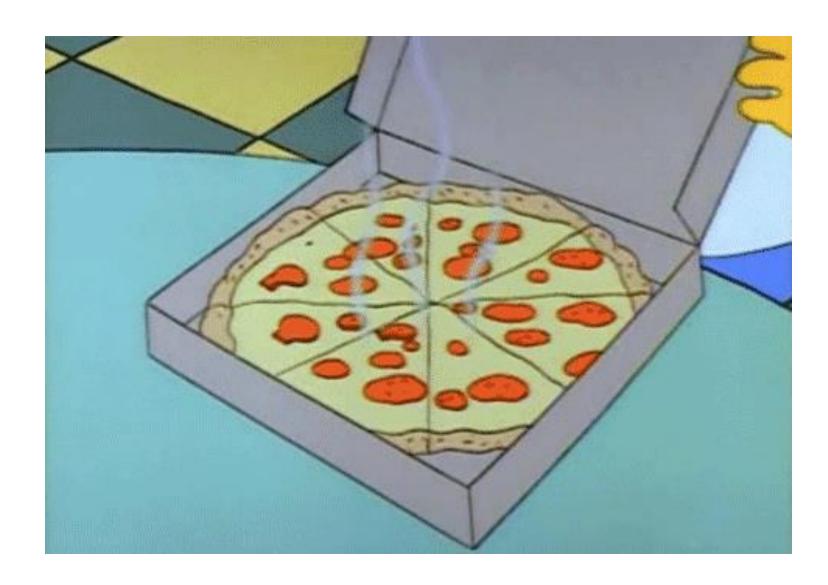




Siegel Rare Neuroimmune Association Make time for mental health each day!



What does pizza have to do with mental health?





How to Find a Neuropsychologist, Psychologist, or Therapist

- American Board of Professional Psychology: <u>abpp.org</u>
- Psychology Today psychologytoday.com
- Referring Provider
- Care Partners
- Insurance Carrier

Thank you!