Webinar Series









It Takes a Village: When Cognition Shifts Roles

May 14, 2019

Presented by:





Celgene | Genentech | Mallinckrodt Pharmaceuticals





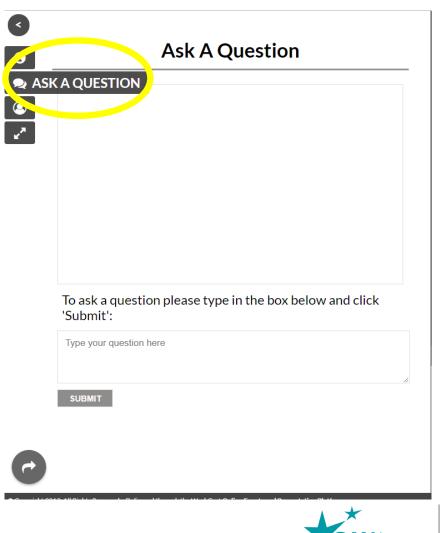
National Multiple Sclerosis Society





How to Ask Questions During the Webinar:

- Type in your question in the "Ask A Question" Box,
- This can be found by expanding the second box in your control panel on the left side of your screen.







Meghan Beier, PhD



Psychologist Baltimore, MD



Darla Freeman M.A., CCC/SLP

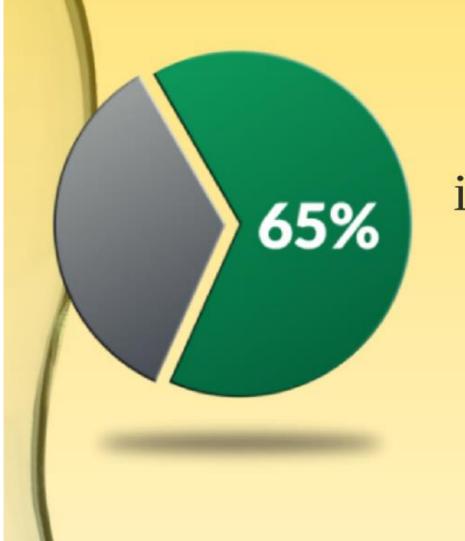


Speech Language Pathologist Tampa, FL



How Cognition Impacts People with MS





Approximately 65% of individuals with MS will experience cognitive difficulties



Cognitive Dysfunction has been detected in all MS subtypes

- CIS 20-30%
- RIS
- "Benign" MS

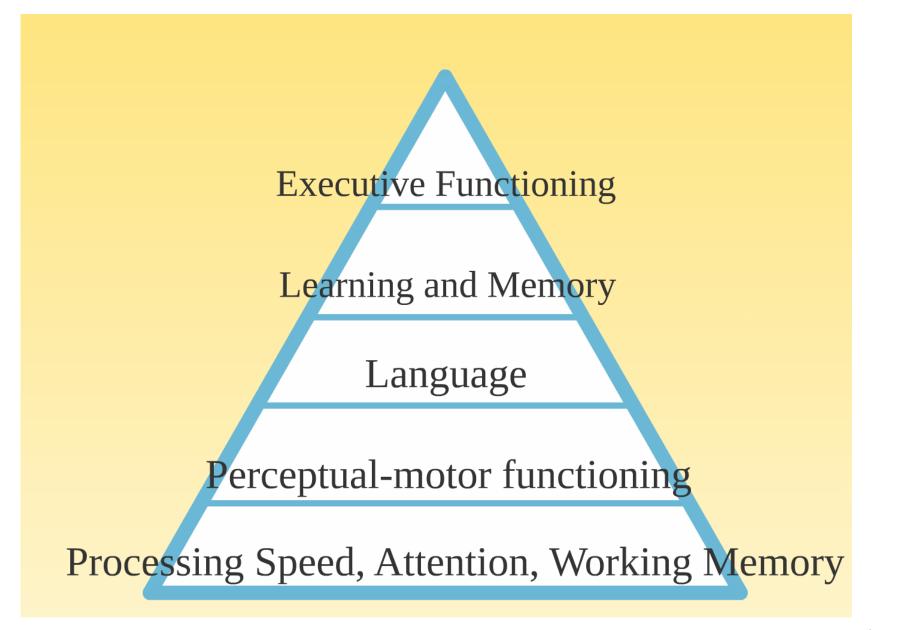
- RRMS 33% early dx
- PPMS
- Most Common: SPMS



Functions Commonly Affected

- Speed of information processing
- Attention & concentration
- Verbal fluency word finding
- Memory acquisition and learning
- "Executive" functions
- Visual/spatial organization







Processing Speed: What is It?

The speed at which you can take in and use/respond to information.

How Slow Processing Speed Looks in Real Life:

- Become overwhelmed by too much info
- Slow to make decisions or respond in conversations
- Need to read more than once for comprehension
- Takes longer to complete most tasks
- May have difficulty getting started if given multiple instructions at once
- Takes longer to get out the door



Processing Speed: How it Impacts Relationships

Example 1:

"Simply trying to figure out and plan my day can become a big struggle. I very much rely on a routine and my wife to get things done, otherwise I can sit for a very long time trying to figure out what to do first."



– Devin Garlit, SPMS dx in 2000

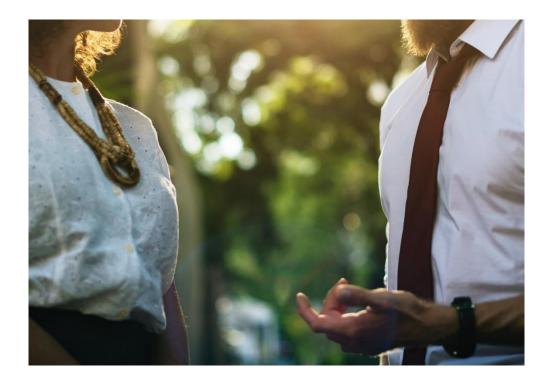
My Cognitive Changes Because of Multiple Sclerosis by Devin Garlit April 13, 2017 https://multiplesclerosis.net/living-with-ms/my-cognitive-changes-because-of-multiple-sclerosis/



Processing Speed: How it Impacts Relationships

Example 2:

- Sue (support partner): "Do you want chicken or pasta for dinner?"
- Bob (person w/MS): looks at support partner, but doesn't respond
- Sue- getting frustrated: "Bob? Did you hear me?"





Processing Speed: Improvement Strategy

Compensate

• Slow down, give yourself / your family member more time

Improve

• BrainHQ



Attention and Concentration: What is it?

- Basic Attention
- Complex Attention / Divided Attention
- Concentration

How Attention Difficulties Look in Real Life

- Makes careless mistakes, forgetful
- Difficulty sustaining concentration during a conversation
- Easily distracted by environment or internal thoughts
- Seems to not listen
- May not follow through on a plan or instructions
- Decreased interoceptive awareness, especially in women (Arora & Brotto 2017)



Attention and Concentration: How it Impacts Relationships

"over the years I have found that when it comes to my attention <u>span</u>... well, I'm a little all over the place. ... An example would be when I am trying to do housework and my husband is trying to talk to me. It's not that I can't talk and do things at the same time, however, if you're trying to relay something of importance to me when I'm elbows deep in housework it may not be the best time. And, I say this because at the time I'm so focused on my current task that it may take me a second to register the importance of what someone is telling me. It can be difficult for me to switch my attention back and forth between competing tasks, especially when one of those tasks is talking (hello, divided attention)."

- Calie Wyatt, November 10, 2016, diagnosed with RRMS when 14yo





Attention and Concentration: Improvement Strategy

- Reduce environmental distractions. Turn off the TV, radio, etc.
- Repeat what you are hearing, ask questions, take notes
- Use organizational strategies
- Minimize activities that take you off task. Example: only check your email once every 2 hours.
- Use verbal rehearsal: talk yourself through steps out loud (e.g., "I just turned off the stove"), this will bring your attention to the task at hand and away from competing thoughts or distractions.
- Practice mindfulness meditation: "4 days of meditation training can enhance the ability to sustain attention" -Zeidan et. al., (2010)



Language: What is lt?



Dictionary

Search for a word



noun

- the method of human communication, either spoken or written, consisting of the use of words in a structured and conventional way.
 'a study of the way children learn language'
- a system of communication used by a particular country or community.
 'the book was translated into twenty-five languages' synonyms: tongue, speech, mother tongue, native tongue, dialect, vernacular; More



Q

Language: How it Impacts Relationships



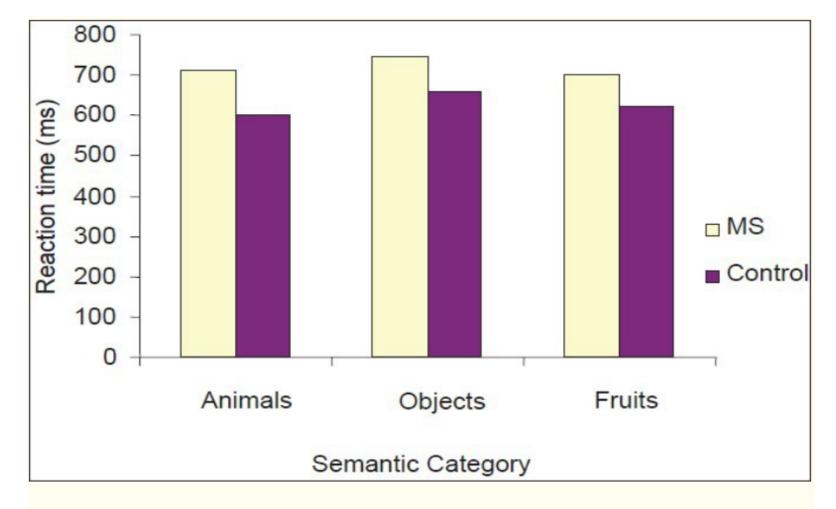


Figure 1

Comparison delay in replying in different stages of MS and control group

Khatoonabadi AR, Nejad VS, Dadgar H, Ashtari F, Ghasemi M. Speed of word retrieval in multiple sclerosis.

Multiple[®] Sclerosis

J Res Med Sci. 2013;18(4):274–276.

Levels of Word-Finding Errors

- Word Level:
 - Unable to recall single words especially in confrontation naming
- Sentence Level:
 - Oral formation impacted
 - May cause use of empty, repetitive speech, fillers or phrasal substitutions
- Discourse Level:
 - Difficulty keeping up with the pace of conversation
 - May reduce conversational interactions



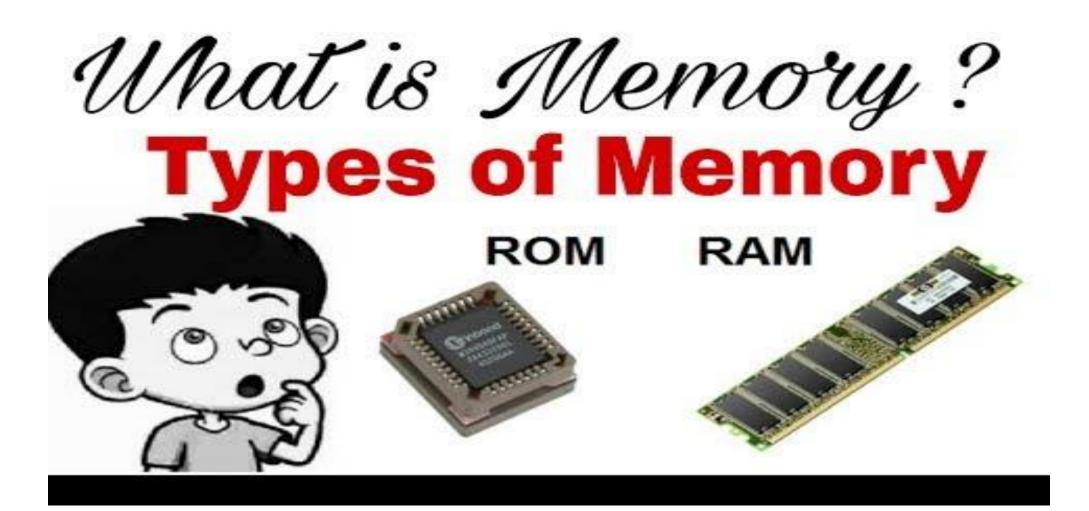
Language: Improvement Strategies

- Work at it!
 - Puzzles
 - Apps
- Phonemic cues
 - For example: I want a bowl of "????"
 - "Ssssss"
- Semantic cues
 - For example: "Let's go to the "????"
 - A place with stores, lots of people, it's very busy

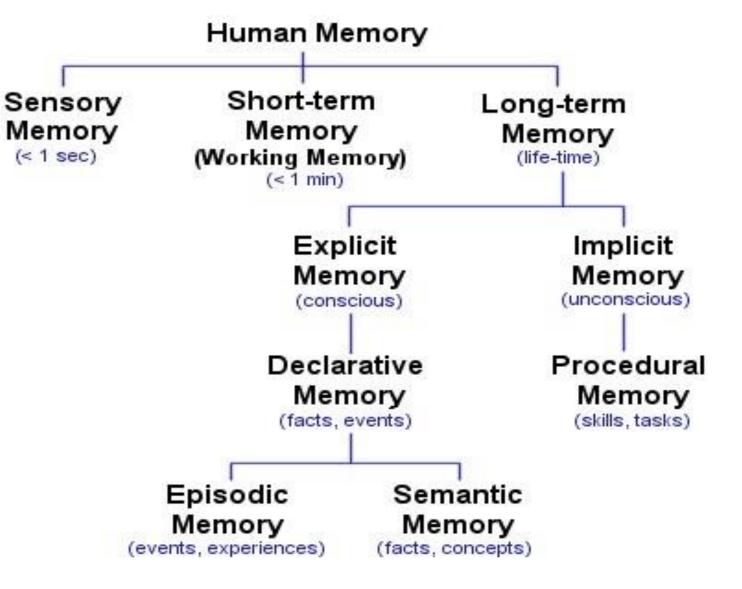
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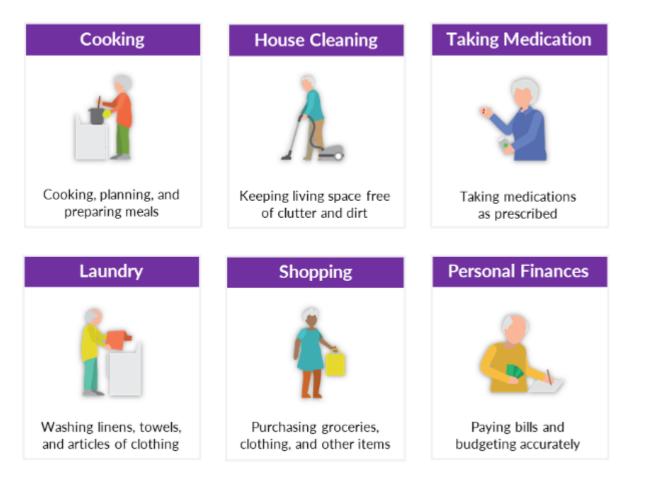








Memory: How it Impacts Relationships







Memory: Improvement Strategies

Restorative activities can include learning and memory exercises:

- Combine modes of learning: You will be more likely to remember something if you "see it, say it, hear it, write it, do it." It's okay to give yourself extra time.
- Repeat & verify: Repeat what you hear and verify that it is correct to improve your attention and memory.
- Spaced rehearsal:

Repeat and practice information at intervals spread out over time to improve your ability to store information.

• Build associations:

Use memory aids! For example, to remember the name of someone you just met, associate her/his name with a friend or family member of the same name, or with a place, color or event that sounds like the new name.



Memory: Improvement Strategies, cont.

Compensatory activities that help make up for functions that are no longer working well may include:

- Consolidate and centralize! Designate one place in your home as the "Grand Central" information center. Include your master calendar, mail, bills, phone messages, to-do lists, keys, wallet, shopping lists and more.
- Plan:

Post a calendar large enough to display everyone's appointments, activities and social engagements, and reminders! Keep pens or markers hanging right beside it. Or use a computer program set up with reminders for routine tasks (synchronize it with your mobile devices so you have your appointments with you while on the go).

• Record:

Dictate your to-do list, notes or other things to remember on a digital voice recorder (available on many phones).

Memory: Improvement Strategies, cont.

• Remind:

Use checklists, the alarm on your watch or phone, your kitchen timer, and more.

• Eliminate or remove yourself from distractions.

Turn off the TV, music and whatever else is "on" when speaking with someone in person or on the phone. Background visual and noise distractions can make learning or remembering more difficult. If you can't eliminate the distraction (for example, people talking at a party) then ask, "Can we talk in a quieter place?"

• Take a break.

If you are having difficulty concentrating, take a breath and refresh.

• Do one thing at a time.

Avoid switching back and forth from one topic or task to another. Finish or find an appropriate stopping place in what you're working on before you switch to something else.



Executive Functioning: What is It?

- Ability to manage oneself and/or one's resources to execute or perform a task
- Think of executive functioning as the coaching staff for a football team. Each part of the coaching staff is helping to direct the entire team to work as a cohesive unit in order to reach the goal.





Executive Functioning: Real Life



Imagine you have a dinner reservation. *<u>Time management</u>* skills are needed to give enough time to get ready and drive to the restaurant. This task also requires *planning, prioritizing* - knowing what step to do 1st, 2nd, 3rd. You need to *initiate* getting ready. If you get side-tracked, you must self-monitor, or internally step back and reorient yourself to the end goal. As you walk through your kitchen to the car, you inhibit an *impulse* to chow down on cookies. You usually *organize* outings by putting them on your phone calendar. You look through the calendar and to your annoyance the restaurant address is missing! Instead of panicking, you use emotional control to manage frustration. You think *flexibly*, and brainstorm ways to find the missing address.



Executive Functioning: Improvement Strategy

Time Management

- Try a Time Timer (timetimer.com)
- Use an alarm clock, kitchen timer, or reminders on your cell phone
- Utilize self-monitoring time yourself to see how long a particular task takes



How long do you think it will take?	How long did it actually take?				
Example: 10 mínutes	Example: 20 minutes				



Executive Functioning: Improvement Strategy

<u>Self-Monitoring:</u> You can try self-monitoring for almost anything: emotions, behaviors, tasks, sleep, fatigue, etc.

• If you want to see how many times you go off task when reading, mark the top of the page with a tic mark every time your attention wanders. Once you make the tick mark, bring your attention back to the page.

Emotional Control:

- Use self-monitoring. Track impulses and emotional outbursts (what happened?, what was the trigger?, how did you feel?, what was the consequence?).
- Regularly practice relaxation techniques such as deep breathing, autogenic training, progressive muscle relaxation, or guided imagery.



Executive Functioning: Improvement Strategy

Organization:

- Use calendars or to-do lists.
- Designate a particular spot (e.g., a memory bowl) to put important items like your keys, glasses, wallet, purse, etc. Put those items in that spot EVERY TIME.

Planning and Prioritizing:

- Break big tasks into smaller more manageable chunks. Write down each "chunk" or step.
- Avoid putting off tasks you can do now. DO IT, WRITE IT, or FORGET IT

(Veteran Top Memory Tips by Ana Soper, Ph.D.)



Executive Functioning: Improvement Strategy Initiation:

- Ask a family member to cue you when it is time to start a new task
- When you want to start a new task, set a timer for yourself, see if you can get the task started before the timer goes off. For example: You need to wash the dishes. Set a 5 minute timer and see if you can get to the sink and start washing before the timer goes off. Reduce the time by 30 seconds each time you are successful.

Flexible Thinking vs. Rigid Thinking:

 Practice flexible thinking. Try brainstorming as many solutions to a problem as you can. Write down EVERY solution you think of, no matter how silly or ridiculous. When you are done go through the list and pick out a solution to try. If it doesn't work out, try another.









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