

Tipping Point #4 - Cognitive Changes

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You can't remember why you came into the kitchen. You keep losing things. You can't remember directions to a place you have frequently driven or telephone numbers you have frequently used. Memory loss: it is the most common mental change associated with MS and can also be affected by aging, depression, and medications. No matter the cause, it can lead to frustration, untold embarrassments and harm - failure to follow your medication regimen, missed appointments, or being unable to find your way home.

Memory loss can affect everyone, especially when under stress, if depressed, or when fatigued. We can all recall times in our past when we forgot things or couldn't find things or had trouble recalling needed information but now cognitive changes are beginning to affect your quality of life. Family members notice and bring it to your attention.

You look on your calendar and realize you missed an appointment. You aren't sure if you took your medicine at the prescribed time. You can't remember what to do when the car won't start. When this happens, you need to take action. You need to protect yourself from possible harm related to the ramifications of cognitive impairment. You need to create systems to help organize information that affects your quality of life.

1. Update your home medical file. Note how changes in cognition are affecting your life. Include a list of ways your memory and other mental functions are changing. Review the list of medications you currently take, including vitamins, supplements, and herbs. Is the list up to date? If not, correct it. Have you included where each medication is filled and the renewal date for each prescription? As always, bring this file with you to all medical appointments.
2. Share your concerns about cognition changes at your next appointment with your primary care doctor or neurologist. Discuss possible treatment or medication options. Ask about strategies to compensate for any changes. Discuss fatigue and depression, if these are relevant. Sometimes it's difficult to tell these apart from cognitive changes.
3. Ask your primary care provider for a referral to a speech therapist (ST) or occupational therapist (OT) for help with cognitive rehabilitation strategies. A ST will focus on

language/communication problems, like word finding and short-term memory. The OT will focus on organizational skills, medication schedule issues, and other things related to daily activities (bathing, dressing, shopping, financial management) if these are affected.

4. Establish procedures for protecting medications. If you move pills from the original bottles to dispensers, store the bottles in a safe place out of reach of children. Once you have filled a dispenser, move the bottles back to the safe storage place. Make sure you have a list of your medications, where each is filled and the renewal date for each prescription. You don't want to run out. A copy of this should be in your medical file.
5. Establish procedures for taking medications when scheduled.
 - Make a list of pills you take and at which time you take each. Check off each pill as you take it. Make many copies of this list so you can use a fresh list each day.
 - If you take pills at several times during the day, use the plastic multi-chambered boxes that have one box for morning, one for afternoon and one for evening. Fill it once per week (on the same day each week) so that you know an empty chamber means you have taken the pill.
 - If you take pills once a day and at the same time you can use the plastic box with 7 chambers, one for each day of the week. Fill it once per week (on the same day each week) so that you know an empty chamber means you took your pills.
 - Use an electronic pill-dispenser. You load the pills once per week (or every two weeks or once per month depending on the dispenser and the number of medications you take). It makes a sound when it is time to take a pill and then drops the pill down a chute. This takes away much of the guesswork. If the chute is empty, you have taken your pills.

For any of these systems, keep a list of how many pills you put in each box of each dispenser. Then you can quickly refill the box or dispenser without having to refigure totals for each pill. Consider having a family member fill the container if you are concerned about your ability to set aside the correct dosages. The most significant features of whichever system you select is that you have a way to know you have taken the right number of pills at the right time each day.

6. Calendars are your friends. Establish a calendar for your appointments, meetings and social engagements so that you can proceed with confidence. Again, there are many systems.
 - Use a white board to list your activities for the current day or week. You can easily erase and make changes or additions.
 - Use a wall-hung monthly calendar and post it at eye level so you can easily see it and refer to it when needed.
 - Use a desktop daily calendar on whose pages you can staple appointment cards, invitations, and announcements. Then, when you turn to the page, you have the information you need for the activities of that day.
 - Use a combination of the above—for example, a white board for a *Do Today* list along with a daily calendar where you can list upcoming events and appointments.
 - Consider adding activities such as bill paying, watering the plants, or routine house cleaning tasks to your calendar.
 - Review your calendar a week at a time: have your scheduled relaxing days around days that are especially busy? Schedule time to prepare for, and recover from, fatiguing activities.
7. Prepare a daily To Do list of what you want to accomplish during the day. Keep it posted where you can easily see it. Think about which system works best for you. Is a simple list best? You make a list and cross off items as you complete them. Or is it better for you to write individual items on sticky notes that you post on the refrigerator? You can easily reprioritize items by moving the notes around on the refrigerator and can throw each out as you accomplish it.

Or, label the activity you wish to complete at the time you wish to complete it on a drawing of a clock. This method works best for some visual learners. Whichever method you use, be realistic when developing and prioritizing your list. Identify what is most important and make sure these 2-4 things get done. If you are realistic, you can avoid being overwhelmed by what needs to be done.

8. Carry a small notebook with you when you leave the house. Use it to write down anything you need to remember - instructions from your doctor, an interesting book someone tells you about, plans you make with friends, new appointments—anything you don't

want to trust to your memory. When you get home, transfer appropriate information to your calendar. The great thing about keeping notes in a notebook is that, if needed, you can always refer to it again.

9. What things do you lose most often? Keys? Glasses? Calendar? TV remote control? Figure out a place for each and then put each item in its place. Make the locations logical. Keys should be by the door. Glasses should be within reach. The remote control should be near your favorite seat in front of the television. ALWAYS return each item to its place.
10. Do you arrive some place and realize you forgot to bring something important with you? Is it sitting on the kitchen counter instead of in the car with you? Here is a poem a friend shared; she doesn't have MS but she has age-related memory issues. It makes her laugh but it also helps her remember to bring what is needed. Make up your own poem that matches your needs, memorize it - or post it by the door. She says it to herself whenever she is leaving the house and was happy to pass it along:

*Purse, phone, keys
Have I peed?
What other stuff
Do I need?*

11. Schedule rest time each day. It will not only give you body a chance to recover and regain energy but it gives your mind a chance to rest as well. Stop and have a cup of tea, read a book, sit in the garden, watch your children play, take a nap. Rest is healing. Remember, you must take care of yourself while helping care for other family members.
12. If you have a computer, play some brain games. There are several available that are fun to play and are designed to help develop your memory skills.
13. Type "*memory games*" in your browser (like Google)— many are free. The National MS Society website also includes links to memory games. Go to their site: www.nationalmssociety.org and type "memory games" in their search window.
14. If you want to read more about cognition and MS, the National MS website is a wonderful source. Go to www.nationalmssociety.org. Go to the pull-down menu for MS symptoms. Click on cognitive function. This will take you to a long list of articles about MS and

cognition. Several are about actions you can take to deal with changes in cognition. Knowledge is power—take advantage of this free information.

15. Learn about MSQLP's Supportive Therapy program. This program's group sessions (one session per week for 8 weeks) offers participants a chance to work on the feelings they have, the challenges they face and how MS affects their relationships. This is a place where you can share how changes in cognition are affecting you and can learn from others in the group who may have similar challenges. Call the office (831.333.9091) to learn more about our program and to discuss whether it might be appropriate for you.
16. If you have not completed an Advance Care Directive (a health care proxy form) and a Physician Orders for Life-Sustaining Treatment (POLST) as described in step 12 of Tipping Point #2, now is the time to do so. If you are experiencing memory loss, it is especially important that you take time to document how you want to be treated if, or when, hospitalization is needed and you are unable to speak for yourself.

Do it now. You do not want others to make these decisions for you or to carry the burden of making these decisions. It is your responsibility. If you have already completed these documents, review them, make revisions if needed and file them with family members and your doctors.

17. Attend an MS support group. If you have not yet attended an MS support group, consider it now. Group members will have advice and stories to share about their experiences with cognition. Use their knowledge to improve your own life. See the end of this newsletter for the list of meeting times and locations of support groups in the Tri-Counties.
18. Continue to share your thoughts, beliefs and experiences with the members of your personal support group: those people with whom you can share what you are going through. If any member wishes to attend a caregiver support group meeting, encourage them. It will give them a chance to talk with others who support persons with MS. Share your written and online resources with them; information will empower them as well as you.

List of agencies and how they might help

All major MS organization websites have valuable information on coping

with cognition issues. See the following list:

MS Association of America: www.msassociation.org

MS Foundation: www.msfocus.org

National MS Society: www.nationalmssociety.org

Rocky Mountain MS Center: www.mscenter.org

The Best Thing I Did When I Began to Have Cognition Issues

—*Victoria Scaccia*

Okay, let's start with some humor here: what cognition issues? I don't remember any memory problems! In reality, of course, it isn't funny at all. Instead, it is terribly painful each time I become aware that my memory is not working the way it used to. It is embarrassing to be told I have already shared a story, or done something, or forgotten something that someone else told me.

My husband thought it would help if he held up a thumb to let me know when I was repeating something but it actually doesn't help at all. He could hold up his thumb 5 times and I wouldn't remember that he had already held it up 4 times before I began to repeat the story the 5th time. The raised thumb just makes me feel stupid and embarrassed.

Sometimes my memory problems make me want to retreat within myself, stop sharing with the outside world, so that I won't have to be told I am repeating myself or annoying others with my forgetfulness.

What have I done to deal with it? Well, I successfully denied it for quite a while. (What do you mean I already told you that? You must be the one who is mistaken.)

But I have learned to take positive action. I am very careful with my calendar. I have a daily calendar and I slip appointment cards into the correct page so an edge pokes out. That way I can instantly see when I have something coming up.

My husband has taken on the responsibilities that require good memory—bill paying for example, taxes, the long shopping lists. When I drive I try to use the same routes and prefer routes with 4-way stop signs and traffic lights.

I have found one interesting thing—I do best when I follow a routine. I look after my granddaughter and have to get up early and follow her schedule on the days she is with me. I seem to do better on the days when I KNOW I have great responsibility.

Thankfully, my sense of humor gets me through it all—and the support of those around me.