

The Way Forward

Living with Mild
Cognitive Impairment



EMORY
BRAIN HEALTH CENTER

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Introduction

This booklet is designed to be a helpful guide for people who have been diagnosed with MCI (mild cognitive impairment) and their families.

Receiving a diagnosis of MCI is life changing, and it's normal to leave the doctor's office feeling confused and unsure of what to do next. Many people who receive a diagnosis of MCI aren't even completely sure what the term means. Some of the questions you and your family may have include:

- What exactly is MCI, and how is it different from dementia?
- How will it affect me and my loved ones in the future? Will it get worse?
- Is there anything I can do to improve my symptoms while preventing decline?
- How do I plan for the future?
- What resources are available to help?

This booklet will help answer these questions and give you some guidance for the next phase of your journey. One of the most important things to keep in mind: you are still YOU. An MCI diagnosis doesn't change that. Almost everyone experiences health problems at some point in their lives, and this is what's happening to you today. Brain-related health issues do have their own set of challenges; but the goal is to get the most out of all the abilities you retain and to help compensate for the ones that have declined. Some people with MCI view their diagnosis as an opportunity to re-examine their lives and create their best possible life. We hope this booklet will help you do that!

Having an action plan is a great first step. But, first of all, let's tackle some of the questions you may have.

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Section I: What is MCI?

First of all, let's talk about the definition of MCI, dementia and Alzheimer's.

Dementia is a generic, “umbrella” term—it means a decline in cognitive function severe enough to interfere with a person's daily activities. The question is: what's causing this decline? There are many conditions that can cause dementia.

Alzheimer's disease is the most common cause of dementia. It causes a progressive decline in memory and other cognitive functions as well as functional abilities. It is diagnosed with a thorough evaluation, including brain imaging, neuropsychological testing and sometimes testing of the cerebrospinal fluid.

Mild Cognitive Impairment (MCI) is a condition in which a person's cognitive abilities have declined beyond what's expected with normal aging, but the decline is not severe enough to be categorized as dementia. People with MCI:

- Have memory or other cognitive declines that are noticeable to family and friends and are severe enough to show up on tests; BUT
- Are able to function normally in most aspects of daily life and usual activities; AND
- Need only minor assistance with more complex activities, such as managing finances.

There are three general categories of MCI:

- Amnesic, meaning it's primarily memory that is affected
- Nonamnesic, meaning cognitive skills other than memory are primarily affected (i.e., judgment, reasoning, language, visual/spatial skills)
- Multiple Domain, meaning memory plus one or more other cognitive abilities are affected

Prevalence of MCI: Approximately 15 to 20% of people over the age of 65 have MCI. People with MCI, especially those whose memory is affected, are more likely to develop Alzheimer's disease or other dementias than people without MCI. However, MCI does not always lead to dementia. The uncertainty about whether MCI will progress, or how fast, is often a source of concern for people with the diagnosis and their loved ones.

Progression of MCI: The 2019 Alzheimer's Disease Facts and Figures Report gives statistics about the progression of MCI to dementia. These statistics are based on multiple studies of people with MCI, regardless of cause:

- After 2 years, 15% of people older than 65 with MCI had developed dementia.
- 32% of people with MCI developed Alzheimer's dementia within 5 years.
- Among people with MCI who were tracked for 5 years or longer, 38% developed dementia.

However, for those people with MCI who have positive Alzheimer's markers in their cerebrospinal fluid (CSF) and possibly shrinkage in the temporal lobes of the brain, there is a substantially higher risk of progression to Alzheimer's dementia. MCI can also lead to other less prevalent forms of dementia such as Lewy Body Dementia or Frontotemporal Dementia. (To learn more about other forms of dementia, you can visit <https://www.lbda.org/go/10-things-you-should-know-about-lbd> and www.theaftd.org.) Identifying which individuals with MCI are more likely to develop Alzheimer's or other dementias is a major goal of current research.

How will MCI affect me and my family?

Depending on which type of MCI you have, your symptoms may vary. But, common ones include:

- losing things

- forgetting conversations
- difficulty finding words
- losing your way in familiar locations
- increased difficulty with planning things
- impulsivity
- poor judgment
- taking more time to complete complex tasks

MCI can affect many areas of brain function. To better understand the anatomy of the brain and how it functions, please visit alz.org/alzheimers-dementia/what-is-alzheimers/brain_tour. Additional resources for learning more about MCI can be found in Section VI.

The experience of having MCI is different from person to person. In addition to the common symptoms listed above, people may also sometimes be irritable, worried or sad. People may struggle with issues around identity: how am I different now that I have MCI, and who will I become? They may also experience changes in relationships with care partners as long-standing roles and habits may shift. If you or your partner experience depression or anxiety, it's a good idea to discuss it with your doctor. Some people find that counseling can also be beneficial when the counselor has a good understanding of MCI and experience in working with people affected by it.

Your care partner, family and friends may at times need to provide assistance if you experience some of the symptoms listed above. But, one of the most important facts to bear in mind is that while a person with MCI does have some cognitive deficits, the majority of his/her abilities remain intact. The key is to learn to make adjustments when challenges arise, and make the most of your current abilities. We'll talk more about how to do this in the next two sections.



Section II: How Do I Manage My MCI and Improve My Brain Health?

There are currently no medications that have FDA approval for the treatment of MCI. However, research suggests that actively keeping your brain and body as healthy as possible, and learning to cope with challenges, can enhance quality of life and hopefully help delay cognitive decline. Here are some suggestions:

Exercise

Some of the strongest research on preventing cognitive decline involves exercise. Of course, it's always a good idea to consult your doctor about what level of exercise is optimal for you. Some data suggests that moderate-to-intense aerobic exercise is most effective, but if that's not possible for you, there are lots of other options. Just walking for 30 minutes a day has great benefits. Some other ideas for exercise include weight training, swimming or water aerobics, dancing, biking and yoga. If you're age 65 or over, you might want to Google "Silver Sneakers" to see if you're eligible. It's a great fitness program paid for by some insurance providers. Always make sure you're drinking enough water, especially when exercising, as even mild dehydration can affect your cognitive abilities.

Diet

What's good for your heart is good for your brain, so just like exercise, a heart-healthy diet is recommended. There is evidence that the Mediterranean diet has benefits for brain health. An article about this diet from the Mayo Clinic can be found here: [mayoclinic.org/healthy-lifestyle/nutrition-and-healthy-eating/in-depth/mediterranean-diet/art-20047801](https://www.mayoclinic.org/healthy-lifestyle/nutrition-and-healthy-eating/in-depth/mediterranean-diet/art-20047801). There are other, related diets you can check into, including the DASH (Dietary Approaches to Stop Hypertension) and MIND (Mediterranean-DASH Intervention for Neurodegenerative Delay) diets.

NOTE:

The FDA advises that you be wary of any dietary supplement or product that touts itself as a “miracle cure” or “scientific breakthrough” to reduce memory loss. Before you buy or use any of these over-the-counter products, you should speak to your doctor first. Many are sold by companies seeking to take advantage of people at a time when they are most vulnerable.

Social Engagement

There are many studies which show the benefits of staying socially engaged. Research indicates that people who stay connected with others and participate in social activities tend to live longer, be healthier, experience less depression and have higher self-esteem. There is also research which has shown that socializing is good for your brain health. Here are some ideas for staying socially engaged:

- Join a “hobby” club—like a gardening, photography or book club.
- Go on a guided tour at a museum with a friend.
- Volunteer! See ideas for volunteering in Section III.
- Get involved with a group at your place of worship.
- If you’re 55 or older, join your local senior center—they have great exercise programs, group outings and classes.
- Play a sport with others, like golf, bowling or tennis.
- Take a class.
- Use Facetime or Skype to chat with friends and family.
- Play cards or board games with others.

Don't let the word Alzheimer's prevent you from taking advantage of your local Alzheimer's Association's social engagement programs for people with early memory loss; you'll find people with MCI there, too. You can get more information by calling 800-272-3900 or visiting their website: alz.org/help-support/i-have-alz/programs-support.

Cognitive Exercise

Keeping your brain active and stimulated has been shown to help slow cognitive decline. But, think beyond doing puzzles and brain games (which are fine, IF they're not too easy or too hard). The goal is to challenge your brain without getting too frustrated. An extreme example of challenging your brain would be learning a new language or learning to play a musical instrument. Having new experiences and introducing yourself to new things can also be very beneficial. So, other than crossword or Sudoku puzzles, here are some things you might try:

- Activities you've never tried before that involve manual dexterity, like drawing, painting or pottery
- Activities which combine learning and exercise, like learning the tango or another dance (it's social, too!)
- Evidence-based "brain training" programs like BrainHQ: brainhq.com

Note: Brain training programs can be challenging and fun. However, it's important to understand that you may only get faster or better at the brain training games themselves. You may not necessarily see a difference in how much faster or better you are able to do specific cognitive tasks in your everyday life.



Sleep Habits

Many people don't realize how detrimental poor sleep habits are to overall health. In addition to increasing the risk of developing hypertension, obesity and diabetes, sleep deprivation can have a negative effect on your ability to focus, learn and form memories. Getting at least 7 hours of sleep at night and keeping a consistent sleep schedule are important—and turn off those electronic devices at least 30 minutes before bedtime. Other tips for better sleep (sometimes called “sleep hygiene”) can be found at sleepassociation.org.

Reducing Stress

Like poor sleep habits, too much stress can contribute to many health problems and may affect cognitive functions like memory, concentration and decision-making. To deal with stress, it's important to be able to identify it. Keep in mind that stress can present itself in ways beyond the common symptoms of worry, anxiety and feeling overwhelmed. Some of the other warning signs include anger, irritability, frustration, social withdrawal, depression and sleeplessness. We also want to identify the triggers that are causing the symptoms and accept help with these situations. Here are some ideas for decreasing and coping with stress from the “Live Well” section of the Alzheimer's Association's website:

- Talk with a trusted family member or friend about how you're feeling.
- Change your environment. For example, if you are in an environment that has too much stimulation that is causing you stress, find a quiet place where you can relax and regroup.
- Even the most difficult situation may have both negative and positive aspects. Work on changing how you view the situation and challenge yourself to look for the positive whenever possible.
- Establish boundaries and let others know your limits. What are you willing to tolerate and what are you not? Be as open as possible about this with others.
- Take breaks and conserve energy.
- Learn what works best to relax you, and use these techniques regularly when feeling stressed or overwhelmed. Some examples are: meditation; exercising/walking; writing your thoughts and feelings in a journal; gardening; listening to music; or watching a favorite television program that you find relaxing or enjoyable.
- Let it go. If something becomes too difficult for you, come back to it later.



Section III: How Do I Develop Coping Strategies?

Some of the things you once did easily may have become more difficult, such as remembering appointments or managing money. Honestly evaluating these changes and developing effective coping strategies can help you remain active and engaged, maximize your independence and well-being, and maintain a sense of control over your life. To do this, the first step is to honestly assess your abilities. Because the effects of MCI on the brain sometimes make it hard to recognize changes in yourself that are easily seen by others, it's important to get input from trusted observers about what they're seeing. Then, you can make an informed plan to adapt to your challenges. The plan should focus on your strengths and the resources that are available to you.

Keep in mind that what works well for one person, may not work for another. And, things that work for you one day, may not work as well the next. Be patient with yourself and try different strategies to find those that work best for you. Here's a model and tips for developing coping skills, also based on the "Live Well" section of the Alzheimer's Association's website:

1. **Identify:** Make a list of tasks that have become more challenging. Focus on developing coping strategies for your more challenging tasks. For example, if you are forgetting to take your medications, but have no problem remembering to do the laundry, focus on creating medication reminder strategies first.
2. **Prioritize:** Determine if the task is necessary. Ask yourself if the task you are trying to accomplish will help you get to your goal. For example, if paying bills has become more difficult for you, can someone help you organize the bills and help with the method of payment? If the answer is yes, consider asking someone to help. You can remain in charge by making decisions and signing checks.
3. **Strategize:** Find the solution that works best for you. For

example, if you are having difficulty cooking dinner, try simplifying the process by using a crockpot. You can make a full meal without spending a lot of time figuring out the cooking process.

Tips that may help you develop good coping skills and strategies:

- **Set realistic goals and focus on what you can do today**

Reduce stress by asking family or friends for assistance, if needed.

- **Develop a daily routine**

Make a daily plan to keep track of the tasks you want to accomplish each day, including regular routines like taking medications. Having a schedule can reduce the time you spend figuring out what needs to be done and when, and makes you more successful in accomplishing your goals and limiting mistakes. To implement a routine, the use of a calendar and a to-do list are extremely helpful for most people. If you're trying out a calendar system, here are some tips:

- › Keep track of all the activities you do throughout the day (even if this means writing them in after you've done them). This will make your calendar a place you can go to see whether an activity was completed or can act as a reminder when someone asks you what you've done that day.
- › Make it routine. Set a time first thing in the morning or last thing before bedtime where you set up the calendar for the coming day. Fill in all the activities you plan to do and list any to-do items (that don't have a specific time) to the side of your calendar or in a note to yourself (sticky-notes are a great option here). When you're first learning to use a calendar, it's helpful to make a routine of checking it either before or after an activity, even when you don't need to. This makes it more likely that you'll check it in times when you don't remember.

- It should travel with you. Maybe the most critical thing about a calendar is that it has to be with you at all times to be effective. So, finding a calendar that you are able to keep in your pocket or purse (or in a gadget that can fit in one of those places) will be most useful.
- Find a system that works for you. Whether you use a paper calendar, digital calendar (like Google Calendar or iCal), or some combination of the two, find a system that works for you and keep it consistent.
- See the illustration for an example of a good calendar layout. Good calendars have a place to write out the activities of the day on an hour-by-hour basis, a place for a to-do list that isn't covering the daily schedule, and a place for you to keep notes to yourself (e.g., important phone numbers, things you don't want to forget about the day, or other little reminders).



Using a calendar system like The Memory Support System, is a great way to keep track of appointments, make to-do lists and keep important information.

- Approach one task at a time, and don't get stuck. Give yourself enough time to complete a task. Don't pressure yourself to succeed. If something becomes too difficult, take a break and try again later. Spending time to change something you cannot control can be a waste of energy and can prevent you from focusing your attention on what you can control.
- Recognize the triggers that cause you stress. What are the triggers that cause you anxiety, worry or stress? For

example, if others are hurrying you, explain what you are trying to accomplish, and ask that they provide you the time needed to be successful. Knowing what causes stress allows you to make plans or decisions about the type of activities/tasks you choose to participate in.

- Know that you have more than one chance to solve most problems. It's not uncommon to have to try different strategies to achieve your overall goal. Assess what could have been done differently, and make adjustments as needed.
- Use your sources of strength. Family, friends, prayer, your inner strength, pets—all these sources can get you through difficult times and daily challenges.

■ **Coping with stigma**

There is still a degree of stigma around memory loss which exists largely due to the public's lack of understanding about brain-related health conditions. People with MCI are often concerned they will be seen by others as “less than” the person they've always been, and they may worry that that friends and family will withdraw from them. These fears often influence one's willingness to tell others about the diagnosis. The process of deciding who to tell, and when, is very personal. But, many people report that being honest and open—starting with the people you're most comfortable with—helps to build your support team and lessens stigma by helping others feel more understanding and more educated about your journey. To learn more about how to tell others about your diagnosis, go to [alz.org/help-support/i-have-alz/know-what-to-expect/sharing-your-diagnosis](https://www.alz.org/help-support/i-have-alz/know-what-to-expect/sharing-your-diagnosis); and for more information on how to cope with stigma, go to [alz.org/help-support/i-have-alz/overcoming-stigma](https://www.alz.org/help-support/i-have-alz/overcoming-stigma).

■ **Coping with apathy**

Apathy is defined as a lack of feeling, interest, concern or motivation. While apathy is sometimes a symptom

of depression, it can also exist on its own. Not everyone with MCI will experience apathy, but it is a very common symptom. Many of the coping strategies included in this guide may help to combat apathy (and depression), but if your symptoms become serious or persistent, you should discuss them with your doctor; there are medications that may help. You can find great information about apathy from the Alzheimer's Society of the UK: [alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/apathy](https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/apathy).

- **Be intentional in living well and fully**

It takes a bit of thought and planning to implement the ideas you create for living a full, meaningful life. But, the benefits can be life changing. Some people with MCI report that their lives have become richer after their diagnosis because they've pursued things that they enjoy; things that enrich their lives and give them a new sense of purpose and meaning. The Alzheimer's Association has an interactive tool (livewell.alz.org/live-healthy-module) which helps you create a plan for doing the following:

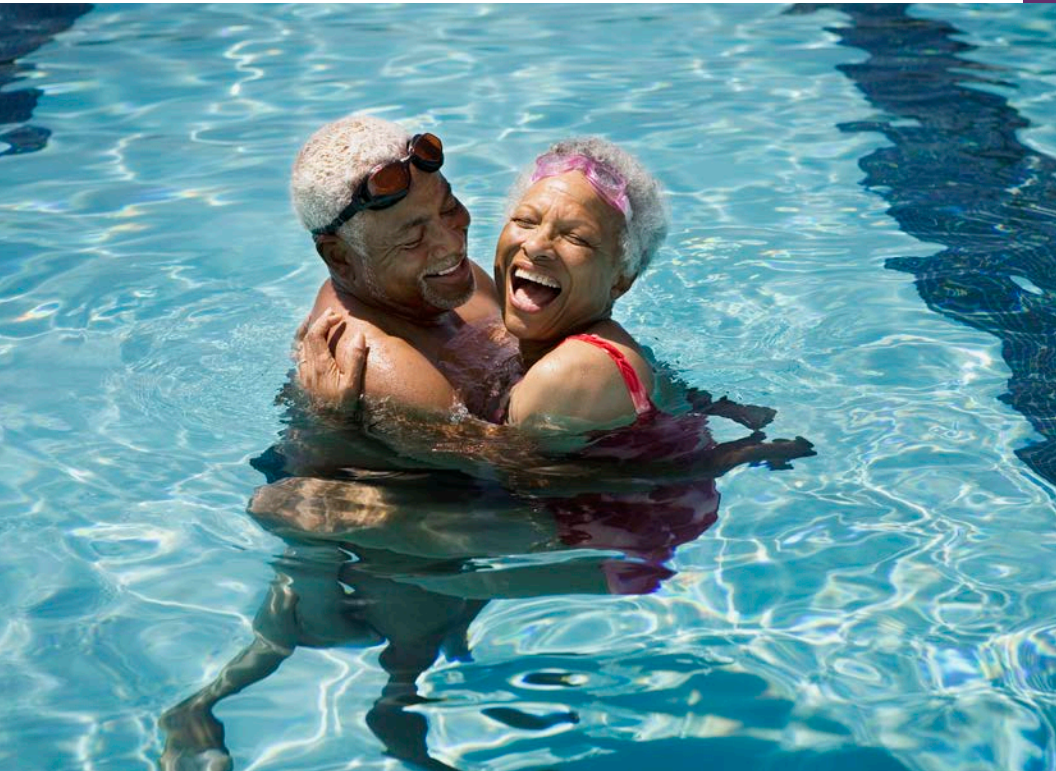


- › Challenge yourself. Do cognitive and physical exercises regularly, set goals, take a class.
- › Create healthy habits. Set an exercise schedule, create a healthy diet plan, get adequate sleep.
- › Stay connected. Build a support team, stay socially engaged with others.
- › Express yourself. Practice asking for and accepting help when needed, keep a journal, attend a support group.
- › Nourish your soul. Connect with nature, meditate, exercise your spirituality.
- › Find your purpose. Mentor someone, volunteer, try new hobbies, become an advocate.

Additional ideas:

- Attend workshops and educational programs (like Olli, Emory's excellent continuing education program for adults: ece.emory.edu/olli).
- Create art, or go to a museum to experience art.
- Go for a walk, or hike in a beautiful place.
- Dance: take a class, or dance at home or at a venue.
- Listen to music you love.
- Laugh! Watch a comedian, see a comedy, read something funny.
- Attend live performances of art forms you love—concerts, theater, ballet.
- Reconnect with old friends.
- Join a group (e.g. book club, walking group—many can be found at MeetUp.com).

- Swim at your local YMCA or in nature.
- Write or record your life story.
- Get involved with places of worship.
- Volunteer:
 - Become a mentor for other people with MCI or memory loss.
 - Support military personnel, veterans and their families through Soldier's Angels: soldiersangels.org/programs.html.
 - Become an advocate. The Alzheimer's Association has a great advocacy program.
 - For more opportunities, visit empowerline.org/volunteer/ or volunteermatch.org.





Good Days and Bad Days

Almost everyone with MCI reports that they have “good days and bad days.” Some days can be so good that you might begin to doubt the doctor’s diagnosis. You’ll also likely have days when your cognitive abilities are worse than usual. Just remember that this fluctuation is normal. Many factors may be contributing to the change—your stress level, how much sleep you’re getting, your diet—and sometimes it happens for reasons we don’t yet understand. When you’re having a bad day, here are some things you can do:

- Simplify your schedule for the day.
- Talk to a friend or loved one about how you’re feeling.
- Try to avoid negative “self-talk,” such as “I should be able to remember that. I’m stupid!” Instead, think “This is normal, and tomorrow will be better.”
- Pay special attention to healthy habits: exercise, stay hydrated, get adequate sleep.
- Do something you especially enjoy—get out into nature, go to a movie, listen to music that you love.

Medication Management

Some people with MCI have trouble keeping track of their medications, so it’s a good idea to set up a medication management system. Even if this isn’t a problem for you now, it’s wise to start using a system and get accustomed to it before you actually begin to have difficulty. For ideas beyond using a simple pillbox marked with days of the week, see Section V: Technology.



Section IV: How Will My MCI Affect My Care Partner?

Although there are similarities, caring for a person with MCI is different from caring for a person with dementia, so the term “care partner” is often used instead of “caregiver.” The care partner has his or her own journey to navigate.

The experience of being a care partner for someone with MCI can be very different depending on the relationship between the care partner and the person with MCI. For example, a care partner who’s an adult child may be dealing with issues around role reversal, or the “sandwich generation” challenges of raising children and supporting a parent. Although there is overlap, spousal care partners face a different array of issues: how do the changes my partner is experiencing affect our relationship? How do they affect my identity and my day-to-day life?

We asked people who have been care partners of people who’ve had MCI for at least a year for suggestions for those just starting on the journey. Their specific suggestions for care partners include:

- Learn all you can about MCI (see Section I of this booklet, including the links listed).
- Find out what resources are available to you. This includes research studies you and your loved one might be eligible for; go to the ClinicalTrials.gov website and enter mild cognitive impairment in the search box. Support groups and social engagement programs can also be extremely helpful. For more information see: alz.org/help-support/i-have-alz/programs-support and alzheimers.emory.edu/patients-caregivers/i-have-alzheimers/finding_support.html
- Develop a support team, and learn how to ask for help. Note: there are several free, online resources to help you put a team together and post requests for help. LotsaHelpingHands (lotsahelpinghands.com) lets you create a calendar where everyone can keep track of who’s helping, when and with what. The system will also send reminders automatically so nothing gets forgotten.

- Hope for stability, but plan for progression: don't put off your advance planning. Make sure your legal and financial affairs are in order and create a "Plan B" just in case you're no longer able to provide care. Consider meeting with an elder law attorney and a financial advisor, especially if you have a complicated estate or family situation.
- Learn more about strategies for how to help your loved one deal with changes and become an empowered care partner: alz.org/help-support/caregiving/stages-behaviors/early-stage.
- Learn about what to do if your loved one experiences apathy: alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/apathy or depression: alz.org/help-support/caregiving/stages-behaviors/depression.
- Learn more about the process of accepting the diagnosis for both yourself and your loved one: alz.org/help-support/caregiving/stages-behaviors/accepting_the_diagnosis. Keep in mind that for some people, the effects of MCI on the brain make it difficult to recognize their impairments. This is called anosognosia, and it is different from denial. For more on anosognosia, see Section X of this booklet.
- Don't ignore your own emotional needs and overall health. Plan ways to practice self-care. More information on how to do this here: alz.org/help-support/caregiving/caregiver-health and here: caregiver.org/taking-care-you-self-care-family-caregivers.
- It's okay to laugh. In fact, it's important.
- Look for joy in the moment, and try not to lose sight of the positive things in your life.

Other suggestions:

- Minor day-to-day changes in your loved one's abilities are normal and expected, but it's important to know that if you see drastic changes in cognitive abilities, mood or behavior over the course of a few hours or days, it might be caused by a physical problem or condition. When this happens, it's referred to as delirium. Delirium can be caused by infections

(urinary tract infections, pneumonia), medications, severe or chronic illness, changes in metabolic balance (such as low sodium), surgery, or alcohol/drug intoxication or withdrawal. The symptoms of delirium vary. Some people become agitated and restless, and some are more lethargic and drowsy—but they are often disoriented, distracted and have declines in memory and speech. If you suspect your loved one may have delirium, it is critical to have them evaluated by a healthcare professional. Failure to do so could lead to long-term consequences. To be prepared, visit this excellent resource from the Mayo Clinic: [mayoclinic.org/diseasesconditions/delirium/symptoms-causes/syc-20371386](https://www.mayoclinic.org/diseasesconditions/delirium/symptoms-causes/syc-20371386).

- Track your stress. Sometimes even the regular practice of self-care may not be enough to counteract the stressors that often accompany being a care partner. Caregiver stress checklists like this, [alz.org/national/documents/brochure_caregiver_stress_checklist.pdf](https://www.alz.org/national/documents/brochure_caregiver_stress_checklist.pdf), can be helpful. Talk to your doctor if you are experiencing any of the symptoms listed.

The following are some additional helpful resources. Some of these will refer to early stage dementia or Alzheimer's because there aren't as many resources available specific to MCI. Try not to be put off by the terms; most of the information designed for people affected by early stage dementia will apply to your situation.

- › Website: [alz.org/help-support/caregiving](https://www.alz.org/help-support/caregiving)
- › For care partners who are still working: [aarp.org/caregiving/life-balance/info-2017/work-benefits-rights.html?intcmp=AE-CAR-CLB-R2-C1](https://www.aarp.org/caregiving/life-balance/info-2017/work-benefits-rights.html?intcmp=AE-CAR-CLB-R2-C1)
- › The Caregiver Family Alliance website has a wealth of information: [caregiver.org](https://www.caregiver.org)
- › Book: *Take Your Oxygen First: Protecting Your Health and Happiness While Caring for a Loved One with Memory Loss* by Leeza Gibbons
- › Book: *Loving Someone Who Has Dementia: How to Find Hope while Coping with Stress and Grief* by Pauline Boss



The Power of Positivity for Caregivers

1. Recognize a positive event each day
2. Savor that positive event and log it in a journal or tell someone about it
3. Start a daily gratitude journal
4. List a personal strength each day and note how you used this strength recently
5. Set an attainable goal each day and note your progress
6. Report a relatively minor stressor each day, then list ways in which the event can be positively reappraised or reframed
7. Understand that small acts of kindness can have a big impact on positive emotion—practice a small act of kindness each day
8. Practice mindfulness through paying attention to daily experiences and with a daily 10-minute breathing exercise, concentrating on the breath

Judith T. Moskowitz, Elaine O. Cheung, Karin Snowberg, Alice Verstaen, Jennifer Merrilees, John M. Salsman, and Glenna A. Dowling (2019). Randomized controlled trial of a facilitated online positive emotional regulation intervention for dementia caregivers, Health Psychology, 38(5):391-402.



Section V: How Do I Plan for the Future?

Most people with MCI and their care partners begin to look at the future in a new light when they receive the diagnosis. A good rule of thumb is that while we hope that your cognitive abilities stay stable, and we do everything we can to promote this, it's a good idea to prepare for the possibility that they might get worse. Many of the things we do to prepare are helpful and important even if progression doesn't happen.

Because none of us—with or without a diagnosis—really knows what the future holds, we should *all* make sure that we have our affairs in order. This includes having advance directives in place, making sure powers of attorney and wills are valid and up to date, and making sure that a designated person knows where to find your documents and other important information. Again, getting a diagnosis like MCI can be an opportunity to think ahead and take action now, when the person with MCI can actively participate in the planning. People often say that doing so gives them great peace of mind. The National Institute on Aging has a great website on advance planning: nia.nih.gov/health/caregiving/advance-care-planning; and the Alzheimer's Association has a section of their website devoted to it: alz.org/help-support/caregiving/financial-legal-planning.

Here are some specific things to consider:

- **Advance Directive for Health Care**

It's important to have a person designated to make health care decisions for you if you are unable to do so. In Georgia, the document for this is called the Georgia Advance Directive for Healthcare, and it also includes a living will. The printable document can be found online here: aging.georgia.gov/sites/aging.georgia.gov/files/GEORGIA%20ADVANCE%20DIRECTIVE%20FOR%20HEALTH%20CARE-2016.pdf. You don't need a lawyer to execute this document, nor does it have to be notarized; all you need is two witnesses. The instructions for filling out the document are included on the website. *Note:* Advance Directives and

other legal documents are often state-specific. If you have documents from another state, you should check with your lawyer to see if they need to be executed again in Georgia.

- **Powers of attorney, wills and other legal documents**

If you don't already have these in place, an attorney who specializes in elder law can help you decide what you need, and help to create and complete the documents. With an eye towards planning for the future, an elder law attorney can also help you make decisions about how to manage your assets and property—for example, whether a living trust might be a good option for you. They can also advise you about long-term care services, including what is provided by Medicare, Medicaid, veterans' benefits and other long-term care insurance.

- **Having “The Conversation” with family**

There is a program called The Conversation Project (theconversationproject.org) which encourages everyone to share their wishes for end-of-life care with loved ones. It's estimated that only about a third of us have had such a conversation, but those who have often report that it was a bonding experience which brought the participants closer together. In this conversation, people also talk about planning for different situations: what would we do if the person who is providing care became ill or unable to continue as a caregiver? What are our options?

- **Make a list of your important documents and where to find them**

A great template for putting this information into a single worksheet can be found here: alz.org/media/Documents/worksheet-financial-legal.pdf.

- **Finances**

Because people with MCI frequently have difficulty with managing finances, it may be wise to discuss the possibility of shifting responsibilities for or co-managing finances.



- **Driving**

For most of us, driving means not only independence, but freedom and control. The thought of possibly having to stop driving is deeply personal and emotional. The challenge for people with cognitive impairment is balancing the desire to be independent with making sure that you and others on the road are safe.

Being diagnosed with MCI does not necessarily mean you're unable to drive safely. But, because it's a part of everyday life, we forget that driving is a very complex task. It requires that different regions of your brain cooperate to receive and prioritize information, anticipate what might happen next, analyze options, plan ahead and use proper judgment. Depending on your symptoms, one or more of these functions may be impaired or become more impaired in the future. It's important to note that if you have a diagnosis of cognitive impairment and cause an accident, it's possible that you could be subject to a higher degree of liability. You may also want to check your auto insurance to see if there's any fine print about the policy being voided if you are diagnosed with cognitive impairment; while this is fairly rare, some policies do include it.

If you're currently able to drive safely, great. But, in the spirit of hoping for the best and planning for progression, it's a good idea to talk openly about the possibility that you may not be able to drive safely in the future and how that feels. Have discussions with loved ones about how you might come to an agreement on when it's time to stop driving—including, possibly, a formal assessment. There are several programs available in Georgia. You should also discuss ideas for alternative transportation and other contingency plans in case you need to stop driving.

A great guide from AARP/The Hartford, specifically designed for people with memory loss and their families, which will help you have these difficult conversations and make decisions can be found here: s0.hfdstatic.com/sites/the_hartford/files/at-the-crossroads-2012.pdf.

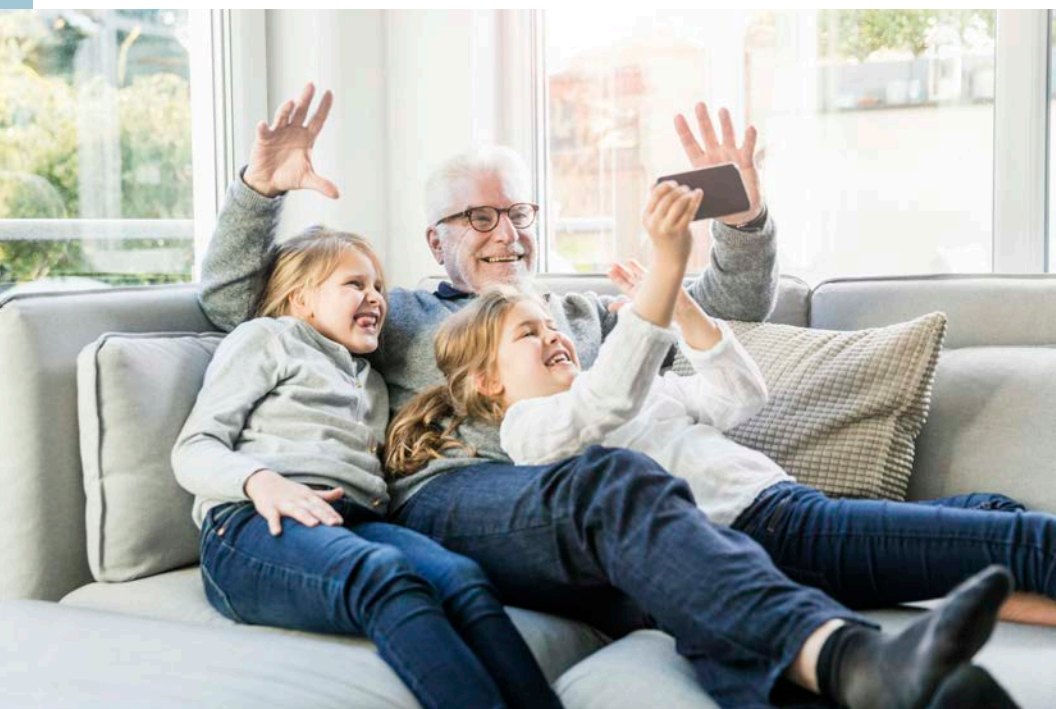
- **Planning appointments with your doctor and other care providers**

In planning for the future, it's important to schedule regular follow-up appointments with your doctor. Preparing for the visits can make them more productive. Here are some tips:

1. Plan ahead. Write down questions and concerns beforehand and bring the list to your appointment.
2. Bring your care partner or a friend/family member with you, someone who can help report on your symptoms and remember the information given to you during the appointment.
3. Be aware of any restrictions, like needing to fast for blood work.
4. Bring medications in their containers or a complete list (including dosages) with you to each appointment.
5. Give details. Make notes about changes in symptoms, routines or eating habits. Be as specific as you can. When does it happen? How often? Does something seem to trigger it?

6. Ask questions. Your doctor is an important source of support and information. If you don't understand something, ask questions until you do.
7. Leave with a plan. At the end of your appointment, ask the doctor to summarize the most important points. Write them down. Note any changes to your treatment plan and any follow-up steps needed (such as scheduling the next appointment or having tests done).
8. Keep good records. After each appointment, make sure to update your records with any test results or changes to medications or care plans. It's important to keep a personal health record so care can be coordinated between doctors and information is available in an emergency. There are many ways to organize and store personal health information, including online services that make it possible to retrieve records at any time.

Many experienced care partners report that in preparing for the future, it is very helpful to be educated about MCI, its possible symptoms and how it might progress. It's important to understand that while it doesn't happen with everyone, some people with MCI may eventually experience behavioral changes and emotional distress. Care partners should recognize that these changes are often a natural result of what their loved one is going through. Identifying triggers for the behavior changes can help the care partner and the person with MCI deal with them. There are many great resources for care partners on learning how to deal with these changes, cope with stress and adjust to changing roles (see section IV). Support groups for care partners and for people with MCI can also be very useful.



Section VI: How Can Technology Be Helpful?

There are many technologies that can help with things like keeping up with appointments and medications, and helping in emergency situations. While some people may resist using technology because they think it is scary or intimidating, there are many solutions that are designed to be simple to use. Since everyone is unique, and may find some tasks more difficult than others, you and your care partner should discuss which technologies will help you most.

Remembering Future Tasks

Future tasks, such as doctor visits, appointments, birthdays and remembering to take medication can be challenging without a reminder system. Scheduling appointments on a shared calendar (for example, a Google calendar on your phone or computer) can help you and your care partner keep track of important dates. For daily chores, such as walking the dog, families can rely on a shared whiteboard with handwritten reminders for the tasks of the day (zapier.com/blog/best-online-whiteboard). For reoccurring reminders, such as remembering to take medications at certain times of the day, electronic clocks such as the American Lifetime Day Clock (americanlifetime.com) can be a useful device. This clock is simple to set up, has a large screen for easy reading, has multiple reminders, and can help you keep track of the time and day.

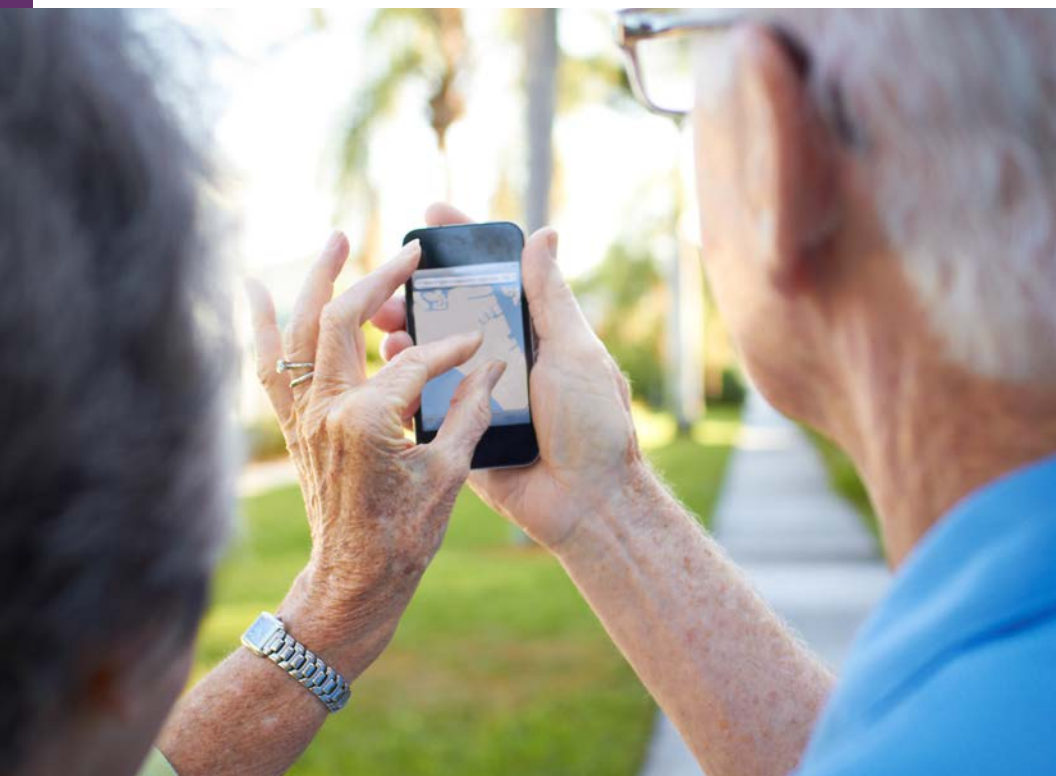
Safety

A Personal Emergency Response System (PERS) can give the peace of mind to you and your care partner that if there is an emergency, such as falling down, help can be quickly available. Depending on your specific safety concerns, PERS can be used inside or outside of the home. In-home PERS can include motion detectors, voice-activated emergency services, etc. For active individuals, mobile PERS (mPERS) look and function as a watch, but also include activity tracking, fall detection, and an

emergency button or two-way voice communication for those who want some level of security while outside the home. The mPERS device design offers the advantage of not looking like an emergency response system (for those who prefer a discrete system). The MobileHelp Smart by Samsung is an example of an mPERS: mobilehelp.com/pages/smart.

Medication Tracking

There are many options for keeping up with medications. From low-cost, low-tech medication boxes to apps for a smartphone to more advanced options which are adjustable to the individual's needs. For example, some have lights, sounds or both for people who need visual and auditory cues, which can be helpful for individuals who are hearing or vision-impaired or reminder-based for those who are forgetful. More advanced systems may allow one to load a week or more worth of pills, alert when it is time to take a dose, and dispense the dose.



Driving

GPS systems (e.g. Google Maps) can help with wayfinding when driving or walking. When used properly and safely, they can help prevent getting lost. You should always enter the destination before beginning to drive to avoid getting distracted while driving. The voice navigation can reduce the need to take your eyes off the road to figure out the next turn. If entering the address into the GPS is hard, you and your care partner can choose the most common places you go, and program it so you select the name of the destination instead of having to enter an address each time. Apps for your smartphone, like Life360, can help in tracking where family members are and alert others in the family's trusted circle when they arrive at locations or alert 911, if a crash occurs.

Social Communication

Smartphones may seem intimidating, but if you give them a chance, they might help you manage reminders, store a trusted circle of friends to call, and see photos from grandkids or other loved ones. Preprogramming phones with numbers and names for frequent contacts can make it easier to sustain social connections. Simple smart phones, like those from Jitterbug, greatcall.com and others, make it easier to store important contacts and their information. Some of these phones even come with a help button that directly calls a representative who can help you through the setup process. Most mobile phones allow you to add a photo for individual contacts making it easier to recognize the identity of an incoming call. Video calling features such as FaceTime on the iPhone can add to the richness of social connections and provide family members visual insights into the well-being of a person living alone.

- › *Digital Social Assistants:* Relatively new are in-home digital social assistants, such as Alexa on the Amazon Echo and EchoDot. By recognizing voice commands, these assistants can answer questions, place phone calls to known contacts, and help record and provide reminders for daily activities.

- › *Apps*: Smartphones allow you to use applications—called apps for short—to get information like weather or news. Some apps may help you with relaxation exercises or allow you to play a list of songs that get you moving to the beat.

Smart Home Technologies

Sensors in the home can help family members keep track of unusual activity in the home, improve safety, and find lost objects. Motion sensors, often used for detecting motion by a security system, can also be used to detect when someone wakes up or when they are in a particular room, like the kitchen. Door sensors can help determine when a particular door, such as the front door or garage door, is opened. There are sensors called “smart plugs” that can monitor and send notifications for the use of electrical appliances, such as the television, microwave or desk lamp. These technologies can help a remote family member notice regular or concerning activity in the home. Other sensors can notify when a kitchen appliance such as an oven has been left on, or detect water on the floor or water left running. For safety, smart doorbells can remotely lock and unlock home entrances and display a video of someone ringing the doorbell or leaving a package at the door, like Ring at [ring.com](https://www.ring.com). Finally, there are tags that can help a person find frequently misplaced objects, such as keys and TV remotes, even when out and about. One example are Tiles (from [thetileapp.com](https://www.thetileapp.com)). Digital Social Assistants (mentioned earlier) can allow voice control of smart plugs, smart thermostats, smart light switches or bulbs, or even smart locks and blinds.

Activity and Sleep Tracking

Activity trackers can be a great way to gain a better understanding of how often you move and what your sleep patterns look like. Studies have shown that individuals are typically bad at estimating activity level. An activity tracker can help you see how often you’re actually active and allow you to set goals (for example, 10,000 steps per day or 250 steps per hour). Many activity trackers also track sleep stages which

can help you see triggers that lead to poor sleep quality. More movement and better sleep habits can help you stay healthier overall.

Technology is always changing. One resource is the technology review by alzheimers.net: alzheimers.net/technology. You and your care partner can talk about which of these technologies might be helpful for your specific needs. The biggest benefit of these, and many other technologies, is they can help to reduce the cognitive burden you are trying to manage.



My Action Plan

Action	Resources needed/ steps to take	Completed?
Educate yourself about your condition		
Start building your support team—identify potential team members and reach out to them		
Make a plan for healthy diet changes		
Make an exercise plan (consult your doctor if you have concerns about your limitations)		
Tackle your advance planning/legal and financial issues		
Consider talking to family and friends about your wishes for the future		
Develop a healthy sleep routine		
Identify your challenges and list steps for how to compensate for them		
Identify stressors and list steps for dealing with them		

Section VII: Your Action Plan

People who receive a diagnosis of MCI and their families have a wide variety of reactions to the diagnosis. Some people feel overwhelmed and need some time to adjust to and fully accept the diagnosis. Others want to dive in and find out all they can about MCI and start taking action immediately. Most people fall somewhere in between. There's no one-size-fits-all plan.

No matter where you fall on this spectrum, here's a list of action items for you to consider:

- › Educate yourself about your condition.
- › Start building your support team—identify potential team members and reach out to them.
- › Make a plan for healthy diet changes.
- › Make an exercise plan (consult your doctor if you have concerns about your limitations).
- › Tackle your advance planning/legal and financial issues.
- › Consider talking to family and friends about your wishes for the future.
- › Develop a healthy sleep routine.
- › Identify your challenges and list steps for how to compensate for them.
- › Identify stressors and list steps for dealing with them.
- › Begin the process of living fully, with purpose and meaning—identify things that nourish and fulfill you, and make a plan for how to make those things happen.

From the list above, identify the first three action items you'd like to get started on. That's a great first step. Use the tool on the left page to help you move forward with your action plan.



Section VIII: Books, Websites and Other Resources

Web-based

- The Family Caregiver Alliance is a great source of information and resources for care partners: caregiver.org. It also has some material for people with the diagnosis in the MCI section.
- The Alzheimer’s Association website has a very robust section especially for people with memory loss. Although the title of this section is “I Have Alzheimer’s,” don’t be put off. It’s designed for people with early memory loss, including MCI, and the information is very pertinent: alz.org/help-support/i-have-alz. They also have a wealth of information for caregivers, including online classes on topics like communication, driving, and legal and financial planning: training.alz.org as well as message boards where care partners and people with a diagnosis can connect with each other: alzconnected.org.
- Blog: blog.alz.org/tag/mci.
- Message Board: alzconnected.org.
- Virtual library: alz.org/help-support/resources/virtual_library
The Green-Field Library is “the nation’s oldest and foremost library and resource center devoted to increasing knowledge about Alzheimer’s disease and other dementias”—including information about MCI. You can email a librarian for information on any related topic, and they will offer suggestions, send you links to online articles, or—if you want a physical book—they can use the Interlibrary Loan system to get it to your local library.
- LotsaHelpingHands (lotsahelpinghands.com) is a website that helps you create a support team, ask for assistance with specific tasks, and create a calendar where everyone can keep track of who’s helping, when and with what. The system will also send reminders automatically, so nothing gets forgotten.

Books

Mild Cognitive Impairment and Dementia: Definitions, Diagnosis, and Treatment by Glenn E. Smith and Mark W. Bondi is for people who want a detailed, clinical look at MCI and dementia.

Living Your Best with Early Stage Alzheimer's is a great resource for people with early memory loss and is applicable for people with MCI.

Mentioned earlier, *Take Your Oxygen First: Protecting Your Health and Happiness While Caring for a Loved One with Memory Loss* by Leeza Gibbons details how important it is for care partners to practice self-care.

The 36-Hour Day is one of the best-known books about Alzheimer's. Now in its 6th edition, it is best used as a reference guide rather than a book to be read from cover to cover. Some care partners of people with MCI like to have it on hand in case their loved one progresses.

A Caregiver's Guide to Dementia: Using Activities and Other Strategies to Prevent, Reduce, and Manage Behavioral Symptoms by Laura N. Gitlin & Catherine Verrier Piersol. Although it is designed primarily for caregivers of people with dementia, this down-to-earth guide will introduce you to some important caregiving skills.

The Alzheimer's Action Plan: What You Need to Know—and What You Can Do—About Memory Problems, from Prevention to Early Intervention and Care by P. Murali Doraiswamy, MD, Lisa P. Gwyther, MSW, Tina Adler. This book includes a lot of practical tips intended to enable caregivers and people with memory loss to live their best possible lives.

Before I Forget: Love, Hope, Help, and Acceptance in Our Fight Against Alzheimer's by B. Smith and Dan Gasby. A memoir.

Other

Your local Area Agency on Aging (AAA) can tell you about the community-based services you might be eligible for. Find your AAA here: eldercare.acl.gov/Public/Index.aspx.

Section IX: References

We are grateful to the following for contributing to the content in this guide:

- › AARP/The Hartford
- › Alzheimer's Association
- › Alzheimer's Society (UK)
- › American Association of Neurology
- › The Conversation Project
- › Emory University
- › Family Caregiver Alliance
- › Food and Drug Administration
- › Georgia Institute of Technology
- › Mayo Clinic
- › National Institute on Aging
- › Judith T. Moskowitz, Elaine O. Cheung, Karin Snowberg, Alice Verstaen, Jennifer Merrilees, John M. Salsman, and Glenna A. Dowling (2019). *Randomized controlled trial of a facilitated online positive emotional regulation intervention for dementia caregivers*, *Health Psychology*, 38(5):391-402.
- › Birju B. Patel, MD, FACP, N. Wilson Holland, MD, FACP (2012). *Mild cognitive impairment: Hope for stability, plan for progression*. *Cleveland Clinic Journal of Medicine*. 2012 December;79(12):857-864



Section X: The More You Know: Additional Information

Anosognosia—Sometimes when a person seems persistently in denial about his or her cognitive impairment, it might be more than just denial—it might be a condition called anosognosia: the inability to recognize one’s own illness or impairments as a result of physiological changes to the brain. A person with anosognosia lacks awareness and insight into the realities of his or her condition. Other symptoms of anosognosia can include an increase in depressive symptoms and behavioral changes, including a decline in performing daily tasks such as personal hygiene. However, anosognosia symptoms vary from person to person and can change over time.

Tips for care partners whose loved ones have anosognosia include:

- Work with your health care professionals to help you identify, understand and deal with the condition.
- Don’t try to convince the person that they are impaired.
- Anticipate potential safety issues and make changes as needed. Present the changes in a positive way: for example, taking things off the person’s plate/reducing their burden.
- Ask for assistance from your support team when faced with difficult situations.

Cerebrospinal fluid (CSF)—a clear fluid that surrounds the brain and spinal cord. It cushions the brain and spinal cord from injury and also serves as a nutrient delivery and waste removal system for the brain. Thus, CSF is sometimes collected via a lumbar puncture (“spinal tap”) to check for the tau and amyloid proteins that form the plaques and tangles seen in the brains of people with Alzheimer’s disease.

Cognition and cognitive decline—Cognition refers to the process of thinking. It is the mental action or process of

acquiring knowledge and understanding through thought, experience and the senses. Cognitive decline refers to a decrease in a person's ability to:

- think
- use language
- remember
- reason
- solve problems
- make decisions
- interpret visual information

Functional decline—a new loss of independence in a person's capabilities. It is typically associated with deterioration in mobility and/or in the performance of activities of daily living (ADLs) such as dressing, toileting and bathing; but can also refer to a decline in the ability to do more complex tasks like managing finances, shopping or driving (also called instrumental activities of daily living or IADLs).

Neuropsychological testing—The purpose of neuropsychological testing is to examine a person's cognitive and behavioral functioning to assist with the diagnosis and treatment of individuals with brain dysfunction. Abilities that are commonly tested include:

Intellectual Functioning

Attention and Processing Speed

Sensory and Motor Function

Visuospatial Skills

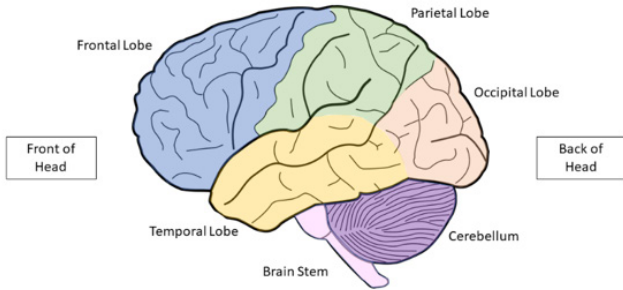
Language

Memory

Emotional Functioning

Executive Functioning (e.g., problem solving)

Brain Diagram and Information



Frontal Lobe: The frontal lobe is responsible for judgment, planning, organization, inhibition, emotional regulation and our ability to understand social situations. Not surprisingly, this lobe also houses areas critical to our personality functioning as well as our ability to initiate movement and speech.

Temporal Lobe: The temporal lobe is involved in processing auditory information and is critical to our ability to understand and produce language. This part of the brain also houses many of our primary memory structures, including the hippocampus, and has a role in our basic emotional responses.

Parietal Lobe: This part of our brain receives and interprets touch-related sensory information and is important to our ability to make controlled body movements (e.g, when grabbing an object), engage in mental imagery and understand spatial relationships between objects in our physical environment.

Occipital Lobe: The occipital lobe is all about vision! Each region in this lobe has a “job” to aid in perceiving visual information.

Cerebellum: The cerebellum is responsible for our ability to make smooth, coordinated movements. It has been found to play a role in coordinating our cognitive processes as well.

Brain Stem: There are multiple structures within the brain stem, but they generally focus on key survival functions, like maintaining our heart rate, breathing, sleep and wakefulness.

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