CAREGIVING TIPS

Early Memory Loss - Help and Hope

The following information was adapted from an article by Jan Phillips, an individual with early-onset dementia. It is intended as a guide and source of help and hope to those newly diagnosed with Mild Cognitive Impairment (MCI), Alzheimer’s disease, or a related memory disorder.

You may have been wondering and anxious about changes that have been occurring, changes that others may not have noticed.

Being diagnosed with MCI or early dementia is upsetting. However, for some who have been worrying about themselves, the diagnosis can come as a relief. They know that something is not right, and having a diagnosis can be helpful. It often helps the person cope with the present and plan for the future.

It’s Important to Know That

You are still the same person:

• The changes you are experiencing are because of changes in the brain, they are not your fault.
• Each person is affected differently and symptoms will vary.
• This is an illness that was not acquired by any action or inaction on your part.
• You will have good and bad days.
• You are not alone. There are people who understand what you are going through and can help.
• Accept help when it is offered, ask for help when you need it.
• There are ways to help yourself – call Alzheimer’s Mississippi, join an Early Memory Loss support group, connect with peers through community activities. Don’t be afraid to continue to learn - challenge yourself. Many resources are available to provide you with the positive support you need.

Feelings

You may feel angry, frustrated or upset about the changes in your life, and even guilty at the thought of becoming a burden. Talking about these feelings and concerns with trusted family members or friends may help. Alzheimer’s Mississippi also has Family Care Consultants and services tailored specifically to your needs. Call 877.930.6190 for more information.
**Seeking Support**

Many people are not ready to seek support. Sometimes they feel overwhelmed by the diagnosis, or not well enough to socialize or talk to others. Apathy and social withdrawal are common and may be experienced early on in the disease. Understanding this may encourage you to embrace help and reach out to others. Sometimes in sharing with others you may find that you are put on the defensive, in a position of having your diagnosis challenged and discounted by well-intentioned people. You may encounter comments such as, “You don’t look like you have Alzheimer’s (dementia)” or, “Oh, that always happens to me”. You must not take it as a personal affront or discounting of your diagnosis; most are simply trying to support you as best they know how. Unfortunately, most of society is uneducated about MCI or early dementia and have a stereotypical image of someone with dementia as being very old and frail in appearance and severely cognitively impaired.

You may find that a support group of others recently diagnosed with MCI or dementia may help you not to feel so isolated in these feelings. They may be experiencing many of the same insensitivities.

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**Focus on Your Abilities**

There is a lot that you can do to make your life easier. Here are some ideas shared by other people with early memory loss.

- **Find out about your diagnosis**
  You have a right to know about and understand your diagnosis. Empower yourself with knowledge so that you can be an integral part of your own care.

- **Seek specialized help**
  Not every doctor is familiar with the unique challenges facing the MCI or dementia patient. Find someone who specializes in dementia care to help you deal with your diagnosis, emotions, changing family dynamics, and coping strategies.

- **Get support**
  We all need extra help at some point in our lives – don’t be afraid to ask for support. Think about joining a group of other people with dementia, either in your community or on the Internet. “In an environment of our peers, we can be completely honest in our sharing without the need to try and hide the fact that we have dementia.”

- **Prioritize**
  Don’t try to resolve all your problems or make all your decisions at once.
• **Become attuned to yourself**
  Try and make your life as stress free as possible. Be aware of noisy malls and restaurants; they may cause extra agitation, decisions may be harder to make, and you may be easily sidetracked.

• **Simplify**
  Try to eliminate the unnecessary clutter in your life, be it material things, or thoughts and worry over things that are not in your control.

• **Regular Routine**
  Try and keep a routine in your life. Doing things in the same order, and putting things away in the same place each time can help.

• **Inform others**
  Explain what you know about your diagnosis; it will help other people to understand what you are going through.

• **Talking Helps**
  If you can, talk to your friends and family about your concerns and worries. Keep in touch with people who are supportive and helpful. Don’t bottle things up. “If you keep it in too long, at some point, you implode!”

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**Everyday Suggestions that May Help**

**Take a break if something is too difficult. Allow yourself a lot of time and don’t let others hurry you.**

• Carry a notepad of paper with you. Write down important things that you want to remember. This might include appointments, people’s names, a list of things to do and any thoughts or ideas you may want to remember.

• Keep a calendar or weekly listing with the things that you want to do, and are scheduled to do – mark each day off at its conclusion. Or try keeping a large desk type calendar where all predicted events of the day are written. Make a habit of checking it each morning.

• Have a daily newspaper delivered; the day and date are always on the front page. Also you may want to look into purchasing a clock with the day and date displayed along with the time.

• Display prominently helpful numbers by the phone. Also include your own address and phone number, and major cross streets to your home. Should an emergency arise it will be there for your easy access.

• Buy a large weekly pill holder for your medications – it will allow you to easily see if you’ve missed a dose.
Communication

You may find that it is difficult to express yourself the way you used to. Not being able to find the right word to express your thoughts is not uncommon. You may also find that at times it is more difficult to understand what others are saying.

Try these hints:

- Take your time.
- Explain that you need a little time and patience.
- Ask a person to repeat a statement or question if you did not understand what they said.
- Often times you may lose your train of thought because of outside disturbances (traffic, phone, loud noises, other conversations, etc.). Don’t be afraid to ask your conversation partner to help you get back on track.
- If you forget a thought, its okay, continue on, and it may come back. Try not to get frustrated when this happens. Relax, slow down a little and it may get easier.
- Oftentimes, too much stimuli - both physical and audible input to your senses can become overwhelming. Try to reduce distractions by finding a quiet place to converse, away from TV’s, radios, and loud talk.

Your Safety

The gradual loss of memory and the difficulties with decision-making and communication often raise concerns about your safety. Here are a few suggestions:

- Make a card that you carry with you at all times. It should include:
  - Your name
  - Your complete address
  - Your home phone number
  - An emergency contact: name/phone number/address
  - Medications you are taking and the dosage
  - Your physician, and any other doctors whose care you are under (name, phone number, address)
- Write reminders to yourself to lock the door at night or put the trash out on a certain day.
- Put a note on the front door to remind you to take your keys with you.
- Install devices such as gas detectors and smoke alarms.
- Carry a small timer with you. Set it when you turn the stove on, or turn the water on. Even if you walk away from your task and get sidetracked, carrying the timer in your pocket will help to remind you.
- Wear a “fanny pack” instead of using a purse or wallet.
- Join MedicAlert®+Safe Return®, a bracelet identification program that identifies, locates and returns persons with dementia who have become lost in the community.
• Arrange for direct deposit of your checks such as retirement or Social Security benefits.
• Leave a set of extra house keys with a trusted neighbor.

Driving
At some point, your ability to make decisions and react quickly may be impaired by the disease affecting your brain. For your safety, the safety of others, and to avoid potential liability in case of an accident, it may be wise to discontinue driving. This is not always easy, as you may feel that you are losing your independence – this need not be the case. There are alternate forms of transportation that you may want to consider: perhaps having a friend or family member take over the job of driving; using public transportation such as buses or taxis. Some cities have transportation services that are no cost or at a nominal fee. You can check with your local city hall for information. AARP offers driver safety courses for drivers age 50 and over – find a location nearest you: [http://www.aarp.org/applications/VMISLocator/searchDspLocations.action](http://www.aarp.org/applications/VMISLocator/searchDspLocations.action)

Getting Lost
Should you find yourself alone and become confused and feel lost, the first thing you should do is try to remain calm, do not panic. You should be carrying with you a card with important phone numbers on it. Find the nearest restaurant or store, tell them you are confused as to your location, and ask them to help you call someone to assist you. People are generally always willing to help when you explain your dilemma.

It might be helpful for future reference when out shopping to remember when you get out of your car, before you move away from it, to find a point of reference – a landmark, to help you remember where you are parked. Before you enter the store, look back and locate your car visually – this will give you a clue as to what you will see when you leave. Also, always try to exit from the same door in which you entered.

Working
We all tend to comment on how we look forward to not working anymore and will enjoy retirement. That is certainly true for most of us. However, we all want it to be on our own terms and schedule. But Alzheimer’s changes the equation somewhat. By the time of the diagnosis, you may have already experienced problems with how you function at work. It can run the whole spectrum from forgetting schedules, to not understanding directions or routine tasks that you previously had no problem performing.
Therefore, sound decisions have to be made about your ability to continue working. There are issues of liability for yourself and your employer that must be considered, such as your ability to function in your current position and the safety of yourself and your co-workers. Seek out advice from your physician, your family, your employer and others who can help you to make the right decision.

**Working**

Receiving a diagnosis of Mild Cognitive Impairment, Alzheimer’s disease, or a related dementia can be overwhelming. By learning more about the changes ahead, one can take control and move forward. Alzheimer’s Mississippi has free programs that can educate, support, and provide tools to help cope with the present and plan for the future. Please call us to learn more at 877.930.6190.