



TAKING ACTION

A Personal and Practical Guide for
Persons with Mild Cognitive Impairment (MCI)
and Early Alzheimer's Disease

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Foreword

Those of you reading this Taking Action workbook have probably been told you have early Alzheimer's disease or a similar dementia. My name is Mike, and I've been in your shoes. Nearly three years ago I was diagnosed with Alzheimer's disease. I was shocked and very upset. Why Me? This can't be true! After giving it some time to set in I started accepting it. I told myself: "Ok, I have it. I'd rather not have it. I'm not going to change it. So what am I going to do about it?"

I knew I was finding an answer when a fellow at a meeting said, "The worst thing that could ever happen to me would be to have Alzheimer's!" I surprised myself saying before everyone, "It's not so bad once you have it. I do, and I've found there is life after Alzheimer's."

Not long after I started accepting it I found some relief. Knowing I have Alzheimer's made it okay to simply work around everything that wasn't operating right. My life became easier doing this. I found a new patience. Working with my limits put me into a different way of life. All I could do is concentrate on making the best of it. This is the key to tolerating your new way.

They tell us, "Eat right, exercise daily and use your thinking skills often." This is the best way to stay where you are right now. I truly believe this works. What works even better is your attitude. I decided early on: "If I gotta have this horrible disease, I want to make having it worth it!" I find I can by remaining in contact with folks, finding new friendships among those with the same disease I have, and getting active about sharing my experiences living with Alzheimer's.

Now I feel like I am making more of a contribution then when I was floundering about trying to figure out, "What's wrong with me?" I have gained a far greater sense of worth and fulfillment. With activity in Alzheimer's circles, I have learned there are lots of people out there working with their disease. One of the support groups was studied and it was found that folks participating in it were staying in their early stage longer because of the social, cognitive and creative activity with which they were involved in the group.

I firmly believe that the sooner we learn we have the disease, the better off we are. Knowing helps us get medicine to slow the deterioration. It gets us out of the isolation that seems to happen with this doggone disease. We can concentrate on doing what works for us. We also get the benefit of getting involved with other people and creative involvement making a difference.

Really, how better can it get? We can't go back. We can gain so much going forward. You've taken the first steps by getting in contact with the Alzheimer's Association. I encourage you to learn all you can about the disease, get active, and start living your best life with Alzheimer's today.

Sincerely,



Mike Donohue
Living with Alzheimer's disease

Knowing helps us...get out of the isolation that seems to happen with this doggone disease.

Mike Donohue

Introduction

Most of us who receive a diagnosis that greatly impacts our health and well being do not want to stand idly by and see what happens. Instead, we want to take action. When we know we are engaging in activities and doing things that can improve our situation, we naturally feel better and we are empowered. This workbook is based on the belief that we cannot let limitations interfere with what we still can do. Persons with early stage dementia can take charge of their own health and take steps to live their best.

This workbook is designed to be used by individuals living with Mild Cognitive Impairment (MCI) and early Alzheimer's disease or a related disorder. Think of it as a guide to help you in learning about the changes you are facing and steps you can take to help yourself.

People learn in different ways - either by reading, writing or talking to others. You may find the workbook a useful way to educate yourself and your family and friends. It can be used as a way to begin conversations about changes you are experiencing. Writing down important



ideas and information is a helpful memory aid. Written information can also be easily shared with others. You may experience new and different feelings associated with the diagnosis. This book may help you to identify and share those feelings with who mean the most to you.

This workbook can be used alone or with family members or friends. It is divided into 12 chapters that address common concerns and includes educational information and perspectives of people living with memory loss.

Congratulations on making the decision to Take Action!

[1]

Understanding Memory Loss

Aging, Memory Loss, Dementia, and Alzheimer's Disease: What's the Difference?



Normal Aging

We all know that many things change as we age. In normal aging, our bodies and brains slow down, though intelligence remains stable. We are less physically and mentally flexible, and we take more time to process information. Memory changes occur as well, and it's common to have greater difficulty remembering names of people, places and other things as we age.

Mild Cognitive Impairment (MCI)

In MCI, a person has problems with memory or another core brain function. These problems are severe enough to be noticeable to other people and show up on tests of mental function, but not serious enough to interfere significantly with daily life.

People with MCI have an increased risk of developing Alzheimer's disease in the near future, especially when their main symptom involves memory. However, not everyone diagnosed with MCI progresses to Alzheimer's or another type of dementia.

Dementia

Dementia is not a disease. It is a general term that describes a set of symptoms that may be caused by a number of different brain disorders. These symptoms involve mental decline severe enough to disrupt daily life that affect more than one of the following core brain functions:

- **Recent memory** — the ability to learn and recall information.
- **Language** — the ability to write or speak, or to understand written or spoken words.
- **Visuospatial Function** — the ability to understand and use symbols, maps and the ability to correctly judge where objects are.
- **Executive Function** — the ability to plan, reason, solve problems and focus on a task.

What lies behind us and what lies before us are
tiny matters compared to what lies within us.

Ralph Waldo Emerson

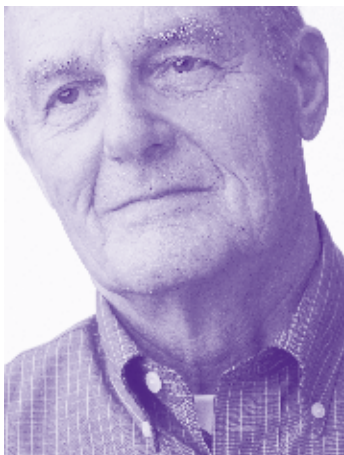
Alzheimer's Disease

Alzheimer's disease is the most common cause of dementia. It is a slow, progressive illness that damages nerve cells in the brain. Symptoms gradually get worse over time as more brain cells are destroyed. Though people can have Alzheimer's in their 30s, 40s, and 50s, the disease is most prevalent in people over age 65.

The first problem many people with Alzheimer's disease notice is forgetfulness severe enough to affect their work, hobbies, or social life. Other common symptoms include mood changes, difficulty multi-tasking, misplacing things, repeating things, confusion, trouble with organizing and expressing thoughts, and becoming disoriented or lost in familiar places. Although there is currently no cure, treatments are available and are most effective when the disease is identified early.

Getting a diagnosis is the first step towards understanding what's causing your symptoms and taking action to fight the disease. Treatment can only be started when the disease has been identified. A complete medical evaluation includes:

- **Physical Examination** includes the evaluation of a person's nutritional status, blood pressure, and pulse.
- **Medical History** provides information about current mental or physical conditions, prescription drug intake, and family health history.
- **Mental Status Evaluation** assesses a person's sense of time and place and his or her ability to remember, understand, talk, and do simple calculations. In early stages, screening of mental status may not detect symptoms.
- **Neurological Examination** tests the nervous systems (brain and spinal cord) for evidence of other neurological disorders. A magnetic resonance imaging (MRI) study of the brain may be used to search for other possible causes of dementia, (i.e. stroke). In the early stages of Alzheimer's, the results are often "normal" or "unremarkable."
- **Laboratory Tests**, such as blood and urine tests, provide additional information about problems other than Alzheimer's that may be causing dementia.
- **Neuropsychological Evaluation** tests memory, reasoning, vision-motor coordination, and language function. This evaluation may provide the only evidence of dementia, especially in the early stages.
- **Psychiatric Evaluation** provides an assessment of mood and other emotional factors that could mimic dementia or that may accompany Alzheimer's disease.



Because there are many causes of dementia, it is important to find out the disease responsible for these symptoms. Alzheimer's disease is the leading cause of dementia, accounting for 70 percent of cases.

AGING, MEMORY LOSS, DEMENTIA, AND ALZHEIMER'S DISEASE

Some people with memory loss say...

“Getting a diagnosis can be a relief.

It helps explain why I feel this way and why things are harder to do. I accept it and live with it...”

“I’m not the same as I was since diagnosis. It’s so exasperating!

Sometimes, my mind goes someplace else...I cannot get a hold of it!”

“It’s much easier when you have a name for your problem, because you know why something is wrong and it is not your fault.”

**The only limits are,
as always, those of vision.**

James Broughton



AGING, MEMORY LOSS, DEMENTIA, AND ALZHEIMER'S DISEASE

My views about getting a medical evaluation

**When I first received my
diagnosis I felt:**

**What the word Alzheimer's or
dementia means to me:**

**What I want to know about
MCI, Alzheimer's disease, and
dementia:**



AGING, MEMORY LOSS, DEMENTIA, AND ALZHEIMER'S DISEASE

Things I can do now

- ☐ **Give myself time to accept this diagnosis.**
- ☐ **Discuss results** of my memory evaluation with my doctor.
- ☐ **Get a second opinion** if needed.
- ☐ **Ask lots of questions.**
- ☐ **Call the Alzheimer's Association** for information on programs and services.
- ☐ **Stay involved in the community.**

[2] Partnering With Your Doctor



Developing a working relationship with your doctor is a very important part of managing your illness. It can take some time. However, it is very important that your doctor gets to know you. You can help by being open and honest with your doctor. Here are a few suggestions from professionals and people with memory loss that may be helpful:

Preparing for the Visit

- **Make a list of questions** as they come up, and take them to your next doctor's appointment. (Sometimes it is hard to remember everything you wanted to ask while you're at the doctor's office).
- **Take a family member or friend** with you. It helps to have someone there to ask questions and remember what the doctor said.
- **Write down all the changes** that you and/or family members have noticed. Share this information with your doctor.
- **List all prescription medications, vitamins, and over-the-counter** medications that you take, and share the list with your doctor (use medication log on page 47).

At the Doctor's Appointment

- **Be open and honest** about how you feel mentally and physically. Truthfully answer the questions that the doctor asks. If you don't know the answers, let him or her know. This helps the doctor to understand how the disease is affecting your brain and what treatments can be prescribed to help.
- **Ask the doctor questions** that you have about the results of your memory testing or any other symptoms that you have.
- **Ask what medications or treatment options** are available. Ask your doctor if it would be worthwhile for you to participate in any clinical studies.
- **Ask for specific information** about how to best care for yourself.



PARTNERING WITH YOUR DOCTOR

Some people with memory loss say...



Doctors can be helpful...

“by giving clear information about memory testing, evaluations, and results.”

“by being honest about the diagnosis, and periodically discussing the progression of the illness.”



“by staying informed about the latest research, medications, and interventions.”

“by treating me as a person – not the disease.”

[In business and in family relationships
the most important thing is trust.]

Unknown



PARTNERING WITH YOUR DOCTOR

My views about partnering with my doctor

The people I want included in my healthcare are:

What qualities I look for in a doctor:

What I want my doctor to know about me:

Questions to ask my doctor:

[Above all, remember that self-care is a right.
In fact, it is a requirement.]
Anonymous



PARTNERING WITH YOUR DOCTOR

Things I can do to be an active partner in my healthcare

- ☐ **Call the Alzheimer's Association** for doctor referrals and information about current treatments.
- ☐ **Write down any physical, mental or emotional changes** that my family and I have noticed. Share this information with my doctor. (Medication log on page 47)
- ☐ **Before each visit**, make a list of my top 3 concerns to share with my doctor. (Appointment log on page 48)
- ☐ **Ask my doctor** how much he or she knows about Alzheimer's disease.
- ☐ **Bring an updated list of my prescription and over-the-counter medications** to each doctor visit. (Medication log on page 47)

[3]

Telling Others About the Diagnosis

When you learn that you have MCI, Alzheimer's disease, or a related disorder you may not believe it, or you may feel overwhelmed, confused, or angry. You may be hesitant to tell family and friends about your diagnosis because you are concerned about what they will think or how they will react. Perhaps you are concerned they will treat you differently or "move away" from you. You may not want sympathy or help, but you may want the people you are close with to know because you care about them. All you may want from others is their support and understanding. The support of your family and friends may be helpful.

Who do you tell?

- People who you know well and trust
- People who you love and that you know will still love you
- People who you are responsible to (your boss, spouse, others)
- People who you may need help or assistance from (strangers, neighbors)
- People who "need to know"



When do you tell family, friends, and others about having MCI or Alzheimer's disease?

- When it feels like the right time
- When you know that they need to know
- When you need help or assistance from someone
- When it helps to explain what is going on with you
- When planning or making decisions about your future
- When you are alone with the person that you want to tell

**Friends in your life are
like pillars on your porch.**

Sometimes they hold you up, and sometimes they lean on you. Sometimes it's just enough to know they're standing by.

- Anonymous



TELLING OTHERS ABOUT THE DIAGNOSIS

Some people with memory loss say...

“Now that they know, they can help if something comes up...it’s a relief that they know.”

“I tell them when they recognize I’m not quite like I used to be. It helps explain what is going on.”

“Your friends are your friends. Tell them what is happening to you.”

“At first I tried to hide that I had memory problems, but when I finally told people, it was like a huge weight lifted off my shoulders.”

Courage and openness go hand in hand. Our courage helps us take the risk to try something new. When we are fearful, we see only one way. Courage opens the ways to new possibilities!

- Anonymous



TELLING OTHERS ABOUT THE DIAGNOSIS

My views about telling others my diagnosis

**What I fear most about telling
others:**

**I will know it is time to tell
others about my diagnosis
when:**

**Making the decision to tell
others about my diagnosis
makes me feel:**



TELLING OTHERS ABOUT THE DIAGNOSIS

Things I can do to include others in supporting me

- ☐ **Be proud of myself** for having the courage to tell people.
- ☐ **Inform my family and friends.** Ask for their help telling others.
- ☐ **Tell people** that I sometimes have difficulties with concentrating and remembering.
- ☐ **Tell people that just because I have MCI or Alzheimer's does not mean I need help with everything.**
- ☐ **Attend a care consultation** for people with early memory loss at the Alzheimer's Association. Invite a family member or friend to go with me.
- ☐ **Educate others** about MCI and Alzheimer's disease.
- ☐ **Let people help me.** Know that it makes them feel good to help.

[4]

Caring for Our Most Precious Relationships: Family and Friends

Memory loss and other symptoms can bring about changes that affect relationships with family members and friends. In the beginning, it is natural for you and some family members to experience denial about your condition. Denial is common and it is a way to buffer oneself from the painful feelings that go along with having a diagnosis of Alzheimer's disease.

It is important to recognize that every individual will have a different reaction to your diagnosis. For each of them, as well as for you, it will take time to adjust. During this time, it may seem like friends and even some family members pull away and distance themselves a bit. At the same time, other friends and family show an increasing amount of support and want to help.

In addition, you may feel that you need to rely on family and friends more than you used to and probably more than you want to. This shift in responsibility can lead to feelings of frustration, guilt or resentment. And unwanted help can feel overprotective or intrusive. Yet, keep in mind that at some point in our lives, we all need help from others. Accepting help from others is a sign of strength even though it can be uncomfortable.



The following questions can help you determine if you need help:

- Is an activity or task persistently frustrating and less enjoyable?
- If I make mistakes repeatedly, can I harm myself or others, such as when driving, paying bills or managing finances?
- Have I stopped doing something I enjoy because I can't do all the steps, such as baking, a hobby, sports or games?
- Have I been confused about my medication or forgotten to take it?

It is essential to listen to trusted family members or friends when they express concern and ask for your cooperation in letting go of an activity or task. They may be aware of a change that you may not be because of your memory loss. As you take on a new role as a care receiver, you can help friends and family by allowing others to help you. This new partnership not only helps in getting tasks done it can also provide the opportunity to spend precious time with family and friends.



FAMILY AND FRIENDS

Some people with memory loss say...



“I don’t like it when they tell me they are caretakers.”

“Together we can get better results.”

“People permitted to help where needed are blessed. You do a favor when you let people help you when necessary.”



“I don’t want to be totally dependent. I find ways that I can still contribute and be involved.”

[The foundation of relationships is based on the premise of mutual purpose.]

Anonymous



FAMILY AND FRIENDS

My relationships with family and friends

The way in which MCI or Alzheimer's has affected my relationships:

Accepting help from others makes me feel:

Ways I would like to see family and friends support me:



FAMILY AND FRIENDS

Things I can do to maintain good relationships

- ☐ **Allow myself to accept help from others.**
- ☐ **Focus on and celebrate the things I can do.**
- ☐ **Learn as much as I can about MCI and Alzheimer's** and encourage family and friends to ask me about what it is like to live with memory loss.
- ☐ **Work with others I trust to identify activities** I need assistance with in order to reduce stress.
- ☐ **Share my feelings about how it feels to accept help** (what am I gaining and what am I losing?)
- ☐ **Attend a support group** to talk to others with similar concerns.
- ☐ **Get individual or family counseling** to help resolve conflict and adjust to the changes.
- ☐ **Remember to say "thank you"** to those who support me.

[5]

Daily Strategies For Living with Memory Loss

You and your family cannot see damaged brain cells in the same way that you can see skin rashes or infections. However, you will probably notice changes in your ability to do the things that you want to do. When you or your family notice these changes, it is time to make adaptations to your environment and/or daily routine to find new ways of doing things.

The disease affects different parts of your brain so, although you may clearly remember things from your past, you may not be able to remember recent events or schedules. Think of the changes you experience as symptoms of your disease and a “disability” that you can learn to live with. You are not helpless. You have many abilities and other people to help you with your disabilities when you need support along the way.

Strategies for Successful Ways of Coping with Memory Loss

- Put less demands on your recent memory
- Write things down using a calendar or notebook.
- Try memory aid suggestions and checklists.



Follow a familiar daily routine

- Write down a daily, weekly or monthly schedule.
- Schedule important activities for the time of the day you feel best.
- Slow down – try to do fewer things each day and allow more time.
- Do one thing at a time.

Partner with other people

- Successfully complete things you can no longer do by delegating the tasks to other people. You can still enjoy the results!
- Be patient with yourself and others. Try not to blame other people or yourself when the disease is really to blame.
- Do things like shopping, preparing meals, housekeeping, exercising, yard work and paying bills with other people.



LIVING WITH MEMORY LOSS

Some people with memory loss say...

“Carry a calendar in your purse or pocket and get a big calendar for the wall.”

“Try to stay organized. I write things down by keeping a journal and making lists.”

“I use labels on cupboards, drawers, etc.”

“Delegate to others or forget it. Let some things go. Ask for help.”

“Ask people to give you reminders.”

It is time for all to stand and cheer for the doer, the achiever – the one who recognizes the challenge and does something about it.

Vince Lombardi



LIVING WITH MEMORY LOSS

My views about coping with memory loss

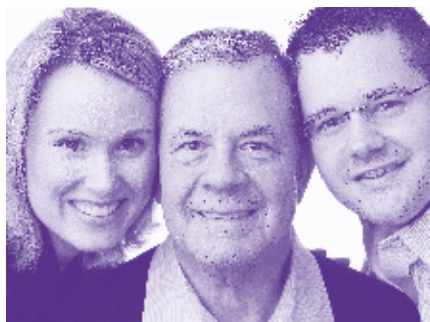
My biggest everyday frustration is: _____

Things I would like help with are:

Things I have found helpful are:

Daily activities I participate in:

- 1) _____
- 2) _____
- 3) _____
- 4) _____
- 5) _____
- 6) _____



LIVING WITH MEMORY LOSS

Things I can do to live my best with memory loss

- ☐ **Keep clocks and calendars around the house** for easy reference. Use the calendar to mark off days and keep track of time.
- ☐ **Have a familiar routine each day.**
- ☐ **Keep important items like keys, purse, glasses in the same place all the time.**
- ☐ **Make a “reminder” book. Keep it with me at all times.** Include emergency information, people’s names, telephone numbers, important health information, a map of where I live, appointments, to-do lists, medications.
- ☐ **Use pillboxes** to remind me when to take my medications.
- ☐ **Hire someone to help** with housekeeping, cooking, yard work, etc.
- ☐ **Use automatic shut-off appliances.**

Courage comes from acting
courageously on a day-to-day basis.

- Tracy

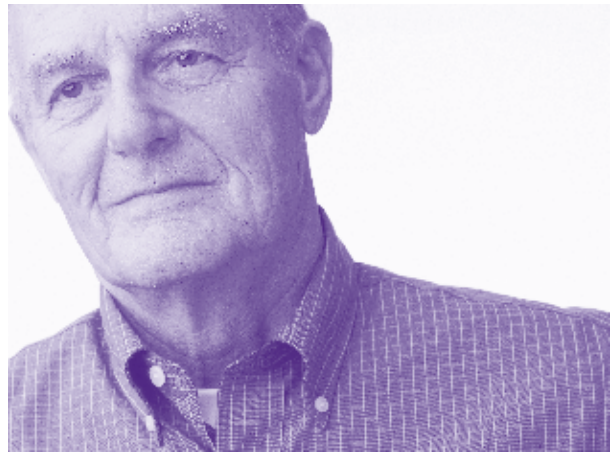
[6]

Coping with Changes

You are learning more about your disease and about what you can and cannot do. You are experiencing many changes in yourself, in your daily routine and in your relationships. Your feelings may be reflecting all of these changes as well. It is very common for people with MCI and Alzheimer's disease to have periods of time when they feel like they are on an emotional roller coaster. You may feel worried, angry or sad more often than usual. You may have times when you feel like you are going crazy or feel so frustrated that you want to scream. You may also have periods of time when you feel lonely, embarrassed or guilty. These feelings and the ways you find to cope with them will be uniquely yours. Having these kinds of feelings are very normal.

Accept your feelings and learn to work through the bad ones to get to the good ones:

- Pay attention to your feelings and discuss them with your doctor, family and friends.



- Try to do things you enjoy to make yourself feel better.
- Cry a little if you need to.
- Use humor to deflect embarrassment and/or frustration at times.
- Use music, massage, writing, gardening, exercise and other ways to turn troublesome feelings into a hopeful, positive attitude.
- If one is available near you, join a support group of people with memory loss who are experiencing similar feelings and want to discuss them.
- Identify times that you have successfully dealt with challenges and feelings in the past.



COPING WITH CHANGES

Some People with Memory Loss Say...

“Live each day to the fullest!”

“Do the things you can do.”

“Get out of the house and walk. It helps keep you mentally and physically active.”

“Don’t give up. Keep trying.”

**[Not everything that is faced can be changed
but nothing can be changed until it’s faced.]**

James Baldwin



COPING WITH CHANGES

My views about coping

My stress increases when:

My stress decreases when:

I feel best when: _____

I feel sad when: _____

I feel happy when: _____

I feel angry when: _____

I feel lonely when: _____

I feel embarrassed when:



COPING WITH CHANGES

Things I can do to cope

- ☐ **Accept my changing feelings** as a normal part of living with memory loss.
- ☐ **Enjoy more time with family and friends.**
- ☐ **Stay active, get involved,** volunteer, exercise, garden, or go to the movies.
- ☐ **Participate in community centers** and activities for persons with memory loss.
- ☐ **Have hope, and advocate** for myself and others.
- ☐ **Laugh as much as possible.**
- ☐ **Be easy on myself** when I feel down. Know that this is normal. See my doctor if sadness persists.
- ☐ **Get a massage.**
- ☐ **Listen to music.**

[7]

Effective Communication

MCI and Alzheimer's disease affects many parts of your brain. Because of this, you may need to explore new ways to communicate with people.

You may experience some of the following changes:

- Problems finding the right words or losing your train of thought
- Repeating words, stories or questions
- Getting words confused or out of order
- Problems understanding what someone is saying to you

Communication is more than talking and listening. Communication is a way of letting people know what you are thinking, feeling or wanting.

Communication is an important part of your relationships with family and friends. If words and sentences become difficult for you, you will want to explore new ways to communicate. Be open and honest with your family and friends about how the disease is affecting you.



Find new ways to keep the channels of communication flowing:

- Slow down, take your time and don't worry about small facts or details
- Find a quiet place where you will not be disturbed or distracted
- Tell people when you are having difficulty speaking or understanding
- Come back to it later
- Try describing the person, place or thing if you cannot recall a name
- If you use a notebook as a memory aid, carry it with you and refer to it as needed to help you communicate.

9 out of 10 times it is ok to remind me of something.

- Anonymous



EFFECTIVE COMMUNICATION

Some people with memory loss say...

“It feels good when people listen to you sometimes instead of them telling you what to do.”

“Do not keep asking me questions. This frustrates me and makes me feel I am being tested.”

“Because I cannot remember does not mean that I am dumb.”

“When I forget, either laugh with me or hug me, but please do not make excuses for me. When you do that it makes me very angry and I feel you do not understand what I am feeling inside.”



EFFECTIVE COMMUNICATION

My views about communication

Talking is most difficult or frustrating when: _____

The best time for me to discuss important matters is:

When I have problems communicating, I want people to:

When I have problems communicating, it helps me to:

[A friend is someone who knows the song
in your soul and sings it back to you when
you have forgotten the words.]

Anonymous



EFFECTIVE COMMUNICATION

Things I can do to maintain good communication

- ☐ **Take my time.**
- ☐ **Tell people that I have problems** concentrating, remembering and understanding at times because of my disease.
- ☐ **If I have a problem,** let it go, move on, forget it; maybe it will come back later.
- ☐ **Write things down.** It may be easier to communicate and remember by using notes.
- ☐ **Find new ways to express myself.** Try painting, singing, writing, drama, massage, etc.
- ☐ **Work out a signal to my family** when I need assistance with a word, thought, or when I want to take a break.
- ☐ **Recognize that I have a neurological disease** that can make it difficult to communicate.

[8]

Making Decisions

We are all faced with making many decisions over the course of our lives. We make decisions everyday such as: what to eat, wear, or do today. Other decisions are more complex and can affect our lives today and into the future. Making decisions gradually becomes harder because the disease can block your ability to process information – to remember, organize things, problem-solve and even recognize when you are having difficulty making decisions.

It is important to choose someone to help you with decision-making.

Things to consider:

- Choose a person you trust to help you – often it is a family member.
- Choose a second person if the first person is unable to help when needed.
- Your feelings about receiving help with making decisions may fluctuate from relief to resentment.
- Get an outside opinion if you disagree with decisions that are made. An Alzheimer's care consultation can help.



- Discuss your wishes with your family or care partner. Important issues to discuss include: handling finances, when to retire if you are still working, when to retire from driving, when to use community services for help with meals, transportation, activities, and time-off for your primary care-partner, and your care and living arrangements when a change is necessary.

Making your wishes known and allowing others to help is one of the most important decisions you can make — for yourself and for your family.



MAKING DECISIONS

Some people with memory loss say...

“Feel okay about the change.
Trust others to understand.”

“Being able to problem solve
with others gives me hope.”

“Every bit of help is so
important and so helpful.
Use please and thank you.”

[We may not always see eye to eye,
but we can try to see heart to heart.]

Sam Levenson



MAKING DECISIONS

My views about making decisions

Two people that I would like to help me with making decisions are:

1) _____

2) _____

I want help with making decisions about/plans for:

If I need to move to a place with more assistance I would choose to go:

Allowing others to make decisions on my behalf makes me feel:



MAKING DECISIONS

Ways I can be involved about decisions that affect me

- ☐ **Delegate decision-making to someone I trust.**
- ☐ **Make a list of things** I want to discuss and for which I need to make plans.
- ☐ **Discuss with my family or care-partner** where or with whom I want to live if I can no longer take care of myself.
- ☐ **Build a support team of family, friends and professionals.**
- ☐ **Tell others my care preferences.** Complete advanced directives and a durable power of attorney.
- ☐ **Be willing to try new services or involve new people** in my life to give my care-partner time off.
- ☐ **Be patient and give myself time to adjust** to transitions.
- ☐ **Speak up for myself.** Make my needs known.

[9]

Legal and Financial Issues

There are a number of legal and financial documents that will help you formalize your plans and wishes. Taking the time to put these documents in place now will be a big help to you and your family in the future.

Work with your family and experienced professionals, such as Elder Law Attorneys, to review or create the following documents:

- **A financial durable power of attorney.** In this document, you name a person to take care of your financial matters, if for any reason you become unable to do so for yourself.
- **A medical durable power of attorney.** In this document you name a person to carry out your medical decisions for you, if for any reason you are unable to do so for yourself.
- **A living will.** This document states your preferences for critical medical procedures, if for any reason, you are unable to do so for yourself (i.e. use of ventilators, feeding tubes).



- **A last will and testament.** This document describes your financial estate and itemizes its distribution in the event of your death.
- **A CPR directive.** This document tells emergency personnel what to do if your heart and/or lungs stop. Talk with your doctor if you want to obtain one. State laws vary.

These are all documents that express your wishes. Legal and financial planning takes time and careful consideration. Once you have completed your plan, you can enjoy a feeling of confidence, knowing that you have helped yourself and your family to establish a solid foundation for dealing with any medical and/or financial needs you may have.

**Failing to plan
is planning to fail!**

Anonymous



**[We have prepared
for the worst and now
we are planning to
live the best. If the
worst comes, we are
ready for it. If it doesn't,
we will have not wasted
today worrying about it.
- Betty Davis]**

LEGAL AND FINANCIAL ISSUES

Some people with memory loss say...

**“I had someone help
complete** my Advance
Directives and Durable Power
of Attorney for Health Care.”

**“Write your wishes down.
Make a list.”**

**“I hope to be able to talk
with my family members about
future plans.”**

**“Give yourself permission
to do only what you can
reasonably manage!** Reduce
obligations and delegate details
whenever possible.”



LEGAL AND FINANCIAL ISSUES

My views about making legal and financial decisions

People that I want involved in my legal and/or financial affairs:

Things that are important to me in my future care:

Questions to ask a legal and/or financial professional:



LEGAL AND FINANCIAL ISSUES

Ways I can manage my legal and financial decisions

- ☐ **Contact my local chapter of the Alzheimer's Association** for referrals to Elder Law professionals for legal and financial assistance.
- ☐ **Make legal, medical and financial decisions early.** Talk with my family or friends about them. Make sure my family and friends know what kind of decisions I want made for my future.
- ☐ **Appoint a trusted family member or friend** to help manage my finances. This person can be a joint signer on bank accounts and could assist with bill paying.
- ☐ **Take family members or friends to appointments** with lawyers or other professionals. They can help explain and interpret information for me.
- ☐ **Write a list of questions to ask** my legal and/or financial professional when I meet with him/her.

[10]

Playing It Safe

Being diagnosed with MCI, Alzheimer's disease or a related memory disorder means taking measures to ensure safety at all times. This can help you and your loved ones feel more relaxed and less overwhelmed.

At Home and Away

Persons in the early stages of the disease can live in the comfort of their own home or a care partner's home, provided that safety measures are in place. Most accidents in the home occur during daily activities such as eating, bathing and using the restroom.

In addition to home safety, traveling away from home also requires careful planning to ensure safety, comfort, and enjoyment for everyone. There are important documents to pack such as a list of medications, phone numbers and contact information. Traveling in airports requires plenty of focus and attention and it is helpful to inform the airline ahead of time of your needs to make sure they can help.

To Drive or Not to Drive

A diagnosis with MCI or Alzheimer's disease or a related memory disorder also means that driving may be impacted. Giving up driving may be one of the



most difficult decisions you will have to face. The very thought of it may loom as a surrender of independence or a loss of freedom.

Even early Alzheimer's disease can impair your ability to drive. Driving demands good judgment, quick reaction, and split-second decision making. Research studies have found that drivers with Alzheimer's are four to eight times more likely to be involved in car accidents.

It is important that you, your family and friends all acknowledge what a difficult decision and change this may be for all of you. Make sure you have alternative ways to continue to stay active and do the things you want to do. Try other forms of transportation such as taking a cab, using public transportation, or asking someone else to drive. Staying active and communicating your feelings about this decision before you retire from driving will help you. Take time to adjust to the change.



PLAYING IT SAFE

Some people with memory loss say...



“Driving is an important way to maintain independence, and it is a thrill! It sure is a darn bother to wait and ask for a ride when you can’t drive.”

“I moved to a senior living facility and now I feel safe. It is reassuring.”



“If you get lost, tell someone. Ask a stranger if you need help or assistance.”

“Take someone with you when you go out. It is safer and more fun.”



PLAYING IT SAFE

My views about playing it safe

People who can help me stay safe are:

Things that are important to me for my safety are:

Making safety plans about my future makes me feel:

I will know it is time to retire from driving when:

The person I trust to tell me when to stop driving is:



PLAYING IT SAFE

Ways I can play it safe

- ☐ **Keep a list of emergency telephone numbers** posted at each telephone.
- ☐ **Call the Alzheimer's Association** for a MedicAlert® + SafeReturn® bracelet.
- ☐ **Schedule a home safety inspection.**
- ☐ **Incorporate kitchen safety strategies** such as written reminders, timers with a buzzer and use appliances like microwaves and coffee pots that shut off automatically.
- ☐ **Use a pillbox** to help organize my prescription medicine and vitamins.
- ☐ **Use nightlights** in hallways, bedrooms, bathrooms and stairways.
- ☐ **Ask someone to assist me** with grocery shopping, meal planning, cooking and household repairs.
- ☐ **Ask family, friends, and my physician** for their advice about when to retire from driving.
- ☐ **Find out about transportation services** in my community.

[11]

Opportunities for Supporting Research



Over the last couple of decades, scientists have made enormous strides in understanding how MCI and Alzheimer's disease affects the brain. Many of these recent insights point toward new breakthroughs for treatment and risk reduction.

Scientists continue to make new discoveries, and progress is advancing very quickly on many fronts. In fact, at any given time, several hundred studies are recruiting participants to help explore these exciting new approaches.

You can make a difference! Research including clinical studies are the engine that powers medical progress. Scientists work constantly to find better ways to treat diseases. Improved treatments can

never become a reality without human volunteers. No one ever chooses to become ill, but anyone can consider helping to advance knowledge about an illness affecting them or someone close to them.

Without participants, however, the progress is stalled, and scientists report growing difficulty finding enough volunteers to complete these studies.

Ultimately thousands benefit from the willingness of those who choose to become involved.

**Participating in research
is an active altruism,
a way to give to future
generations.**

Unknown



RESEARCH

Some people with memory loss say...

“Trust that doctors are trying to find the cure.”

“Research gives you courage.”

“We can all help contribute to research by participating and advocating.”



RESEARCH

My views about research

**I would be willing to participate
in research studies if:**

**Some questions I would have
for the researchers are:**

**Being in a research study
would make me feel:**



RESEARCH

Things I can do to support research

- ☐ **Stay informed** of new research findings and stories about Alzheimer's disease.
- ☐ **Ask my doctor** or call the Alzheimer's Association about current research studies that I might be interested in participating in.
- ☐ **Work with the Alzheimer's Association, family and friends** to help raise money for research.
- ☐ **Spread the word** that research is the key to a world without Alzheimer's disease.
- ☐ **Inform my doctor about any research studies** I am participating in.

[12]

Resources for People with MCI and Early Alzheimer's Disease

Individual and Family Care Consultation

Care Consultation is a service that can help you and your family develop a road map to navigate through the many thoughts, emotions, and questions you may have about memory loss and dementia. Care Consultation can be useful whether you or someone you love has just been diagnosed, or if you and your family are seeing things from different perspectives and perhaps disagreeing about the next steps to take.

Care Consultation services can help you build around your future. You will receive valuable one-to-one assistance that will enable you to better understand the disease, manage care and make more informed decisions regarding services and treatments. Phone and in-person individual sessions are offered when it may be too difficult to involve others or if you feel alone in this process. The length of phone consultation varies, while in-person sessions are 60 to 90 minutes.



Education Classes

For persons with memory loss, their families and friends, there are classes and webinars to help you understand memory loss, develop a partnership with your doctor and learn skills to make legal and financial plans.

Please contact the Alzheimer's Association Minnesota-North Dakota for more information at **952-830-0512** or visit **www.alz.org/mnnd** about these programs.

On-line Resources

On-line resources for people with MCI and early Alzheimer's disease are available:

- **www.alz.org/mnnd**
Minnesota-North Dakota Chapter
- **www.alz.org/messageboards**
national message boards
- **www.alz.org/townhall**
specifically for people in the early stages
- **www.nia.nih.gov/alzheimers**
National Institute on Aging
- **www.sharpbrains.com**
brain fitness products

MEDICATION LOG

MEDICATIONS: PRESCRIPTION • OVER-THE-COUNTER • VITAMINS • HERBAL SUPPLEMENTS

DATE	PATIENT
------	---------

MEDICATIONS						
PRESCRIBING DOCTOR	MEDICATION	DOSAGE	DATE STARTED	WHAT FOR	SIDE EFFECTS	INSTRUCTIONS
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						

ALLERGIES

MEDICAL CONDITIONS

THINGS TO AVOID

APPOINTMENT LOG

APPOINTMENT

DATE		PATIENT	
TIME	AM/PM	DOCTOR	

TOP 3 CONCERNS

1	
2	
3	

NOTES

TO DO

1	
2	
3	
4	
5	

NEXT APPOINTMENT

DATE		PATIENT	
TIME	AM/PM	DOCTOR	

[illegible]

[illegible]

[illegible]

[illegible]

TAKING ACTION

Here are some things you can do:

A diagnosis of Alzheimer's doesn't mean you stop taking part in life. Keep doing the things you enjoy. Find comfort in your family and friends. Plan for your future. And consider getting involved with the Alzheimer's Association and our mission.

ADVOCATE

Speak to others about the issues you face. Become an Alzheimer advocate and make an impact on the decision-makers for Alzheimer funding. As an advocate, you can talk to legislators about your personal experiences and the need to increase funding for research and care programs.

VOLUNTEER

Our volunteers are passionate, inspired and want to make a difference in the fight against Alzheimer's disease. Whether you can spare a few hours a week or can make a more significant time commitment, please consider becoming an Alzheimer's Association volunteer.

Make the first call:

1.800.272.3900

24/7 Information Helpline

Visit us online:

www.alz.org/mnnd

alzheimer's  association™

the compassion to care, the leadership to conquer