Coach Broyles' Playbook for ALZHEIMER'S CAREGIVERS

A PRACTICAL TIPS GUIDE

A Note From Coach Frank Broyles

Dear Caregiver,

My name is Frank Broyles, Athletic Director Emeritus for the University of Arkansas Razorbacks. Much like you, my life has been touched by Alzheimer's Disease. When my wife, Barbara, was diagnosed with Alzheimer's disease, I didn't know much about the disease or the impact it would have on our lives. What I did know was that Alzheimer's was not going to destroy our love for life. Our family came together and decided to focus on what we did have instead of what we didn't have. We chose to celebrate our "todays" and our memories, and to make each day the best, with no regrets. Like so many others, we experienced our share of heartbreaks. We also experienced happy times, and those we will remember forever.

You will notice that the information in this book is organized a lot like a coach's playbook. That's because I approached Alzheimer's disease much like I would an opponent on the field, with a solid game plan and a dedicated team.

I had many questions and spent a lot of time looking for

answers before I could put together my game plan. This is what I learned. What I learned is contained in this Playbook. This "Playbook for Alzheimer's Caregivers" is a social model, not a medical model (doing things with her, not for her). It was written to give you practical tips to help guide you in taking care of your loved one with Alzheimer's disease.

It wasn't always easy for me to find the answers my family needed about Alzheimer's disease, and at times I was frustrated and confused. I promised myself that one day I would share all that I had learned—from my research and my experience—with other families that were dealing with Alzheimer's. This dream came true when the Playbook was created and made available to my fellow Arkansans. We received calls and letters from so many people thanking us for sharing our story and information that I decided to make my dream bigger, and share the Playbook with people across our country. I gathered my team, and together, with the help and support of many Arkansan people and companies, we were able to generate the funding needed to make this Playbook available nationwide, free of charge, to anyone wanting information on how to care for a loved one with Alzheimer's disease. It is our gift to you, in hope that you can benefit from my experience.

There is a saying that I've carried with me in my

career as a coach, and again in my passion to create this Playbook: “Most coaches get things done right. The winners get the right things done.” I hope this Playbook is an example of a winner getting the right things done, and that you find it useful. It is my gift to you in the hope that you can benefit from my experience.

My best advice to you is to treasure each day and live it to the fullest. Cherish the time you spend together and, perhaps most important, love each other. I hope you find peace in knowing that it is still possible to live and love when someone you love is living with Alzheimer’s disease.

Sincerely,

Frank Broyles
University of Arkansas,
Razorback Athletic Director Emeritus

How to Use This Playbook

The letters "AD" will stand for the words "Alzheimer's disease."

The person you are caring for will be talked about as "she." Many men also have AD, but there tend to be more women than men with AD, and switching from "he" to "she" gets a bit confusing as you read.

This Playbook will talk about three stages of AD:

- Early Stage
- Middle Stage
- Late Stage

Each stage is color coded at the top or bottom of the page, and has a divider page to make the information easier to find.

Early Stage AD may last from 2 to 4 years, though it can last longer. Many people don't know they should see a doctor during this stage. This is tragic because your doctor can order drugs that will slow down the changes in your loved one's ability to think and talk.

Middle Stage AD may last from 2 to 10 years. In the middle stage, people start to act differently, and need someone to be with them all the time.

Late Stage AD may last from 1 to 3 years. Her needs will change greatly during this stage of AD. This is the time of total care, when she is no longer able to do for herself.

The Resources guide at the end of this Playbook lists contact information for organizations that are available to help caregivers.

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Know Your Opponent: Early Stage AD

Early Stage AD may last from 2 to 4 years, though it can last longer than that. Many people don't know they should see a doctor during this stage. This is tragic because there are drugs your doctor can order that will slow down how quickly AD causes damage in the brain. This brain damage changes how people are able to think and talk in this stage. People with AD lose some memories and can't get those memories back no matter how hard they try.

> "Before the players on my football team took the field, we studied and learned everything we could about the team we were playing. Preparation is the key to facing any opponent.
>
> "Learn all you can about Alzheimer's disease. It will help you prepare for the months and years ahead."
>
> —Coach Broyles

What are Dementia and AD?

Dementia (di men sha) is a medical word that is used when damage in the brain causes at least four changes. These are:

1. Memory loss
2. Changes in how people talk
3. Changes in how people act (wandering off, hitting)
4. Trouble doing things (getting dressed, bathing)

Alzheimer's (alz hi merz) *disease* is just one of many diseases that can cause dementia.

Having a family member with AD is not a cause for shame or a reason to hide away. As a caregiver, you are going to need help—help from family, help from friends, help from members of your church. AD affects the entire family, not just the person who has it.

It is important to know that AD is a disease of the brain, NOT a type of mental illness.

The chance of getting AD increases as we age. People over the age of 85 are the most likely to get AD. Some may get it as young as 65 years old, or even younger. We still don't know why someone gets AD or how to cure it.

We do know that AD causes brain damage. AD changes how people think, act and are able to take care of themselves. People in middle and late stages of AD need someone to take care of them all of the time.

There is no cure for AD at this time, but we are hoping for a medical breakthrough in the future.

AD causes both short-term and long-term memory loss.

Short-Term Memory

Short-term memory holds recent memories:

- What you had for lunch today
- Who you talked to on the telephone last night
- What plans you have for tomorrow

Short-term memory loss starts during Early Stage AD.

Long-Term Memory

Long-term memories are memories you have from the past. These may be memories of "how to do things" or of "people and family." Long-term memories may include:

- Faces and names of people you have known all of your life
- Your children's names and how old they are
- How to get home from the store
- How to take a bath and get dressed

Long-term memories are mostly lost in Middle Stage AD or Late Stage AD.

Early Stage AD

Early Stage AD may last from 2 to 4 years. Many times the person with Early Stage AD, as well as her family and friends, don't notice the changes at first.

Many of the changes have to do with her forgetting things and, over a period of time, how she talks. We tend to make excuses for the small changes. Many of the things she may forget are things that we all forget from time to time.

AD causes these "forgetful times" to happen more often. This is why it is so important for you to learn about what signs to look for. The first signs are that she will often:

- Misplace her keys or put her glasses in an unusual place
- Look up a recipe but not be able to follow it
- Start something and forget to finish it
- Have a hard time keeping up with tasks she has done every day of her adult life

LIST MAKING

A good way to help someone with AD who is having trouble keeping up with tasks is to ask her to make a list of the things she needs to do each day.

One sign you might look for is if she seems to be having trouble with numbers. You may see that she needs help with paying the bills:

- She may forget to mail the bills.
- You may find checks returned in the mail because she forgot to sign them.
- Checks may be returned that were written for the wrong amount.

Another clue may be if your loved one stops doing things she has always enjoyed, such as:

- Meeting friends to play cards or bingo
- Helping out at church
- Leaving the house by herself to shop or visit friends

This may be the first sign that she knows something is wrong. She may be worried that her friends will see that she is not her normal self.

If your loved one stops doing things she has always enjoyed, she may be worried that her friends will see that she is not her normal self.

Finding the Right Doctor

The one thing that usually gets families to the doctor is when their loved one gets lost coming home from work or the store. This is very common. When this happens, your loved one may begin to worry about the other things she is having a hard time doing. She may:

- Begin to limit how much she is around other people
- Become sad or draw into herself
- Stop doing things she has loved to do all of her life
- Stop talking to you

This is a good time to see a doctor and find out what is going on.

Some family doctors don't have the extra training needed to find the cause of your loved one's memory loss. They may say it is just "old age" and "you should not worry about it." Please don't stop there.

"I was the head football coach at the University of Arkansas but I had many important people to help me. I had assistant coaches, team doctors, trainers, equipment managers and many other experts who specialized in different parts of the game. I couldn't have done it all by myself.

"You, as the caregiver, can't take care of someone with AD all by yourself either. You don't need to. There are many people out there to help you. "

—Coach Broyles

Picking the right doctor is very important!

It takes a doctor with special training to find the cause of memory loss. There may be doctors with this training in your area. Your local Alzheimer's Association chapter can help you. (See Resources on page 93.)

Memory loss is NOT "just a part of getting old."

Questions to Ask

Talk with your loved one about what questions to ask before you get there. Make a list of questions and take it with you on the visit. See the sample list (at right) for things to ask the doctor.

SAMPLE LIST OF THINGS TO ASK THE DOCTOR

What are some reasons for the changes I've seen?

What medicine helps with memory loss?

Is there help to pay for the medicine?

Can she still stay alone?

Is driving still safe?

What services does my town have to help with care?

The Visit to the Doctor

The doctor will want to ask a lot of questions.

Ask to go into the exam room with her. You may want to take notes. This may make her feel more at ease and give you a chance to see how well she is answering the doctor's questions.

Let her talk as much as possible. Try not to give her answers during the talk with the doctor.

The doctor may ask questions about:

- When the changes first started
- What changes you and she have seen
- How both of you are coping with these changes

The doctor may use words that are new to you when talking about what may be going on with her. If you don't "get" what the doctor is talking about, say so! Ask the doctor to talk plainly to you. Take notes. Don't leave the doctor's office until you feel like you know what has been said.

Tests the Doctor May Order

The doctor may order blood tests. These tests will help tell if there is something else causing the changes you are seeing. The doctor may ask your loved one a list of questions. These are part of a test that helps the doctor tell which parts of the brain may have been damaged. The doctor may even order tests at the hospital to take pictures of her brain to see exactly where it may have been damaged.

After these tests, the doctor can tell you what disease may be causing the memory loss.

Ask the doctor to talk plainly to you. Don't leave the doctor's office until you feel like you know what has been said. Write down things you need to remember.

Putting Together Your Special Team

After finding the right doctor, you need to find out what services are offered in your town. The first thing to do is to join a support group! There may be support groups for both you and the person with AD.

- The national Alzheimer's Association has a helpline you can call 24 hours a day if you need to talk or find help in your area.

- Local chapters of the Alzheimer's Association can be great places to get information on special problems you may be having.

- Check out your local churches and see what help they may have to offer. To help give you a break, some churches offer respite (short period of rest or relief) care or may have church members who will come to your home and stay while you run errands.

- Many towns have adult day care or adult day health care centers. These can be great places for your loved one to spend time during the day when you are at work or need some time off. Be sure to ask if the programs in your area:
  - Accept clients with AD or dementia
  - Have staff with special training for working with people who have AD
  - Have a nurse on staff if your loved one needs medicine during the day

Housing Services

This may also be a good time to think about different housing services available in your area. Residential Care and Assisted Living are good choices for many families during Early Stage AD. Many of these housing options offer:

- Low levels of supervision
- Help with personal care
- Meals
- Medicine reminders
- Social activities

This can be a great help for the busy caregiver while keeping your loved one as independent as possible.

Taking Care of Yourself: Protecting the Quarterback

Get into the habit of making time for yourself each day so that you can stay healthy. Don't give up the things you love to do. Exercise, eat right and spend time with your friends. Share what is going on with family and friends.

Do this early, because as a caregiver you will be at risk for feelings of:

- Sadness
- Stress and strain
- Anxiety
- Anger
- Guilt
- Grief
- Frustration

These are all normal feelings, but it helps to talk to people who are going through the same things.

"*Playing offense* is when your team has the ball and your goal is to score points. In order to score, we would practice all week a number of important plays. Sometimes we had to change our plays in the middle of the game to respond to what the other team was doing.

"As a caregiver, it will be important for you to have a plan for every day. But also be ready to change your plan. Some days the person with AD may not feel like doing the things you had in mind."

—Coach Broyles

Becoming the Caregiver

Changing your role in the family is tough. This takes place when you become the caregiver of a family member with AD. Your roles will start to change. She may become more like a child, and you'll become more like a parent.

You will need to slowly take over the jobs she has always done. This can be paying the bills, cooking, washing clothes, feeding the dog or putting gas in the car.

You need to make a plan now for sharing as much of her care as you can with others. Talk with your close family about her AD if she says that it is OK with her. Tell them about the kind of help you will need to keep her at home. Don't be shy about asking for help with:

- Family spending time with her often
- Shopping and cooking meals with her
- Taking her for doctor visits, to get her hair done, and other errands
- Cleaning her house
- Setting up time off for yourself

If your family does not live close by, they can still help:

- Ask them to send money each month to help with paying someone to spend time with her when you are working or need time off.
- Ask them to plan on coming to town and watching over her once a month for a day or a weekend to relieve you.
- Ask them to call her each week just to say "I love you" or "How are you doing?"

Do not try to do this alone. Share what you are learning about AD with your family. This will make it easier for them to help you with planning for the next stages of AD. It will also help them understand why you need planned time off for yourself.

Set up regular time off with members of your family or friends. Use this time off just for yourself. Take a walk, take a nap, or go shopping. If you do this now during Early Stage AD, the plan will already be in place when you need it the most.

Take time each day to celebrate positive things. Focus on what your loved one can still do—not what she has lost.

Taking Care of Practical Matters

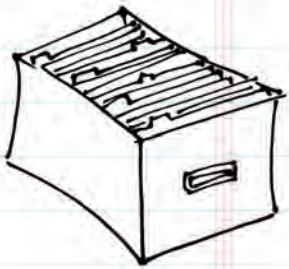
Now is a good time to look for any personal papers in the house that have facts about your loved one with AD. Make copies and store them safely outside the house.

The personal papers you will need are:

- Birth records
- Marriage or divorce records
- Social Security card

The health care papers you will need are:

- Medicare and/or Medicaid card
- Doctor's name and telephone number
- List of current medicines



Other papers your loved one may have are:

- Life or burial insurance
- House insurance
- Car insurance
- Medicare supplement insurance
- Medicare Part D medicine plan
- Long-term care insurance

This is just good planning. It is much harder to gather up this information in a hurry if you should suddenly need it.

Three Important Legal Documents

You will need to contact your family lawyer or legal aid service to help you take care of three very important legal documents while your loved one can still talk with you about them:

- Living will
- Durable power of attorney for health care
- Durable financial power of attorney

The living will and durable power of attorney for health care have to do with what kind of health care choices she might want made in the future. These are referred to as "advance directives."

Living Will

This legal paper states her wishes to die a natural death without using heroic means to keep her alive. She can choose what actions the doctor may take to keep her comfortable. You will need to take this with you each time she goes into the hospital.

Durable Power of Attorney for Health Care

This legal paper names you, the caregiver, as the person who can make health care choices for her when she is no longer able to give medical consent.

Durable Financial Power of Attorney

This legal paper gives you the ability to pay bills and make decisions about her money and property when her choices about these things may no longer make sense.

Guardianship

"Guardianship" means that you have asked for and been legally chosen by a court to watch over your loved one and make decisions about her money and health care needs. This is often a very touchy issue. If you have already taken care of the legal papers (the durable power of attorney for health care and the durable financial power of attorney), guardianship is often not required.

- If you were unable to get these legal papers, then asking the court for guardianship may be your only choice.
- The time to ask for guardianship is when she can no longer make good decisions about money and how to care for herself.

SURVIVAL TIPS

- Put staying healthy at the top of your list.
- Have a backup plan in case something unexpected happens to you.
- Take one day at a time.
- Keep your sense of humor.
- Pat yourself on the back for the good job you are doing.
- Get enough rest and eat right.
- Make time for the things you like to do.
- Talk about how you feel with others.
- Listen to your friends.
- Make a list of all the things your loved one can still do.

Playing Defense

It doesn't matter if you are the spouse, child, grandchild, sister, brother or friend of the person with Early Stage AD—now is the time to love her with everything you've got! Please do this while she still knows who you are!

"*Playing defense* is when your team tries to keep the opponent from scoring points against you. My team would practice a number of plays and schemes each day that we believed would work best to stop our opponents from scoring. It was our job as coaches to try to anticipate what our opponents would do and make sure that we called the right play to stop them.

"There are certain behaviors that are common in Alzheimer's disease. There are certain things that you can expect to happen. By preparing for those things, you can keep your loved one safe and prevent some of the problems that can occur during the disease process."

—Coach Broyles

Making Memories

Her memory loss will get worse as AD causes more brain damage. It is now your job to become her "memory." These are some things you will want to do:

- Spend time with her.
- Make a memory scrapbook with her while she can enjoy it.
- Have pictures taken with both of you in them.
- Find old pictures and talk about them.
- List on the backs of the pictures who is in them, what the people are doing and when they were taken.
- Include pictures of her as a child or of the family home, if you can find them.
- Add old love letters or pictures drawn by the grandchildren.

This may be your last chance to sum up who this wonderful person has been. Don't waste it!

Another thing you can do is to ask her to help you make a pretty box to hold things with special meaning to her. These might be:

- Bits of jewelry
- Prayer beads
- Baby booties she knitted
- Dried flowers
- Perfume

Write down the story of what makes each thing in the box special to her.

All of these can be used as activities for her during all stages of AD.

You may also find it helpful to pull these out and read them on the bad days. These things may give you comfort and remind you of why you're still the loving caregiver for this person who doesn't know you anymore.

A memory scrapbook or "treasure box" will be a great help to both of you on your long journey with AD.

Home Safety: Making Her Home Safe and Comfortable

These home safety tips will help her do more by herself:

- The less mess the better. Put away things lying around the house that are not used every day.
- Keep her favorite chair and other things she uses a lot in the same spot.
- Put a bowl on the table next to her chair, and tag it as the key bowl or the glasses bowl.
- Increase the amount of light in each room. Shadows may look scary to her. Stand back and look to make sure that there are no shadows in corners or on walls. Check this at different times of the day.
- Remove or tack down loose throw rugs to keep her from tripping and falling.
- If your property has a pond or swimming pool, fence it off and put a lock on the gate.

Increase the amount of light in each room. Shadows may look scary to her.

Driving

This may or may not be a problem for you. A lot depends on where you live. If your loved one is driving around your property and you think it is safe, let her do it. Some people with AD give up driving on their own. For others, it becomes a last sign of freedom lost.

If driving becomes a problem, ask your doctor to talk with her. Many people with AD will do what their doctors tell them. Ask the doctor to write out "Do Not Drive" on a prescription pad. Then you can pull the note out when you need to remind her that her doctor has told her not to drive.

Communication Changes

You may see, as time passes, that your loved one with AD does not talk like she used to. She may have a hard time finding the right words to say what she means. She may use a word that sounds like the word she is looking for, such as:

- Saying "car rack" instead of "clothes rack"
- Saying "pup" when she means to say "cup"

If she can't find a word at all, she may say things like:

- "Thing-a-ma-jiggy"
- "What's it?"

If you try to help her find the word, she may get upset with you. It is often better to give her time to come up with the word on her own.

Her trouble with thinking and trying to talk will get worse. She may not remember:

- What you just told her
- If she just asked you a question
- If you answered the question

She may no longer be able to keep track of time so "one minute" and "one hour" seem the same to her. This is partly why she asks the same questions over and over.

She may not be able to talk about one thing very long, or may forget what she was saying before she can finish her thought. There may be gaps between the words as she tries to find the next word in the sentence.

It is now your job to change how you talk with her to match what she can understand.

Communication Tips

Learning these talking tips are a must for anyone spending time with a person in Early Stage AD:

- Turn off the TV or radio before you start talking.
- Keep what you are telling her short and simple, but not child-like.
- Don't tell her more than she needs to know at one time.
- Be patient.
- Give her lots of time to answer your question.
- If she loses the thought, ask the same question again.
- Give her lots of time to finish what she is trying to say.
- Don't butt in.
- Don't fill in the missing words unless she says it is OK.
- Pay close attention to what her body language is telling you.
- If you guess at what is being said, ask if your guess is right.
- If she can't say what she means, ask her to point to it.

It is now your job to change how YOU talk with her.

Eating Problems

A person with Early Stage AD, as a rule, doesn't have trouble eating. In Early Stage AD, the eating problems have more to do with her loss of memory. She may have trouble with:

- Planning meals
- Shopping for food
- Fixing meals

"Before every game, I made sure my players ate a meal together. We called it the *training table.* They had good, healthy food, and plenty of it.

"You, as caregiver, can't do your best unless your body has the energy it needs from eating healthy foods three times a day."

—Coach Broyles

You may need to start going on the shopping trips. Offer to help cook meals ahead of time for the week. You will also want to find reasons to check for food that has gone bad. She may think the food is still OK to eat.

If you can't be there for a meal, try:

- Dropping by later in the day to see if she has eaten
- Calling her and asking what she had to eat

If she tells you that she had something to eat other than what you know is in the house, this may be a clue that she needs more help from you.

You might also try:

- Calling her on the telephone at mealtimes
- Leaving a note by the phone reminding her to eat
- Asking a neighbor to drop by around lunch time
- Asking your church group or Meals on Wheels organization to deliver a meal to her home

Serious problems with eating are usually not seen until Middle Stage AD and Late Stage AD. For help finding programs that will deliver meals to your loved one, contact your local Area Agency on Aging.

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"Every game was important, but some opponents were stronger, which meant we had to prepare even harder.

"In Middle Stage AD, the disease will cause more changes in your loved one. You will need to know what to expect from these changes so you can help the person with AD have the best quality of life possible."

—Coach Broyles

Know Your Opponent: Middle Stage AD

Everyone's safety has to be the top concern now. You will need to think about safety every time you make a decision. Her memory loss will not get better. It will get worse. The plans that worked in Early Stage AD will stop working. Your loved one will get more confused. This will lead to changes in how she acts that don't make sense to you.

Middle Stage AD may last from 2 to 10 years. Changes in how people act and the need for someone to be with them all the time are part of this stage. The changes in how our loved ones act are the hardest to deal with.

The parts of the brain that are being damaged in Middle Stage AD tell us how to do things such as:

- Act
- Walk
- Sit down and get up
- Go to the bathroom
- Find our way around the house
- Get dressed
- Deal with noise, lights and crowds

Memory Loss

In Early Stage AD, you could still leave notes for her to remind her to eat. You could call her on the phone and tell her to check the stove to be sure she had turned it off.

She was able to stay alone a good part of the time as long as you were checking in with her. None of this will work any longer.

The changes in her ***short-term memory*** mean she can no longer:

- Read as she has in the past (for instance, she may only recognize a few words)
- Make sense of phone messages
- Use notes as cues, or reminders
- Take a bath or brush her teeth without your help
- Eat without cues from you
- Find words or put her thoughts into words as well as she could before
- Stay alone

Her memory loss in Middle Stage AD will get much worse.

Changes caused by damage to her ***long-term memory*** are starting to be seen. She may begin to:

- Make up stories as her memory fails
- Mix up who people are
- Hug people in stores that she doesn't know

- Think her husband or other family member is a stranger
- Sleep more during the day
- Wake up at night and think it's time to fix breakfast

Other Changes You May See

She may:

- Tell the same story over and over again
- Ask the same questions over and over again
- Talk but the words don't make much sense
- Argue with you about certain tasks like taking a bath
- Fidget with things
- Walk around the house all the time
- Try to leave the house and go "home"

She may also tend to fidget and act nervous late in the day. She may become easily upset and hard to calm down. This is called "sundowning" since it happens late in the day as the sun goes down.

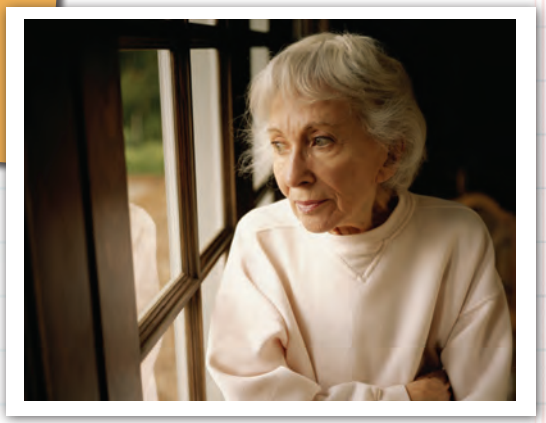
She may say over and over again that she needs to go home, and try to leave the house. She may become angry and try to hit you. The idea of "going home" is not what you may think. To her, "home" is not always where she grew up or where she lived most of her life. "Home" means feeling safe. "Home" may not really be a place at all. "Home" may be more like a feeling.

As her AD gets worse, she will have trouble sorting out what is real and what is not real. She may start thinking that what she is seeing on a TV show is real or that the people on TV are in her house. She may begin to see and hear things that aren't there. She may also think that a family member is stealing from her or that her husband is cheating on her.

Changes in how she acts are also seen in this stage. She may try to hit, bite or push you when you try to help her take a bath or get dressed. She may begin to make threats or curse at you during her care.

REMEMBER!

The changes in how she acts are caused by brain damage. She cannot control how she acts. It is part of the disease!



Tough Choices to Be Made

You need to be there to watch, step in when needed, and take charge. You will need to decide one of three things:

- Are you going to move in with your loved one?
- Are you going to move your loved one in with you?
- Are you going to pay a nursing home or someone else to care for your loved one?

"When I was faced with a new situation, I got all the advice I could before making a critical play, call or decision about my players.

"Stay in touch with the doctors and resources who can give you the latest information and suggestions on how to handle tough situations."

—Coach Broyles

The one you are caring for can no longer safely live alone.

Putting Together Your Special Team

Talk with her doctor before you make your plan. Talk with your support group. Things such as money, family, where you live, and if you work will all play into what you decide.

Families often do not agree on the best way to plan care for the person with AD. Call the family together. Get all ideas out on the table. Once your family is talking, decide how each person is going to help. You will need help with the day-to-day care, and you may need help with money.

Don't expect her to be happy about you moving in with her or her moving in with you. This change will be tough on everyone. You may need to explain to her why you need to live together, such as:

- "Money is tight and this will really help me out."
- "I would really like the company."
- "We can share the bills."
- "You always seem tired. I can help with laundry and cleaning the house."
- "I want to spend more time with you."

Think about what services are in your town that may be of help. These include:

- Adult day care centers
- Adult day health care centers
- Respite (short period of rest or relief) programs
- Sitter programs
- Home health services
- Area Agency on Aging
- Local Alzheimer's Association

Many caregivers use these services during the day so they can keep on working at their jobs.

Taking Care of Yourself: Protecting the Quarterback

This is one of the most important things you must do! The next years are going to be hard on you. You may feel tired, weighed down or angry by all you have to do. The demands of caregiving seem never-ending. Your need for support from your family, friends and church will be much greater now.

"With a tougher opponent, I had to make different game plans and focus a lot more on how we executed them.

"As a caregiver, you will need to be flexible. Don't be upset when one idea doesn't work. Try another."

—Coach Broyles

Many families decide in the middle stage that keeping their loved one at home is just not possible any longer. Check out which services are on hand where you live. Moving her out of her house and into an Assisted Living facility may be a really good choice.

There are often different levels of care offered in Assisted Living facilities. For more information about which services may be right for your loved one, contact your local Alzheimer's Association chapter or your local Area Agency on Aging.

REMEMBER

Take a deep breath!

Be patient!

Giving lots of hugs will make you feel better!

Make time for yourself every single day!

You Must Ask for Help

With any luck, you already set up a plan with family and friends to come to the house and give you a break during Early Stage AD. If not, you must set this up now!

Nothing is better than knowing help is on its way when you have reached the end of your rope after a long day.

Get Help From Your Family

If you have family members who live close by, ask them to share some of your burden. A couple of hours a week away from caregiving can be a lifesaver for you.

Use this time to do the things that you used to do in your life, such as:

- Get away from the house
- Go out for a walk
- Meet friends for lunch
- Go to a prayer meeting
- Listen to music
- Work in your garden
- Read a book
- Take a nap

It can also help to have family or friends share the hard jobs with you. Two heads are better than one, and four hands can help get some jobs done faster and safer. So ask your family to come when it will be the most help for you. Don't leave them alone to do the hard jobs. Doing them together can get you through some of the tougher times:

- Mealtimes
- Bathing times
- Late afternoon

If your family lives too far away to help you, ask them to send money. Use this money to pay for day care or for a sitter to stay with her. Use the time to go to the store, go to a movie, take a bath in peace, or go to church.

Set up a calendar for visits from family members who live out of town. Visiting one weekend every couple of months is not too much to ask. They can come and stay at the house, where things are well-known to her. If they come to her, it will be less confusing for her.

Talk With Other Caregivers

A support group is a wonderful thing! You will learn that it is OK to cry or be angry. You will learn tips and tricks you never thought of to help deal with the changes in her actions during this stage.

SURVIVAL TIPS

- Put staying healthy at the top of your list.
- Have a backup plan in case something unexpected happens to you.
- Take one day at a time.
- Keep your sense of humor.
- Pat yourself on the back for the good job you are doing.
- Get enough rest and eat right.
- Make time for the things you like to do.
- Talk about how you feel with others.
- Listen to your friends.
- Make a list of all the things your loved one can still do.

Home Safety

Middle Stage AD is when you, the caregiver, have to make the biggest changes. The one you are caring for can't change so it is up to you. This is the time that can make or break you. Every change you make to your home life is likely to make you feel a little sad.

"Football is a dangerous game and there will be injuries. However, I made sure my players had good equipment and were in good condition to play the game. I never wanted anyone to get hurt and I did what I could to protect them.

"There are many products and services that can help keep your loved one safe. And good old common sense will help too. Be on the lookout for things around the house that could be dangerous to a young child."

—Coach Broyles

You already did a lot to make the home safe for her in Early Stage AD. Now it is time to do more. In Middle Stage AD, she is more easily upset and confused.

Some of her confusion may be caused by the damage in her brain that changes how she "sees" things. While there is nothing wrong with her eyes, she is losing the ability to figure out what the images she sees really mean.

The way she sees the real world around her has changed. Because she doesn't see things the way you do, she acts differently.

Example 1:

You and I see a bathroom with flowered wallpaper and curtains and think it looks nice.

The person with AD sees a bunch of lines on the walls that make no sense. She is afraid of what she sees and won't go into the bathroom.

Example 2:

Supper is ready and she has helped you set the table. The white plates are on placemats with a white background and red and black dots. The food includes baked chicken, mashed potatoes and green beans. When you sit down to eat, she spends the mealtime picking at the placemat and eating a few green beans.

She cannot see the light-colored chicken and the mashed potatoes on the white plate. She can see the green beans because they are a color that stands out from the white plate. She is picking at the dots because they stand out from the white placemat, but she does not know what they are.

Example 3:

You have light-colored floors in your house. To add a bit of color, you bought small rugs in dark blue and green to put on the floor. You put one rug in front of the hall doorway that leads to the bathroom. Later, your loved one says she needs to use the bathroom. You tell her the way and point to the bathroom door in the hall. You watch her as she walks through the room. Each time she comes to a rug, she stops and goes a different way. You tell her to go on but she doesn't move. Finally you get up, walk over to her, and take her arm to get her moving. She lifts her foot high off the ground as if stepping over a hole or stepping down stairs.

Your loved one does not see the small rug as a rug. She sees the rug as a dark hole that is not the same as the rest of the floor. That is why she stopped. That is why she lifted her foot high off the ground as she tried to step over the rug.

It is the little things that we don't know that make caregiving a tougher job.

More Tips for Home Safety

- Try to make her world simple.
- Use plain-colored placemats, tablecloths, bath towels and sheets.
- Block off stairs so she can't fall up or down them.
- Have all of your house locks keyed to the same key.
- Place latches up high or down low on doors leading outside.
- Have her wear the ID bracelet provided by the Alzheimer's Association's Safe Return® program.
- Use locked cabinets for soaps, cleaners, poisons and medicines.

Light reflecting off windows and patio doors can cause more confusion for a person with AD. Things you can do:

- Pull down the blinds or close the curtains before you take her into a room in the evening.
- Make sure the string pulls on blinds are wrapped around a hook as high on the wall as you can reach. She can get her arms and legs tangled in the strings the same way a child can.

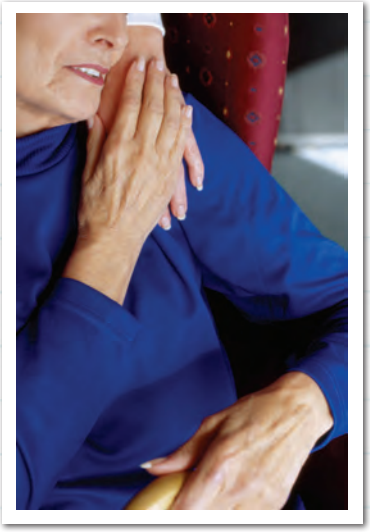
- Think about changing glass windows in the bedroom and bathroom to plastic. Fits of anger happen in these two rooms the most. Glass can be broken.

While facing these changes is hard, they can make your life as a caregiver much easier.

Communication Changes

The first step is to change how you talk with your loved one, again. The changes you made in Early Stage AD were good, but more is needed. Her memory loss has gotten much worse. This will keep on until there is little or no memory left at all.

She may still know who she is, but not the time or place she lives in. She may think it is 1935 and that she lives in the small town she grew up in.
There is no harm in this. Correcting her will only upset her.



She can only make sense of very simple ideas. She can no longer follow directions that have three or more steps.

For example, you say to her "Mom, (1) pick your plate up off the table, (2) take it to the sink and (3) wash it off." She may just pick up the plate and stand there. *Why?* She has already forgotten the last two parts of what you asked her to do. This means you will need to re-think how you say everything!

> The time will come when you must do all things for her, but it is not here yet!

This new way of talking is called "task breakdown." This means that you must ask her to do one step at a time. Wait until she has done the first step of what you have asked, and then tell her the next step.

This way of talking needs to be a part of everything you say from here on out.

Breaking things down into small steps will help her be able to do more for herself. It will help her feel useful and happy.

Changes in How She Communicates With You

You may have seen that she does not talk like she used to. She is having more trouble finding words. Her sentences are short and choppy. The loudness of her voice may have changed. Her words may not make any sense. This is called "word salad." As you listen, you know she is trying hard to tell you what she wants. The words just come out wrong.

Communication Tips

- Be patient and calm.
- Touch (holding hands) is very important.
- Don't use baby talk.
- Stop what you are doing. Really listen to what she is trying to say.
- Think about the feelings behind the words she is trying to say.
- Look at what her body is trying to tell you.
- If she looks upset or angry, then ask her if she is.
- Treat her with dignity and respect.
- Say exactly what you want her to do.
- Use ordinary words. Instead of saying "Hop in the bed," say "Please get in the bed."
- Turn your questions into answers for her. Instead of "Do you need to go to the bathroom?" say "The bathroom is right over there. I can walk with you."

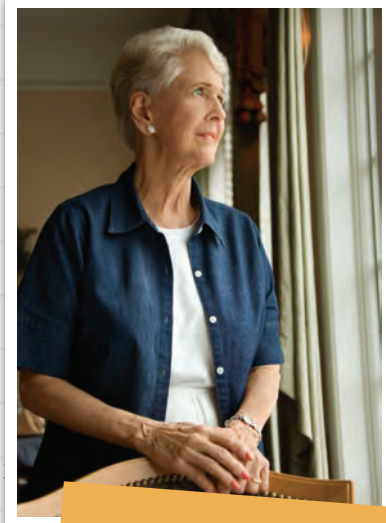
Communication "Dos and Don'ts" to Get You Through the Day

- Do take a deep breath.
- Don't argue with her. It is easier to agree with her and then do what you had planned anyway.
- Don't try to reason with her. You will just get angry and she won't know why. Change what you're talking about to something she likes.
- Don't correct or fuss at her for getting something wrong. Does it really matter? It will only make her feel bad.
- Don't say "I just told you that." Just repeat the answer you have already given to her.
- Don't ask her to "remember" things that happened in the past. Talk about what you remember happening and how she was a part of it.
- Don't say "You can't do that by yourself." Say "Do as much as you can and I will help you."
- Don't demand things from her. Always show her what you want her to do.

You may find as time passes that she will not be able to start a talk with you. She may not ask many questions either. She may sit or walk around the room and say nothing unless you begin talking to her first.

Other Changes

You may notice that she is no longer able to see things from any point of view but her own. Trying to "make your point" while talking to her is a waste of breath.



If you think she has begun to act self-centered and uncaring, try to be more patient. This is not something she has control over. It is the AD.

In the past she may have loved you may find that she has a hard time when lots of people are around her. She may get upset and seem more confused. This happens because she is losing the ability to grasp what people say when they are talking to her. It is getting hard for her to shut out noises around her. She can't focus on what is being said. You could:

- Try to limit the number of guests in the house at the same time.
- Have guests talk with her away from the crowd and noise.
- If she gets upset, move to a quiet area with her until she becomes calm.

The Daily Plan

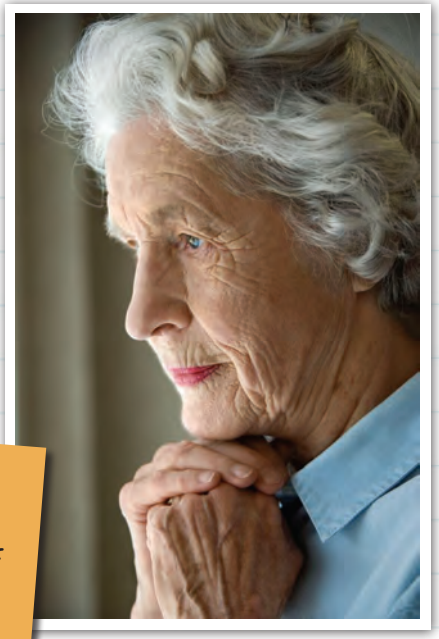
You know more about the person you are caring for than anyone else in the world. Use what you know to make a daily plan of care and activities. People with AD do better if there is a plan for each day.

To make this plan work, you need to think about these things:

- What time of day did she always eat breakfast, dinner and supper?
- What were her favorite foods?
- What were her least favorite foods?
- Did she snack during the day?
- Did she drink alcohol in the evenings?
- Did she take a shower or a tub bath?
- What time of day did she bathe or shower? How many times a week?
- Did she have problems with hard or loose bowel movements?
- What time did she get up in the morning and go to bed at night?
- Did she take naps?
- What style of clothes did she wear? Dresses, pants, a uniform?
- Did she have favorite TV shows she always watched?
- Did she have hobbies?
- What were her favorite things to talk about?

- What day of the week did she do her shopping?
- Did she go to church service on Sundays? Or any other day of the week?
- Did she take a walk each day? If so, what time?
- How did she spend her time each day?

With these facts about her life, you are ready to put a plan into action. Use what you know about her to plan each day.



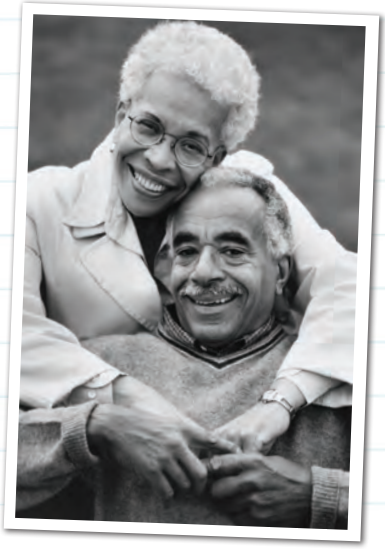
People with AD do better if there is a plan for each day.

Choosing the Right Things to Wear

You will want to make this task as easy as you can. You also want her to be able to help dress herself as long as she can. Think about the kinds of clothes she wears as her AD gets worse and she needs more help getting dressed. Here are some tips:

- If she has trouble putting on a bra and no one cares, don't bother with it.
- Putting on pantyhose can be hard, so if she doesn't need them, don't bother with them.
- Try tube socks so that she does not have to find the heel to put them on right.
- Try pull-on pants with an elastic waist and shirts that she can pull over her head.
- Get her shoes that slip on or fasten with Velcro®. Shoes with a wide heel base, like tennis shoes, can help keep her from falling.
- If she keeps taking off her shirt or dress in public, try clothes that zip or button in the back.
- Check for the right fit. Many times people with AD take off their clothes because they don't fit right or they are scratchy.

Helping Her Get Dressed



As her memory loss gets worse, trying to make even easy choices will become hard for her. To help her choose, offer only one or two clothing choices at a time. Pick them out before she comes into the room to get dressed. Say to her "Do you want to wear the blue or yellow pants today?" Show her the outfits as you ask her. Here are other ideas:

- She may do well if you lay out her clothes in the order that she needs to put them on, with underwear on top.
- She may be able to dress herself if you hand her one piece of clothing at a time.
- Give a cue if needed, like "Here is your shirt." Help her by showing her how to put her arm in the sleeve of the shirt.
- Set aside lots of time for her to get dressed, and let her do as much as she can.
- Tell her what a good job she is doing.
- If she wants to wear the same clothes over and over again, try buying more clothes that look just like them.

Using the Bathroom

The time will come when she is no longer able to find the bathroom by herself. She may not be able to get her clothes off to use the bathroom. She may not remember how to sit on the toilet seat without your help. As her AD gets worse, the loss of these skills may cause her to wet or soil her clothing. This will be very upsetting for her. Some things to try may be:

- Mark the bathroom clearly.
- Use a sign that has the word "bathroom" written on it.
- Put a picture of a toilet on the door.
- Watch for cues like fidgeting with clothing or pacing.
- Write down the time of day when she has toilet accidents so that you can predict future accidents. This will help you set up a routine that works for her.
- Walk her to the bathroom every two or three hours. Don't wait for her to ask.

If she is having occasional bed-wetting:

- Use a plastic mattress cover.
- Use adult-size protective, pull-up underwear. This is much less embarrassing than wearing an adult-size diaper.

Bathing

Bathing is very private. Set the time for her bath or shower close to the same time she used to take one before the AD.

- Gather everything you will need ahead of time: towels, bath mat, washcloth, soap, shampoo, comb, lotion and powder.
- Make sure the room is warm enough.
- Test the water to see if it's at a safe temperature.
- Use a hand-held shower sprayer.
- Have a shower bench for her to sit on.

Bathing two or three times a week is plenty unless she is having toileting accidents.

Making Bathing a Success, Not a Battle

- Tell her what is happening one step at a time.
- Ask her to check the water to see if it is warm enough.
- Invite her to help. Give her spoken cues to allow her to help in any way she can.
- Give her a washcloth to hold even if she can't help with the washing.
- Help her cover her face with a towel when you wash her hair. This keeps the water from getting in her face.
- To keep her from feeling "uncovered," lay a towel over her lap or across her chest, and use a washcloth to clean under the towel.

- If she seems upset about getting wet, start at her feet and slowly move up.
- Try talking, singing or asking her to hold the soap.

Mouth Care

Daily mouth care keeps her gums and teeth healthy. If you find the task unpleasant, use plastic gloves. Healthy gums are needed to keep good levels of nutrition.

Give her step-by-step instructions:

- "It's time to brush your teeth."
- "Come with me."
- "We're going to the bathroom to brush your teeth."
- "I will help you."
- "Here is the toothpaste."
- "Take the top off."
- "Squeeze the toothpaste on the brush."
- "You're doing great!"

Start the brushing motion for her by guiding her hand.

Sleeping

AD can cause people to change how and when they sleep. They may wake up, need to use the bathroom and get afraid because they don't know where they are. Many people with AD are up and down all night. This leads to daytime napping, which makes staying asleep at night harder. Here are some hints for helping her sleep through the night.

- Keep a small light on in her room if she is afraid of the dark.
- Fear, seeing or hearing things that are not real, and confusion may get worse in the dark, so sitting with her for a while may help.
- Check to see if the room is too warm or too cool.
- Try "white noise," like the hum of a fan or soft music.
- Give her a back rub, brush her hair, or talk softly when she is restless.
- Offer a snack. She may be hungry.
- Keep her from napping during the day if you can.

If you have tried everything you know to help her sleep better, and nothing has worked, it may be time for a visit to her doctor. The doctor can look for other things that may be causing the changes in her sleep. Pain and not enough exercise may be two causes.

Take turns with family members sleeping in her room so you can get some rest.

Dealing With Problem Behaviors

You know that your loved one with AD has no control over how she acts. You may hear the way she acts called a "problem behavior."

A "behavior" is the way a person acts or responds to the people and things around them.

Each of us has pet peeves or things that bother us. Some people can't stand to be in small places because it makes them nervous or feel like they can't breathe. Others don't like being in large crowds or talking in front of groups of people. Most of us just say what is bothering us. With Middle Stage AD, the person can't tell you how she feels with words.

The things that bother her could be called "triggers." A trigger is the reason for the way she acts when she doesn't like being where she is.

People, feelings and physical things in a room can act as a "trigger" to problem behavior for people with AD.

Problem behaviors seen in this stage are a way of letting you know that things are not right. She may not be able to tell you in words what is wrong. What you see are actions that cry out "Fix me!" "I am so angry!" or "I am so afraid!"

Steps for Successfully Dealing With Problem Behaviors

First, you need to identify the behavior or action that you are seeing. Then ask yourself:

- Did it hurt anyone?

Next, you need to figure out why it happened. This is where being able to identify the trigger is so important. Questions to ask are:

- What happened just before the behavior started?
- Where did the behavior happen?
- What happened right after the behavior?

Then you need to think about:

- How did you handle it?
- What did you say or do?
- Was there anything you could have done differently that might work better next time?

Keep track of your answers each time you see the behavior. These are clues that you can use to help make your caregiving easier. If you can change or prevent the triggers, you may be able to keep the behavior from happening in the same way again.

Agitated Behavior

This is very common. It can happen when she is not able to identify the people, places or things around her. She may feel confused or can't figure out what you're asking her to do. She may be bored and need to move around. She will act nervous and upset. She may pick at her clothes, wring her hands, cry or argue with you. Identifying the triggers for these actions can help you steer clear of them.

Common triggers:

- Asking her to do more than she can
- Having too much noise and activity in the house
- Changing caregivers without giving her time to adjust
- Changing where she lives
- Having too many people in the house
- Planning bath time
- Asking her to change her clothes

Things you can do that are helpful:

- Stay calm.
- Take her to another place where it is quiet.
- Break down what you are asking her to do into easy steps.
- Say comforting words:
  - "May I help you?"
  - "You're safe here."

- "Everything is under control."
- "I apologize."
- "I'm sorry that you are upset."
- "I know it's hard."
- "I will stay until you feel better."

- Listen to her.
- Try to understand what is going on.
- Use a quiet tone of voice.
- Check for pain, hunger, thirst, constipation, full bladder or tiredness.
- Check to see if her clothes may be too tight or too loose.
- Try using art, music or touch to help her relax.
- Pull out the memory book or treasure box you made together. Use the pictures or items to talk about good memories. If these don't work, she may be bored.
- Take a walk, play ball or go for a car ride.

Things you may do that are ***not*** helpful:

- Raising your voice
- Arguing or trying to reason with her
- Trying to grab or corner her
- Showing you are afraid
- Letting her hurt your feelings

Suspicious or Accusing Behavior

Memory loss and confusion may cause her to think in odd ways. She may become suspicious of you and others around her. She may accuse you of stealing, cheating or lying.

Common triggers:

- Mistaking what she sees or hears
- Losing or misplacing things
- Forgetting where she is but not who she is

Things you can do that are helpful:

- Let her know she is safe and that you care.
- Listen to her point of view.
- Listen to the feelings behind her words.
- Give her a simple answer.
- Offer to help find what is lost or missing.
- If she keeps losing the same items over and over again, keep several on hand (for instance, two black wallets with the same information in them, three blue toothbrushes, spare glasses and favorite shirts).
- Provide her with what has been "lost" and then distract her (for instance, by asking her to help with a chore).

Things you may do that are ***not*** helpful:

- Raising your voice
- Getting angry or upset with her

- Arguing or trying to reason with her

Aggressive Behavior

These behaviors can be shouting or name-calling as well as hitting and pushing. They can start suddenly for no reason you can see. They can also be the result of anger and frustration.

It is important to try to figure out what's causing your loved one to become so angry or upset.

Common triggers:

- Your emotions (for instance, anger)
- Anxiety
- Feeling threatened
- Feeling out of control
- Too much noise
- Too many people

Things you can do that are helpful:

- Stay calm.
- Be safe.
- Respect her personal space.
- Stay an arm's length away.
- Give her some time.
- Try again later.

Things you may do that are *not* helpful:

- Shouting back
- Demanding an explanation
- Putting your hands on your hips, frowning or pointing your fingers at her
- Getting too close so she feels crowded
- Making her feel threatened

Hallucinations

If your loved one sees or hears things that no one else does and it doesn't seem to bother her, ignore it. If she does this a lot and is afraid of what she sees and hears, consult a doctor. She may be sick. Have her eyesight and hearing checked. Make sure she wears her glasses and hearing aid.

Common triggers:

- Patterns on the walls
- Shadows on the walls from poor lighting
- Reflections from mirrors or windows

Things you can do that are helpful:

- Reassure her.
- Respond calmly.
- Tap her gently on the shoulder to turn her focus back to you.
- Look for the feelings that are causing her to see or hear things that aren't there.

- Say “It sounds as if you’re worried” or “I know this frightens you.”
- Suggest taking a walk or sitting in another room.
- See that she is in a well-lighted area where other people are present.
- Try to turn the focus on music or activities you enjoy together.
- Check for noises from a TV or an air conditioner.
- Look for lighting that casts shadows on floors, walls and furniture.
- Cover mirrors with cloth or remove the mirror if she thinks she is looking at a stranger.

Things you may do that are ***not*** helpful:

- Arguing with her about what she thinks she sees
- Ignoring her fear

Repetitive Behavior

Your loved one with AD may do or say things over and over again. She may repeat a word, question or task. In most cases, she is looking for comfort and security. These actions are harmless but can be very annoying if you're the caregiver.

Common triggers:

- Short-term memory loss
- Anxiety
- Depression
- Boredom

Things you can do that are helpful:

- Stay calm and be patient.
- Reassure her with a calm voice and gentle touch.
- Look for a reason behind the repetition.
- Try to find out the cause for the behavior and remove it.
- Respond to how she is feeling, not the behavior.
- Turn the action or behavior into an activity.
- If she is rubbing her hand across the table, give her a cloth and ask her to help with dusting.
- Give her the answer she's looking for, even if you have to repeat it several times.
- If she asks the same questions over and over again, remind her with notes, clocks, calendars or photographs.

- Accept the behavior and work with it.

Things you may do that are *not* helpful:

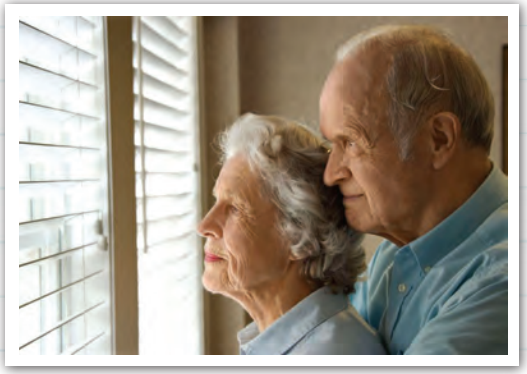
- Raising your voice
- Telling her you have already answered her question a hundred times
- Ignoring her
- Demanding that she stop
- Telling her she is making you crazy

Shadowing Behavior

People with AD will often follow, or shadow, their caregivers from room to room. This behavior can be understood if you consider how strange the world must seem to your loved one who constantly forgets. Few things are more irritating than being followed around all the time.

Common triggers:

- Short-term memory loss
- Confused sense of time



Things you can do that are helpful:

- Take a deep breath.
- Stay calm.
- Use child-proof doorknobs and latches.
- Ask your family members and friends to relieve you.
- Find simple tasks that she can do and feel useful, such as:
  - Winding a ball of yarn
  - Dusting
  - Stacking magazines

Things you may do that are *not* helpful:

- Raising your voice
- Hiding from her
- Locking her in another room
- Using medications to slow her down

Wandering

Keeping your loved one safe is one of the most important things you can do as a caregiver. Some people with AD may wander away from their home or their caregiver. Knowing what to do to limit wandering can protect your loved one from getting lost.

Common triggers:

- Medication side effects
- Stress
- Confusion related to time
- Restlessness
- Agitation
- Anxiety
- Inability to recognize familiar people, places or objects

Things you can do that are helpful:

- Keep a recent photograph or videotape of your loved one to help the police if she should become lost.
- Keep all of the doors locked.
- Consider installing a keyed deadbolt.
- Use safety latches up high or down low on doors leading to the outside.
- Have her wear the ID bracelet provided by the Alzheimer's Association's Safe Return® program.

- Make sure she gets enough exercise and sleep.
- Let her do chores, such as folding clothes or helping with dinner.
- Cover the doorknobs with cloth—or paint them the same color as the wall—so she won't notice the doorknobs.

Things you may do that are ***not*** helpful:

- Raising your voice
- Restraining her
- Locking her in a room
- Leaving her alone
- Giving her sedatives

Eating Problems

These tips will help her pay attention to the task of eating.

- Take her to a dentist at least once a year because sore gums or poorly fitted dentures can keep her from eating.
- Serve meals at the same time every day.
- Serve foods with different colors and textures.
- Make the table a calm place to eat.
- Use plain-colored dishes with no pattern that set off the color of the food on the plate so she can see the food.
- Use a shallow bowl with a lip on it if she keeps pushing her food off the plate.
- Put only the fork or spoon she needs to eat with next to her plate.
- Take things like sauces, ketchup bottles, or salt and pepper shakers off the table. These make the table look confusing to someone with AD.
- You may need to remind her to eat and drink. Sometimes it helps to offer four or five small meals plus snacks instead of three meals a day.

"Not all of my players liked the same foods. So I made sure there were many things they could choose to meet their varying needs.

"The person in Middle Stage AD may not want to eat the same foods as before. Or they might not be able to handle a knife and fork. Your loved one with AD will need even more calories from healthy food because she may become very physically active as the disease progresses."

—Coach Broyles

If she refuses to eat, it may be because:

- She has too many choices on her plate. Try offering one food item at a time.
- She may not know how to get started. Show her the act of eating.

Once she gets started, she may eat on her own. If not, then cue her again. Allow her lots of time to finish her meal.

If she wants to eat all the time or does not eat enough:

- Fix healthy finger foods that she can eat during the day.
- Offer her more choices of fresh fruits and vegetables.
- You can make finger foods out of anything. Just put the food between small pieces of bread with butter or margarine.

Losing Touch

The behaviors of people with Middle Stage AD come and go. As your loved one moves through this stage, she will go from being "active and demanding" to being "quiet and less able to get around." She will slowly lose touch with who you are. She will lose the ability to talk at all. She will lose the ability to walk unassisted and will require total care. These are the signs that the last stage of caregiving is near.

Hopefully, you have taken good care of yourself on this long, long journey. There is still much to do and many decisions to make in your role as caregiver over the next couple of years.

The Lou Ruvo Brain Institute, Las Vegas, Nevada

OPENING SUMMER 2009

The Lou Ruvo Brain Institute is dedicated to enhanced treatment of and ultimately the prevention of Alzheimer's, Huntington's, Parkinson's, Amyotrophic Lateral Sclerosis (ALS) and other chronic brain disorders.

Devoted to healthy "Vital Aging" for all citizens, the LRBI seeks to enhance the quality of life for the burgeoning numbers of people living with dementia today **and to one day ensure a hopeful reality where memory disorders are a memory of the past for all.**

The Institute fosters worldwide cooperative research networks to develop new detection technologies for early and accurate diagnosis of dementia, facilitate the discovery of treatments for various forms of memory impairments and to provide a new clinical model of specialized treatment and support for both those affected with dementia and their family caregivers.

To learn more about supporting the Coach's Caregiver Playbook and the programs and research of the Lou Ruvo Brain Institute, visit us at www.LRBI.org

LOU RUVO BRAIN INSTITUTE

KEEP MEMORY ALIVE
Supporting the Mission of the Lou Ruvo Brain Institute
Alzheimer | Huntington | Parkinson | ALS | Memory Disorders

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LATE STAGE

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> "In order to be a champion, you have to play the best game of your life against the best teams in the country. The best teams have some of the best players and coaches in the country, and knowing their strengths and weaknesses can make the difference between a win and a loss.
>
> "Late Stage AD creates even more challenges to the caregiver. Learn all you can about what you will face."
>
> —Coach Broyles

Know Your Opponent: Late Stage AD

You have spent the last years dealing with your loved one's need to pace, wander or follow you around. You have battled with her over taking a bath and changing clothes. You have spent years with little or no sleep because she was up and down during the night. You have lived to tell the tale of giving care in Middle Stage AD.

Late Stage AD may last from 1 to 3 years. Her needs will change greatly during this stage of AD. Giving care in this stage will be mostly about meeting the care needs that she is no longer able to do for herself.

In Late Stage AD, the damage to her brain may cause her to be unable to:

- Know who you are
- Know who she is
- Make sense when she talks
- Walk or sit up without help
- Eat without help
- Control her bowels or bladder
- Understand what she sees

While your loved one may not know who you are, she still has feelings. Her need for love and touch has never been greater than it is now. She can still feel:

- Scared
- Rejected
- Lonely
- Sad

Things you can do to show your love and support may be to:

- Hold her
- Talk to her
- Sing or hum to her
- Put a furry stuffed animal where she can feel it
- Comb her hair
- Stroke her gently
- Play music she likes
- Rock with her

This is the time to make hard choices. You have survived the demands of Middle Stage AD. Caregiving in Late Stage AD is totally different. It is a 24-hour-a-day job that is hard on your body. You will need to be able to lift her from a lying to a sitting position. You will need to be able to take all or most of her weight when you move her from the bed to a chair. You will need to be able to hold her up when you walk her. Most of these tasks take two people to do safely.

> "I surrounded myself with the best coaches I could find. Winning was always important, but more important was whether or not we gave 100%. Even if we didn't win, I could honestly say we'd done our very best.
>
> "No matter what you and your doctor try, in the end Alzheimer's will win. But you will know in your heart that you did all you could to give your loved one the best quality of life possible."
>
> —Coach Broyles

In-Home Programs

You are going to need help if you choose to keep her at home until the end. You will need to find out what programs in your area offer in-home care. Some choices are:

- Your local Area Agency on Aging may have personal care as a part of its services.

- Home health care agencies have personal care aides you can pay by the hour. They will come into your home and help with bathing, dressing and grooming.

- Private nursing assistants in your area may be willing to come into your home for a fee and help with bathing, dressing and grooming.

Nursing Homes

Many caregivers make the choice to move their loved one into a nursing home during this stage. Many people with Late Stage AD have multiple chronic illnesses that can best be cared for by trained staff in a nursing home setting. This can free you from the demands of physical care. Your time with her can then be spent letting her know how much she is loved and that you will be with her to the end.

If this is your choice, it does not mean you have failed! More caregivers than you think have made this choice for end-of-life care. Before making your choice about which nursing home to select, be sure to visit them and ask questions about the types of care they provide.

Things you can ask the nursing home staff:

- Does each shift have enough nursing help to be able to take care of the residents as they'd like?
- Do they enjoy their work?
- Are the nursing assistants always given the same residents to care for?
- Is there a family council?

- Are the nursing assistants involved in the care planning process?
- How much training about AD is given to the staff? Is it enough?
- How often are residents who need help assisted with toileting or have their disposable briefs changed?
- How long has the current administrator been at the nursing home?
- Has the nursing home recently had a change in ownership or management?
- Can they give you an example of how special care is given to the residents with AD?
- What happens if someone has a complaint or problem?

Things you can learn from talking with other families of nursing home residents:

- Is attention given to residents at night if they wake up?
- Is the staff responsive to family and resident requests?
- Does the staff assist the residents with going to the bathroom?
- Does the staff make sure that bedridden residents eat and drink regularly?
- Has their resident family member had anything lost or stolen?
- Who handles the resident's concerns?
- What are the best and worst things about living in the nursing home?

Getting the Best From Nursing Home Care

Your daily visits and love are the key to getting good care for your loved one in the nursing home. Make sure you:

- Speak up if you have problems or concerns
- Thank the staff for a good job
- Attend family council meetings
- Attend care plan meetings
- Make sure her doctor knows what is in the care plan
- Get to know the staff and help them get to know your loved one
- Tell the staff about her likes, dislikes and daily routines

The Alzheimer's Association can help you find nursing homes with special Alzheimer's care. (See Resources on page 93.)

Hospice Programs

Hospice may be another program available in your area. Hospice care is about "quality of life" and "death with dignity." For Medicare to pay for this, your doctor must state that your loved one with AD has no more than six months to live.

Taking Care of Yourself: Protecting the Quarterback

Right now you may feel too tired to think about what you need. However, your years of caregiving are coming to an end.

This last stage of AD is a sad time. You will grieve as she slowly approaches death. Take comfort in your family and what a good job you have done as a caregiver.

If you have chosen to keep her at home, you will need to learn new skills. Moving a bed-bound person requires skill and training. You will need to learn how to move and turn your loved one over without hurting her or yourself.

"Sometimes even my best offensive plans didn't work out. Sometimes even my best players got frustrated. But we never gave up, no matter what the score.

"You may feel discouraged many times. You will become angry at the disease and upset that you can't do more. You may decide you need more help or that your loved one needs a nursing home. That doesn't mean you failed. It means you do whatever it takes to stay in the game. And even in the late stages, there are things you can do with and for your loved one that make the day worthwhile."

—Coach Broyles

It is time for you and your family to talk about her end-of-life care. If she does not have a living will, you will need to talk about what type of care she would want. Families often choose only “comfort care”. Comfort care means keeping her pain-free. It may include giving her oxygen to help her breathe better. It does not include giving her drugs for an infection or fluids and food through a feeding tube.

Letting Go

As time passes, she won’t be able eat or drink without choking. You will need to make a choice about letting her slip away or feeding her through a tube in her stomach.

What you should know before making this choice:

- She will not feel hunger or thirst as she approaches death.
- Lack of food and fluids can reduce pain.
- A feeding tube will not prevent her weight loss.
- A feeding tube or IV may make her more uncomfortable.

Hopefully, you have already talked with her about what she would like done at this stage. If not, talk with your family and her doctor before making these decisions.

The time for letting your loved one go is very close.

SURVIVAL TIPS

- Put staying healthy at the top of your list.
- Have a backup plan in case something unexpected happens to you.
- Take one day at a time.
- Keep your sense of humor.
- Pat yourself on the back for the good job you are doing.
- Get enough rest and eat right.
- Make time for the things you like to do.
- Talk about how you feel with others.
- Listen to your friends.
- Make a list of all the things your loved one can still do.

Your loved one's world has shrunk to one or two rooms in the house. She has lost all interest in what goes on around her. She can no longer use her sight to help tell her what is happening in the world. Part of this is because of her severe memory loss. She no longer recognizes any objects or people. She will spend most of her time in bed or sitting propped up by pillows. Since she can't move around much, she will be at risk for:

- Sores on her skin
- Painful stiffness in her joints
- Infections like pneumonia

"Sometimes another team would roll over us and score a lot of points with relative ease. No matter what we tried, they scored. At those times, even our best wasn't good enough—we just faced a stronger team. We hated to lose, but we also had to realize that there would be teams out there that were stronger than we were. It made our team stronger because we shared both the successes and the defeats.

"In Late Stage AD, the caregiver knows that the best he or she can do is keep the person with AD safe and comfortable. This is the time when you, your family members and your friends should celebrate the small victories. This is the time when love is the best thing we have to offer."

—Coach Broyles

Communication Changes

- In Late Stage AD, she will no longer be able to tell you what she needs or if she is in pain. You will need to learn how to tell what she needs by looking at her.
- She is now limited to grunts and moans.
- The muscles in her face don't work anymore.
- She may cry or make laughing sounds.

Helpful things you can do:

- Love her.
- Talk to her. Sing to her.
- Hug her. Touch her. Hold her hand.
- Stick to your plan for meeting her daily needs.
- Write down how much she eats and drinks each day.
- Write down when she has bowel movements.
- Write down how often you turn her from side to side.
- Write down how often she is up in the chair.
- Write down if she cries out when moved a certain way. This may be a sign of pain she cannot tell you about.

Changes in Body Control

- She has little or no control over her body.
- She can't turn over in bed.
- She leans to one side if sitting up.
- She falls over in the chair if she is not propped up.
- She is limited to a chair or the bed.

Helpful things you can do:

- Love her.
- Touch her often.
- Reassure her.
- Change her body position every two hours.
- Gently rub her skin if she has areas of redness.
- Rent a "geri-chair" that can be put into several positions.
- Make sure her clothing is not bunched up if she

is sitting.

- Use pillows or a wedge to prop her upright.

Muscle Changes

- The muscles that bend her arms and legs will stop working.
- She will lie curled up in the bed like a baby.
- Her joints will become very stiff.
- She will forget how to sit up.

Helpful things you can do:

- Be very gentle when moving her.
- Slowly unbend her arms and legs. Do not force the joints.
- Give her medicine for any pain.
- If she can help you hold her weight, stand her up.
- Get another person to help you stand her up or walk her from bed to chair.

Skin Changes

- Her skin loses its stretch.
- She bruises easily.
- Her skin tears easily.
- She may get sores on her elbows, hips, heels and bottom.

Helpful things you can do:

- Be very gentle when you touch or move her.
- Keep her skin clean.
- Keep her arms, elbows, back and legs moist by using lotion.
- Use soft booties to keep her heels off the bed.
- Change her position in the bed or chair every two hours.
- Look at her skin for any tears or sores.
- Look at her skin for red spots when you move her.
- Use gentle rubbing and lotion if you see a red spot on her skin.
- Mark the size of the red spot with a pen.
- Keep an eye on the red spot to see if it gets bigger.
- Touch the skin around the red spot to see if it feels mushy. This can be a sign that she is getting a sore under her skin that you cannot see yet. Keep her weight off of the red spot.
- Use a special mattress cover designed to protect the skin.

Bowel and Bladder Changes

Many people with AD have lost control of their bowels and bladder in Middle Stage AD. You may have taken her to the bathroom at regular times to help with this.

In Late Stage AD, you will need to make a plan to check her every few hours. The goal is to keep her clean and dry. This will help the skin around her bottom stay healthy. Be sure to write down if she was wet or had a bowel movement so that you can keep track of this.

Helpful things you can do:

- Use a rubber or plastic cover on the mattress.
- Use adult-size diapers.
- Make sure that the diaper fits well and does not pinch.
- If she is in the bed, open the diaper so that air can get to her skin.
- Use a gentle soap and rinse carefully when you clean her.

Mouth Care

Keeping her mouth clean and her tongue and lips moist is very important. It is also comforting. Think about how your mouth feels and tastes when you wake up in the morning. Your tongue is dry and your mouth tastes terrible.

- She is no longer able to ask for water or help you clean her teeth.
- She can't follow directions to "rinse and spit."
- She can't open her mouth when you ask her to.
- She doesn't understand why your hands are in her mouth.
- Her dentures don't fit because she has lost weight.

Helpful things you can do:

- Get all of your supplies together before you start.
- Talk to her and tell her what you are doing.
- Never force her mouth open.
- Take her dentures out if they don't fit.
- Use a soft toothbrush to gently clean her teeth, gums and tongue.
- Use very little toothpaste or fluid so she does not choke.
- Put her on her side so the fluid can run out of her mouth.
- Use small amounts of glycerin on her tongue to increase the amount of spit in her mouth.
- Offer small sips of water throughout the day.
- Put petroleum jelly on her lips. It is not water-based so it does not dry out.

Weight Loss

This is a common change. It happens because her body can't get the nourishment it needs from the food she eats anymore. There is really nothing you can do about it. She will continue to lose weight no matter what she is eating.

"No matter how picky my players might be, I always found something they would enjoy eating. They were big, healthy boys, and I loved watching them enjoy their food.

"But as a caregiver, I was told that in the late stages my wife was not going to be able or willing to eat. I tried everything I could think of until her body finally forgot how to chew and swallow. I learned that this was nature's way of telling me it was almost time for her to go."

—Coach Broyles

Eating Changes

In Late Stage AD, you will find that she doesn't seem to care about eating or drinking anymore. This is very common. She will begin to have more trouble with chewing and swallowing. This will increase her risk of choking. When she chokes, the food or fluid in her mouth is going into her lungs instead of her stomach. This can cause pneumonia.

Helpful things you can do:

- Get her into a sitting position before you feed her.
- Don't rush her.
- Play soft music.
- Serve soft foods.
- Use your blender to change the texture of food.
- Thicken liquids so she doesn't choke.

- Keep a list of foods she will still eat.
- Try sweet, salty, sour or spicy foods/seasonings. Be flexible. Her tastes may change daily.
- Check to see if she has swallowed before feeding her the next bite.
- Try ice cream, thick soups or milkshakes with an egg or protein mix added to them.

CONCLUSION/ RESOURCES

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Poem

Acknowledgments

Conclusion: A Note From Coach Frank Broyles

Dear Caregiver,

By the time you have finished working your way through this "Playbook for Alzheimer's Caregivers," and caring for your loved one, you will have experienced many emotions—sadness, joy, frustration, hope and fear, to name a few.

When a person decides to be a caregiver for a loved one with Alzheimer's disease, he or she has no idea of the physical hardships, personal sacrifices and emotional rollercoaster rides that lie ahead. Only another caregiver can truly appreciate and understand your experience. As a former caregiver, I do appreciate and understand that you have completed a labor of love—the most wonderful gift you could ever give a loved one.

But now it is time for you to take care of YOU. Be proud of your accomplishments. Give yourself credit for all you have done. Remember to celebrate even the smallest successes. Allow yourself to grieve your loss. Give your body time to regain strength. Take care of your own health. Once you have given yourself a chance to heal, remember this: You have joined the ranks of a special group of people—Alzheimer's caregivers. You have

become a role model for those who will follow. There are millions of people living with Alzheimer's and millions of caregivers who are starting out just like you did. Chances are, you will meet some of them in the months and years ahead. Share your story with them. Share the wisdom and knowledge you gained during your journey. Let your labor of love live on.

Sincerely,

Frank Broyles
University of Arkansas,
Razorback Athletic Director Emeritus

Resources: A Quick Reference

There are many resources available for caregivers in your area. Here is a listing of phone numbers and web pages to get you started.

ALZHEIMER'S ASSOCIATION
24-hour helpline: 800-272-3900 (toll-free)
Web site: www.alz.org

GOLDEN LIVING
877-870-0162 (toll-free)
Web site: www.goldenlivingcenters.com

BEVERLY LIVING
877-841-0342 (toll-free)
Web site: www.beverlycares.com

WEB RESOURCES: NATIONAL

- Administration on Aging
  www.aoa.gov
- Alzheimer's Disease Education & Referral Center
  www.alzheimers.org
- Family Caregiver Alliance®
  www.caregiver.org/caregiver
- Hospice Net
  www.hospicenet.org/html/find.html
- National Institute of Mental Health
  www.nimh.nih.gov

Do not ask me to remember.
Don't try to make me understand.
Let me rest and know you're with me.
Kiss my cheek and hold my hand.

I'm confused beyond your concept.
I am sad and sick and lost.
All I know is that I need you
To be with me at all cost.

Do not lose your patience with me.
Do not scold or curse or cry.
I can't help the way I'm acting,
Can't be different 'though I try.

Just remember that I need you,
That the best of me is gone.
Please don't fail to stand beside me,
Love me 'til my life is done.

—Author unknown

The Playbook was absolutely a labor of love for Coach Broyles. He assembled a most impressive "All American" team, to help formulate a much needed caregiver tool, and make it a reality—in the format of guide and reference book for Alzheimer's caregivers.

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Playbook on the Web: www.alzheimersplaybook.com

Available for download in English (Audio Available), Spanish (Audio Available), Hindi, Arabic, Chinese, French, Italian, Japanese, Portuguese, German, Danish

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For additional Playbook copies and Alzheimer's disease information:

alzheimer's association

www.alz.org • 24-hour helpline
800-272-3900 (toll-free)

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