The following is a collection of our most requested information sheets about Alzheimer’s, caregiving, and the Heart of America Chapter.

Each of these sheets can also be accessed individually on our website (alz.org/kansascity, click on Resource Library/Information Sheets) or in our Main Chapter Resource Library during regular office hours.

If you have any questions about these information sheets, please contact our Main Chapter Office at: 913.831.3888
The Heart of America Chapter has resources and support services for those with memory loss, their families, and care partners. We are here to help you 24 hours a day, seven days a week.

• 24-hour Information and Support line: 800.272.3900
• Family Connections Program: Individualized care consultations provided by dementia care specialists
• Chapter Resource Library: A collection of books, videos, brochures, and resource lists
• Support Groups and Breakfast Clubs: Meet regularly throughout the area for peer support and to exchange information
• Social Engagement Groups: Engaging activities for individuals with dementia

We offer regularly scheduled classes and workshops for individuals with memory loss, their care partners, and health professionals.

Educational programs include:
• Understanding Alzheimer’s and Dementia
• Living with Alzheimer’s
• Legal and Financial Planning
• Effective Communication Strategies
• Understanding and Responding to Dementia-related Behavior
• Online and remote learning opportunities available
• A full listing of available educational programs is available at communityresourcefinder.org or by calling 1.800.272.3900

The Heart of America Chapter staff and volunteers work to raise awareness of, and advocate for, the needs and rights of people with dementia.

• Action Alerts: Timely electronic updates on policies related to dementia
• Weekly e-news with national and local information
• Chapter website and social media interaction
• Chapter representatives speaking out on dementia issues at a variety of community venues
• Grassroots legislative efforts

BE AN ADVOCATE. Yours is the voice we are missing. You can urge support for critical Alzheimer’s legislative changes and work locally and nationally to advance key initiatives.
Providing programs and services in 66 Kansas and Missouri counties

KANSAS
Allen    Dickinson    Linn    Republic
Anderson  Doniphan    Lyon    Riley
Atchison  Douglas    Marshall    Saline
Bourbon   Franklin    Miami    Shawnee
Brown     Geary    Morris    Wabaunsee
Cherokee  Jackson    Nemaha    Washington
Clay      Jefferson    Neosho    Wyandotte
Cloud     Johnson    Osage
Coffey    Labette    Ottawa
Crawford  Leavenworth    Pottawatomie

MISSOURI
Andrew    Clinton    Jackson    Putnam
Atchison  Daviess    Johnson    Ray
Bates     Dekalb    Lafayette    St. Clair
Buchanan  Gentry    Linn    Sullivan
Caldwell  Grundy    Livingston    Worth
Carroll   Harrison    Mercer
Cass      Henry    Nodaway
Clay      Holt    Platte

HELPING YOU every step of the way

In addition to the regional offices listed below, personal consultations are available in all counties we serve.

Main Office and Education Center
3846 W. 75th Street
Prairie Village, KS 662086

Northeast Kansas Regional Office
3625 SW 29th Street, Suite #102
Topeka, KS 66614

Northwest Missouri Regional Office
927 Faraon
St. Joseph, MO 64501

Southeast Kansas Regional Office
2601 Gabriel, UCDD Building
Parsons, KS 67357

24-hour Information and Support Line
800.272.3900

alz.org/kansascity

1/2/2019
Alzheimer’s (AHLZ-high-merz) disease is a progressive brain disorder that gradually destroys a person’s memory and ability to learn, reason, make judgments, communicate and carry out daily activities. As Alzheimer’s progresses, individuals may also experience changes in personality and behavior, such as anxiety, suspiciousness or agitation, as well as delusions or hallucinations.

In late stages of the disease, individuals need help with dressing, personal hygiene, eating and other basic functions. The duration of the disease can vary from 2 to 20 years.

Although there is currently no cure for Alzheimer’s, new treatments are on the horizon as a result of accelerating insight into the biology of the disease. Research has also shown that effective care and support can improve quality of life for individuals and their caregivers over the course of the disease from diagnosis to the end of life.

Causes of Alzheimer’s disease
Alzheimer’s disease has no known single cause, but in the last 15 years scientists have learned a great deal about factors that may play a role.

Late-onset Alzheimer’s, which chiefly affects individuals over age 65, is the more common form of the illness that is most often associated with the term “Alzheimer’s disease.” Known risk factors for late-onset Alzheimer’s are increasing age, a family history of the disease, diabetes, hypertension, high cholesterol, head injury and other risk factors. The likelihood of developing late-onset Alzheimer’s approximately doubles every five years after age 65. By age 85, the risk reaches nearly 50 percent. Scientists have so far discovered one gene that increases risk for late-onset disease.

Rare, familial types of Alzheimer’s found in a few hundred families worldwide have been linked to specific genes. Individuals who inherit these genes are virtually certain to develop the disease, usually before age 65, and sometimes as early as their 30s or 40s.

Researchers are working to discover other factors that affect Alzheimer risk. Some of the most exciting preliminary evidence suggests that strategies for general healthy aging may also help reduce the risk of developing Alzheimer’s. These measures include controlling blood pressure, weight and cholesterol levels; exercising both body and mind; and staying socially active.

How Alzheimer’s disease affects the brain
Scientists believe that whatever triggers Alzheimer’s begins to damage the brain years before symptoms appear. When symptoms emerge, nerve cells that process, store and retrieve information have already begun to degenerate and die. Scientists regard two abnormal microscopic structures called “plaques” and “tangles” as the hallmarks of Alzheimer’s disease. Amyloid plaques (AM-uh-loyd plaks) are clumps of protein fragments that accumulate between the brain’s nerve cells. Tangles are twisted strands of another protein that form inside brain cells. Scientists have not yet determined the exact role that plaques and tangles may play.

Diagnosing Alzheimer’s disease
Although Alzheimer symptoms can vary widely, the first problem that many people notice is forgetfulness severe enough to affect performance at home, at work or in activities. Sometimes the decline in memory may be more obvious to a family member or close friend than to the affected individual. Other common symptoms include getting lost in familiar places and difficulty with language. The Alzheimer’s Association encourages everyone who notices these symptoms in themelves or someone close to them to consult a physician.

A skilled physician can diagnose Alzheimer’s disease with 90 percent accuracy. Because there is no single test for Alzheimer’s, diagnosis usually involves a thorough medical history and physical examination as well as tests to assess memory and the overall function of the mind and nervous system. The physician may ask a family member or close friend about any noticeable change in the individual’s memory or thinking skills.

Most diagnostic uncertainty arises from occasional difficulty distinguishing Alzheimer’s disease from a related disorder.
Alzheimer’s is the leading cause of dementia, a group of conditions that all gradually destroy brain cells and lead to progressive decline in mental function. Vascular dementia, another common form, results from reduced blood flow to the brain’s nerve cells. In some cases, Alzheimer’s disease and vascular dementia can occur together in a condition called “mixed dementia.” Other causes of dementia include frontotemporal dementia, dementia with Lewy bodies, Creutzfeldt-Jakob disease and Parkinson’s disease.

One important goal of the diagnostic workup is to determine whether symptoms may be due to a condition other than dementia. Depression, medication side effects, certain thyroid conditions, excess use of alcohol and nutritional imbalances are all potentially treatable disorders that may sometimes impair memory or other mental functions. Even if the diagnosis is dementia, timely identification enables individuals to take an active role in treatment decisions and planning for the future.

Treat Alzheimer’s disease
Alzheimer medications approved by the U.S. Food and Drug Administration (FDA) may temporarily delay memory decline for some individuals, but none of the currently approved drugs is known to stop the underlying degeneration of brain cells. Certain drugs approved to treat other illnesses may sometimes help with the emotional and behavioral symptoms of Alzheimer’s.

One important part of treatment is supportive care that helps individuals and their families come to terms with the diagnosis; obtain information and advice about treatment options; and maximize quality of life through the course of the illness.

Impact on caregivers
Alzheimer’s has a major impact on those who help care for an affected individual. Seventy percent of people with Alzheimer’s live at home, where family and friends provide most of their care. As the disease progresses, it places physical, emotional and financial stress on caregivers as they assume growing responsibilities that may include meeting physical needs, managing daily routines and making important medical and legal decisions.

Impact on society
Alzheimer’s takes an enormous toll on society. The Alzheimer’s Association estimates that current direct and indirect costs of caring for the more than 5 million Americans with Alzheimer’s disease amount to more than $148 billion annually. By 2030, when our entire baby boom generation is over 65, the number of Americans with Alzheimer’s will soar to levels that may exceed our ability to absorb the added cost.

Hope for the future
As the pace of research accelerates, scientists funded by the Alzheimer’s Association, the pharmaceutical industry, universities and our federal government have gained detailed understanding of basic disease processes at work in the Alzheimer brain. Experts believe that several of these processes may offer promising targets for a new generation of treatments to prevent, slow or even reverse damage to nerve cells. Many experts are also convinced that ongoing research will soon clarify the role of cardiovascular factors or other aspects of risk that individuals may be able to influence through lifestyle. A strategy to delay the onset of Alzheimer’s by five years could halve the number of affected individuals over the next 50 years.
Alzheimer’s Disease and Other Dementias

About dementia
Dementia is a general term for a group of brain disorders. Alzheimer’s disease is the most common type of dementia, accounting for 60 to 80 percent of cases. This face sheet briefly discusses Alzheimer’s and some other dementias.

All types of dementia involve mental decline that:

- occurred from a higher level (for example, the person didn’t always have a poor memory).
- is severe enough to interfere with usual activities and daily life.
- affects more than one of the following four core mental abilities.
  - recent memory (the ability to learn and recall new 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, etc., and the brain’s ability to translate visual signals into a correct impression of where objects are in space).
  - executive function (the ability to plan, reason, solve problems and focus on a task).

Alzheimer’s Disease
Although symptoms can vary widely, the first problem many people with Alzheimer’s notice is forgetfulness severe enough to affect their work, lifelong hobbies or social life. Other symptoms include confusion, trouble with organizing and expressing thoughts, misplacing things, getting lost in familiar places, and changes in personality and behavior.

These symptoms result from damage to the brain’s nerve cells. The disease gradually gets worse as more cells are damaged and destroyed. Scientists do not yet know why brain cells malfunction and die, but two prime suspects are abnormal microscopic structures called plaques and tangles.

Vascular Dementia
Many experts consider vascular dementia the second most common type, after Alzheimer’s disease. It occurs when clots block blood flow to parts of the brain, depriving nerve cells of food and oxygen. If it develops soon after a single major stroke blocks a large blood vessel, it is sometimes called “post-stroke dementias.”

It can also occur when a series of very small strokes, or infarcts, clog tiny blood vessels. Individually, these strokes do not cause major symptoms, but over time their combined effect is damaging. This type used to be called “multi-infarct dementia.”

Symptoms of vascular dementia can vary, depending on the brain regions involved. Forgetfulness may or may not be a prominent symptom, depending on whether memory areas are affected. Other common symptoms include difficulty focusing attention and confusion. Decline may occur in “steps,” where there is a fairly sudden change in function.

People who develop vascular dementia may have a history of heart attacks. High blood pressure or cholesterol, diabetes or other risk factors for heart disease are often present.

Mixed dementia
In mixed dementia, Alzheimer’s disease and vascular dementia occur at the same time. Many experts believe mixed dementia develops more often than was previously realized and that it may become increasingly common as people age. This belief is based on autopsies showing that the brains of up to 45 percent of people with dementia have signs of both Alzheimer’s and vascular disease.

Decline may follow a pattern similar to either Alzheimer’s or vascular dementia or a combination of the two. Some experts recommend suspecting mixed dementia whenever a person has both (1) evidence of cardiovascular disease and (2) dementia symptoms that get worse slowly.
Dementia with Lewy bodies (DLB)
In DLB, abnormal deposits of a protein called alpha-synuclein form inside the brain’s nerve cells. These deposits are called “Lewy bodies” after the scientist who first described them. Lewy bodies have been found in several brain disorders, including dementia with Lewy bodies, Parkinson’s disease and some cases of Alzheimer’s.

Symptoms of DLB include:
- Memory problems, poor judgment, confusion and other symptoms that can overlap with Alzheimer’s disease.
- Movement symptoms are also common, including stiffness, shuffling walk, shakiness, lack of facial expression, problems with balance and falls.
- Excessive daytime drowsiness.
- Visual hallucinations.
- Mental symptoms and level of alertness may get better or worse (fluctuate) during the day or from one day to another.
- In about 50 percent of cases, DLB is associated with a condition called rapid eye movement (REM) sleep disorder. REM sleep is the stage where people usually dream. During normal REM sleep, body movement is blocked and people do not “act out” their dreams. In REM sleep disorder, movements are not blocked and people act out their dreams, sometimes vividly and violently.

Parkinson’s disease (PD)
Parkinson’s is another disease involving Lewy bodies. The cells that are damaged and destroyed are chiefly in a brain area important in controlling movement. Symptoms include tremors and shakiness; stiffness; difficulty with walking, muscle control, and balance; lack of facial expression; and impaired speech. Many individuals with Parkinson’s develop dementia in later stages of the disease.

Frontotemporal dementia (FTD)
FTD is a rare disorder chiefly affecting the front and sides of the brain. Because these regions often, but not always, shrink, brain imaging can help in diagnosis. There is no specific abnormality found in the brain in FTD. In one type called Pick’s disease, there are sometimes (but not always) abnormal microscopic deposits called Pick bodies.

FTD progresses more quickly than Alzheimer’s disease and tends to occur at a younger age. The first symptoms often involve changes in personality, judgment, planning and social skills. Individuals may make rude or offensive remarks to family or strangers, or make unwise decisions about finances or personal matters. They may show feelings disconnected from the situation, such as indifference or excessive excitement. They may have an unusually strong urge to eat and gain weight as a result.

Creutzfeldt-Jakob disease (CJD)
Creutzfeldt-Jakob disease (pronounced CROYZ-felt YAH-cob) is a rare, rapidly fatal disorder affecting about 1 in a million people per year worldwide. It usually affects individuals older than 60. CJD is one of the prion (PREE-awn) diseases. These disorders occur when prion protein, a protein normally present in the brain, begins to fold into an abnormal three-dimensional shape. This shape gradually triggers the protein throughout the brain to fold into the same abnormal shape, leading to increasing damage and destruction of brain cells.

Recently, “variant Creutzfeldt-Jakob disease” (vCJD) was identified as the human disorder believed to be caused by eating meat from cattle affected by “mad cow disease.” It tends to occur in much younger individuals, in some cases as early as their teens.

The first symptoms of CJD may involve impairment in memory, thinking and reasoning or changes in personality and behavior. Depression or agitation also tend to occur early. Problems with movement may be present from the beginning or appear shortly after the other symptoms. CJD progresses rapidly and is usually fatal within a year.
Huntington’s disease (HD)

HD is a fatal brain disorder caused by inherited changes in a single gene. These changes lead to destruction of nerve cells in certain brain regions. Anyone with a parent with Huntington’s has a 50 percent chance of inheriting the gene, and everyone who inherits it will eventually develop the disorder. In about 1 to 3 percent of cases, no history of the disease can be found in other family members. The age when symptoms develop and the rate of progression vary.

Symptoms of Huntington’s disease include twitches, spasms, and other involuntary movements; problems with balance and coordination; personality changes; and trouble with memory, concentration or making decisions.

Wernicke-Korsakoff syndrome

Wernicke-Korsakoff syndrome is a two-stage disorder caused by a deficiency of thiamine (vitamin B-1). Thiamine helps brain cells produce energy from sugar. When levels of the vitamin fall too low, cells are unable to generate enough energy to function properly. Wernicke encephalopathy is the first, acute phase, and Korsakoff psychosis is the long-lasting, chronic stage.

The most common cause is alcoholism. Symptoms of Wernicke-Korsakoff syndrome include:

- confusion, permanent gaps in memory and problems with learning new information.
- individuals may have a tendency to “confabulate,” or make up information they can’t remember.
- unsteadiness, weakness and lack of coordination.

If the condition is caught early and drinking stops, treatment with high-dose thiamine may reverse some, but usually not all, of the damage. In later stages, damage is more severe and does not respond to treatment.
ABC’s of Coping

1. The desire not to think about what you are facing is normal, but you can grow beyond it. Recognizing that this is a progressive, degenerative disease is painful. One of the biggest challenges you face is to accept what is happening.

2. The process of this disease is predictable. Your loved one will lose functional ability. While change is inevitable, the timeline of change varies. It is important for you to watch for the time at which your loved one becomes a danger to himself or others (for example: driving, using the stove, forgetting to eat, taking medicine or not remembering they have already taken the medicine, wandering, becoming combative, etc). At such times you will have to make decisions on behalf of your loved one.

3. Your loved one can still do many things. Celebrate the abilities your loved one continues to have and explore new expressions of those abilities. Help them find ways to do for you and others. Consider exercise, use of creativity and activities outside.

4. Your loved one is doing the best he can. Behaving badly is a result of their confusion and disorientation. He/she is not doing these things on purpose just to upset or get back at you. Individuals with Alzheimer's disease cannot “just try harder” and it is not realistic to expect them to do what they used to do.

5. Educate yourself. Understand both the biology of the disease and the emotional toll it takes on the person with the disease. Be open with your physicians and bring questions/concerns to them and others. Encourage other family members to learn as well.

6. You, not he/she, will have to change. Your loved one's ability to change is extremely limited and will diminish as the disease progresses. This means that you will have to learn to accept your loved one's behavior and learn how to alter your expectations and reactions. It will help both of you if you build as much of a routine as possible into your day and break tasks into single simple steps.

7. Your emotional relationship with your loved one will change. Relationships can become closer. New versions of relationships can emerge and there will be parts of the relationship that will be missed.

8. Be aware of the grief that accompanies the process of loss. All kinds of emotions can be part of the grief experience and depression is common. Take emotional care of yourself which often means continuing in enjoyable hobbies, being honest with close family and friends, taking time for yourself, participating in support groups and seeking help from a counselor when needed.

9. Some families successfully care for their loved one at home and many successfully place their loved one under the care of others. Many people have had to change their plans as circumstances change. There may come a time when placement becomes necessary. Whether a person remains in the home or transitions to long term care, what is important is securing enough help to allow you to enjoy time with your loved one.

10. This is the rainy day for which you have saved. Be willing to plan effectively and to use your resources to care for your loved one and yourself.

11. There is life after Alzheimer’s. Involvement in support groups like the Alzheimer’s Association will help you and others. You must plan for your future. YOU DO HAVE ONE!
How to Contact the Alzheimer’s Association – Heart of America Chapter
1.800.272.3900 • alz.org/kansascity

The Heart of America Chapter provides programs and services in 66 counties in Kansas and Missouri. These programs and services are made possible thanks to generous donations from individuals, corporations, and foundations. Contributions and donations allow the Chapter to provide supportive services, including care consultations, free of charge to individuals and families.
Communicating with Health Care Professionals

Physicians and other medical professionals play a central role on a person with dementia’s care team — a group of people that often includes family, friends and other individuals who work together to ensure the best care possible. Effective communication is important among the entire care team, particularly when meeting with health care providers, as it can help ensure comfort in asking questions and expressing needs and concerns.

Advice for the person with dementia

Prepare for visits

The following can be helpful as you prepare for a visit with a health care professional:

- Document any changes in health, including mood, memory and behaviors, and any questions that should be addressed at the next appointment
- Make note of any progress you have noticed since your last appointment
- Create a list of current prescriptions and over-the-counter medications
- Write down any vitamins or supplements added to the medication regimen

Ask questions

Whether you are newly diagnosed or experiencing recent changes, it’s normal to have questions about the disease, and it’s common to forget what you’d like to ask a doctor. Consider bringing a list of questions to each appointment so that you are prepared to discuss. Also, be sure to let the physician or other medical professionals know if you need additional information or clarification.

The Alzheimer’s Association National Early-Stage Advisory Group – comprising men and women from across the country living with early-stage Alzheimer’s or other dementias – developed a list of questions to help others make the most of doctor visits. These questions may be helpful as you create your own list to share with the doctor.

Diagnosis

- What test(s) or tools were used to determine the diagnosis?
- Can symptoms be attributed to any other causes?
- How will the disease progress?
- How will the diagnosis impact daily health or other pre-existing conditions?

Treatments

- What treatment options are available?
- Which symptoms are being targeted by each medication?
- Are there alternative treatments available?
- How will the effectiveness of each treatment be measured?
- Are there any possible side effects?
- Is one treatment option more likely than another to interfere with medications for other conditions?

Clinical Studies

- What clinical studies are available?
- Is published information about clinical treatment studies available?
- What are the possible risks and benefits for participation in a clinical study based on my medical history?

Health care team

- How familiar are you with Alzheimer’s Disease?
- Who will be responsible for overseeing my care moving forward?

continued
Communicating with Health Care Professionals

- If hospitalization is necessary, will you be able to provide care in this setting?
- How frequently will follow-up appointments be scheduled?
- Under what circumstances should I contact you?
- Who else might be recommended as a member of my care team (e.g., specialist, counselor)? What would their roles be?
- At what point will you consider me unable to make my own health care decisions?
- How will you work with my care team during the course of the disease? What information will be shared?

**Care and support**

- What resources and support services are available to learn more about the diagnosis and help me live well with the disease for as long as possible?
- Are there any lifestyles changes that may help me continue to live well with the disease?

**Advice for care partners**

**In the early stage**

While in the early stage of Alzheimer’s, the person should be included in all conversations regarding care and encouraged to independently share any health-related observations with the physician and other members of the medical team. If you need to help interpret any changing needs, you may want to ask before interjecting.

At this point, you may want to ask the person with dementia to sign a release of information so that you can freely communicate with the doctor on the person’s behalf when the disease becomes more advanced.

**As the disease advances**

Over time, as the person’s needs change and ability to communicate declines, the care team should consider what adjustments to make in order to ensure good health care. The team will also need to provide any updates on behalf of the person with dementia in order to maintain accurate health records that are accessible in case of emergency.

---

**How to Contact the Alzheimer’s Association – Heart of America Chapter**

1.800.272.3900 • alz.org/kansascity

The Heart of America Chapter provides programs and services in 66 counties in Kansas and Missouri. These programs and services are made possible thanks to generous donations from individuals, corporations, and foundations. Contributions and donations allow the Chapter to provide supportive services, including care consultations, free of charge to individuals and families.
Driving

Driving is a complex activity that requires quick thinking and reactions, as well as good perceptual abilities. For the person with Alzheimer’s disease, driving becomes a safety issue. While he or she may not recognize that changes in cognitive and sensory skills impair driving abilities, you and other family members will need to be firm in your efforts to prevent the person from driving when the time comes.

That said, it’s important to consider the person’s feelings and perceived loss of independence when explaining why he or she can no longer drive. Helping the person with dementia make the decision to stop driving — before you have to force him or her to stop — can help maintain a positive sense of self-esteem.

How dangerous is it?

Previous studies demonstrate that poor driving performance increases with increased dementia severity. However, not all people with Alzheimer’s are unsafe drivers at a given point in time. What’s more, drivers with dementia are not in more crashes than non-demented elderly drivers, suggesting that dementia should not be the sole justification for suspending driving privileges. Instead, an on-the-road driving test, or other functional test, is the best way to assess driving skills in dementia.

Some state agencies have special drive tests to determine how well a person sees, judges distance and responds to traffic. Ask the person who administers the test to explain the results to you and the person with dementia. If your state does not offer special testing, private assessments (generally fee-for-service) may be available. Your local Alzheimer’s Association may be able to provide a list of these programs.

How do you know when the time has come?

There are also a number of steps you can take to assess the person’s ability to drive.

1) Look for signs of unsafe driving

Signs of unsafe driving include:

- Forgetting how to locate familiar places.
- Failing to observe traffic signs.
- Making slow or poor decisions in traffic.
- Driving at an inappropriate speed.
- Becoming angry or confused while driving.
- Evidence of car contact with garage, curbs, etc.
- Entering intersection before coming to a stop.
- Trouble with lane control.
- Inappropriate distance between self and other cars.

Keep a written record of your observations to share with the person, family members and health care professionals.

2) Learn about your state’s driving regulations

In some states, such as California, the physician must report a diagnosis of Alzheimer’s to the health department, which then reports it to the department of motor vehicles. That agency then may revoke the person’s license. Check with your local Alzheimer’s Association for information on driving regulations in your state.
Driving

Tips to limit driving

Once it’s clear the person with dementia can no longer drive safely, you’ll need to get him or her out from behind the wheel as soon as possible. If possible, involve the person with dementia in the decision to stop driving. Explain your concerns about his or her unsafe driving, giving specific examples, and ask the person to voluntarily stop driving. Assure the person that a ride will be available if he or she needs to go somewhere.

Other tips to discourage driving include:

• Transition driving responsibilities to others. Tell the person you can drive, arrange for someone else to drive, or arrange a taxi service or special transportation services for older adults.
• Find ways to reduce the person’s need to drive. Have prescription medicines, groceries or meals delivered.
• Have individual evaluated at a medically-based driver’s evaluation program such as at Shawnee Mission Medical Center and the Rehab Institute.
• Solicit the support of others. Ask your physician to advise the person with dementia not to drive. Involving your physician in a family conference on driving is probably more effective than trying by yourself to persuade the person not to drive. Ask the physician to write a letter stating that the person with Alzheimer’s must not drive. Or ask the physician to write a prescription that says, “No driving.” You can then use the letter or prescription to tell your family member what’s been decided.
• Ask a respected family authority figure or your attorney to reinforce the message about not driving. Also ask your insurance agent to provide documentation that the person with dementia will no longer be provided with insurance coverage.
• Experiment with ways to distract the person from driving. Mention that someone else should drive because you’re taking a new route, because driving conditions are dangerous, or because he or she is tired and needs to rest. Tell the person he or she deserves a chance to sit back and enjoy the scenery. You may also want to arrange for another person to sit in the back seat to distract the person while someone else drives. If the disease is in an advanced stage, or there is a history of anger and aggressiveness, it’s best not to drive alone with the person.
• If the person with dementia wanders, he or she can also wander and get lost by car. Be prepared for a wandering incident and enroll the person in MedicAlert® + Alzheimer’s Association Safe Return®, a 24-hour nationwide emergency response service for individuals with Alzheimer’s or related dementia that wander or who have a medical emergency. To find out more information or to enroll, contact your local Alzheimer’s Association, call 1.888.572.8566 or register online at www.alz.org.
• In the later stages, when the person is no longer able to make decisions, substitute his or her driver’s license with a photo identification card. Take no chances. Don’t assume that taking away a driver’s license will discourage driving. The person may not remember that he or she no longer has a license to drive or even that he or she needs a license.

What if the person won’t stop?

If the person insists on driving, take these steps as a last resort:

• Control access to the car keys. Designate one person who will do all the driving and give that individual exclusive access to the car keys.
• Disable the car. Remove the distributor cap or the battery or starter wire. Ask a mechanic to install a “kill wire” that will prevent the car from starting unless the switch is thrown. Or give the person a set of keys that looks like his or her old set, but that don’t work to start the car.
Driving

- Consider selling the car. By selling the car, you may be able to save enough in insurance premiums, gas and oil, and maintenance costs to pay for public transportation, including taxicab rides.

- In some states, it might be best to alert the department of motor vehicles. Write a letter directly to the authority and express your concerns, or request that the person’s license be revoked. The letter should state that “[the person’s full name] is a hazard on the road,” and offer the reason (Alzheimer’s disease). The state may require a statement from your physician that certifies the person is no longer able to drive.
For You: The Person with Early Memory Loss

1. Learn all you can about the disease.
2. You are not alone.
5. Take care of your health. Include a nutritious diet, adequate rest and regular exercise.
6. Accept your feelings of sadness and anger without guilt.
7. Forgive yourself for mistakes or outbursts; you are only human.
8. Try to be realistic about what you can do. Decisions must be based on your changing needs.
9. Don’t hide; this is a disease. Use your voice to advocate for improved understanding of early stage Alzheimer’s.
10. Humorous things will happen. Greeting these with a laugh can really help.
11. Keep a journal of your past and present history. It is often helpful in sorting out your feelings. Journaling also gives you a way to organize your thoughts and keep track of changes.
12. Hold onto hope. There is much research being dedicated to finding disease modifying solutions!

Hints for Around the House

1. Give your neighbors a spare house key in case you are accidentally locked out.
2. Carry only a small amount of cash.
3. Have a list of your medications, hospital number, doctors’ numbers and numbers of close family and friends on your refrigerator and in your wallet.
4. It’s wise to rid your house of all guns.
5. We have all forgotten something on a stove burner at one time or another. A nearby smoke detector can help to prevent kitchen fires as well as burned pots.
6. Appliances that automatically shut-off are also useful.
7. Find and practice a medication reminder system.
8. Set up a Durable Power of Attorney and Living Will.
9. Set up a check and balance system for bills and account management. Numbers can be affected early or along with short term memory. It is best to have a mechanism to double check when finances are involved.
10. Find out about research studies going on in your area.

How to Contact the Alzheimer’s Association – Heart of America Chapter
1.800.272.3900 • alz.org/kansascity

The Heart of America Chapter provides programs and services in 66 counties in Kansas and Missouri. These programs and services are made possible thanks to generous donations from individuals, corporations, and foundations. Contributions and donations allow the Chapter to provide supportive services, including care consultations, free of charge to individuals and families.
Providing for safety is an important job for caregivers. A safe environment can help prevent injuries, and it can help the person with dementia feel relaxed and less overwhelmed. To enhance safety, assess the environment for hazards. Try to see the world through the eyes of a person who has Alzheimer’s and adapt the environment to his or her needs.

**Focus on prevention**

- Don’t expect the person to do things safely.
- Eliminate potential hazards.
- Be patient and slow down. Accidents can happen when a person is rushed.
- Simplify routines and provide step-by-step guidance, especially during complex personal care activities such as bathing, toileting and dressing.
- Be prepared to balance safety with needs for privacy and independence.
- Be realistic. You can’t anticipate every risk or prevent every problem.

**Guard against choking and poisoning**

- Due to changes in the brain, the person may not understand swallowing foreign substances could cause choking or poisoning.
- Lock cabinets and work rooms that contain toxic chemicals.
- Lock up all medications. Keep track of how many pills are being taken.
- Hide potentially dangerous toiletry items such as razor blades.
- Remove toxic plants such as poinsettias or mistletoe.
- Don’t let food spoil in the refrigerator or pantry.
- Test the temperature of food before it’s served. The person may not be able to tell when food is too hot to eat.
- Be prepared for the unusual. Some people may eat items such as gravel and dirt.

**Be careful about knives, appliances and electric tools**

- Be aware that the person may not remember how to use appliances and tools. Potential hazards include toaster ovens, stoves, coffee makers, power tools, lawn mowers and barbecue grills.
- Know that even apparently safe devices can be hazards. For example, a person may try to open a can by jabbing it with a screwdriver.
- Place at eye level appliances that the person can safely use.
- Discourage the person from entering the kitchen without you.
- Consider precautions such as locking up knives, hiding appliances and removing knobs from the stove when not in use.
- Unplug all heat-producing appliances, such as coffeemakers, when not in use.
- Consider turning off the gas and electricity in certain areas.
- Regularly check electrical cords for frays, breaks and other damage.
- Don’t let electrical cords dangle.
- Put safety covers on electrical outlets
Be careful about heat, cold and fire

- Keep in mind that a person with Alzheimer’s may lose sensitivity to temperature extremes and may forget about their dangers.

- Be cautious about items such as stoves, space heaters, curling irons, microwave-prepared food, and electric blankets and heating pads.

- Take precaution against scalding hot water. Set your hot water heater to 110 degrees F. Install anti-scald devices on faucets. Help the person test water temperatures and mix cold water with hot.

- Avoid accidents associated with cooking and eating:
  - turn pan handles toward the middle of the stovetop.
  - Do not let the person wear loose clothes while cooking.
  - Do not place containers of hot liquid near the edges of tables and countertops.
  - Pour hot liquids away from the person’s body; keep the pot as far away as possible.
  - Test the temperature of microwave-prepared foods.
  - Use place mats instead of tablecloths.

- Listen for sizzling and crackling sounds that indicate something is heating up.

- Cover all light bulbs with shades or globes.

- Hide matches and cigarette lighters.

- Keep the person from smoking, if possible. Or supervise an individual with dementia while he or she smokes.

- Install fire extinguishers and smoke alarms; check them monthly.

Prevent slips and falls

- Make sure the person wears non-skid shoes.

- Reduce clutter.

- Remove throw rugs, extension cords and other obstacles; don’t let pets sleep in traffic areas.

- Provide sturdy items to lean against along frequently traveled paths.

- Avoid rearranging furniture.

- Make sure carpets are properly tacked down on all sides.

- Wipe up spills immediately.

- Make stairways safe. Keep them well-lit, provide handrails on both sides, make sure steps are even and uniformly deep, and consider using a contrasting color along the edge of steps.

- Install child-proof gates at both the head and foot of stairs.

- Make sure lighting is evenly distributed to avoid “hot spots” and shadows.

- Install night lights on the path to the bathroom.

Ensure safety in bathrooms

- Install devices such as grab bars, bath seats and commode chairs.

- Put non-slip mats or appliqués in tubs and showers.

- Remove electrical appliances to reduce the chance of electrocution or shock.

- Install ground-fault outlets near all water sources.
Prevent wandering

- Consider installing safety doorknobs.
- Put locks at the top or bottom of doors, out of the person's line of sight.
- Camouflage the outside door or place a dark rug in front of it to discourage the person from approaching.
- Get an intercom system (such as those used in infants' rooms) or install Dutch doors, so you can stay aware of the person's activities while in another room.
- Hang chimes on doors.
- Install electronic alert alarms.
- Make sure the person wears an identification bracelet, like the one available through MedicAlert® + Alzheimer's Association's Safe Return®.

Get rid of guns

- Remove guns from the house. At minimum, lock guns away in a cabinet or drawer.
- Don't keep guns loaded; store ammunition in a separate place.
- Never let a person with Alzheimer's handle a gun.

Create emergency plans

- Prepare a list of emergency phone numbers, such as the police and fire departments, hospitals and poison control centers.
- Develop escape plans in case of fire.
- Recruit someone who lives nearby to help in case of emergency.
Stages of Alzheimer’s Disease

Experts have documented common patterns of symptom progression that occur in individuals with Alzheimer’s disease. Based on these patterns, they developed several methods of “staging.”

Alzheimer’s disease advances at widely different rates. Not everyone will experience every symptom, and symptoms may occur at different times in different individuals. People with Alzheimer’s live an average of eight years after diagnosis, but may survive anywhere from three to 20 years.

Determining which stage an individual has reached helps families and health care professionals make better care decisions. Individuals with the disease and their families can prepare themselves for the progression of the disease. People with dementia can get involved with clinical studies through Alzheimer’s Association TrialMatch®.

Staging the disease using the Global Deterioration Scale (GDS)

The Global Deterioration Scale is a system that outlines key symptoms and is characterized by seven stages ranging from unimpaired function to very severe cognitive decline.

NOTE: GDS stages correspond to the widely used concepts of mild, moderate, moderately severe and severe Alzheimer’s disease. Also noted are which stages fall within the more general divisions of early-stage, mid-stage and late-stage categories.

Stage 1 – Preclinical Stage

Description: A newly defined stage reflecting current evidence that measurable biomarker changes in the brain may occur years before symptoms affecting memory, thinking or behavior can be detected by affected individuals or their physicians. While the guidelines identify these preclinical changes as an Alzheimer’s stage, they do not establish diagnostic criteria that doctors can use now. Rather, they propose additional research to establish which biomarkers may best confirm that Alzheimer’s-related changes are underway and how to measure them.

Symptoms: No impairment (normal function). No experience with memory problems. An interview with a medical professional does not show any evidence of dementia symptoms.

Stage 2 – Early Stage

Description: Mild cognitive decline.
- Difficulty in social or occupational settings
- Friends or family may notice change

Symptoms: Very mild cognitive decline (may be normal age-related changes or earliest signs of Alzheimer’s disease). The person may experience memory lapses — forgetting familiar words or the location of everyday objects — but no symptoms of dementia can be detected during a medical examination or by friends, family or co-workers.

Stage 3 – Early Stage

Description: Mild cognitive impairment (MCI) due to Alzheimer’s disease. In this stage, mild changes in memory and thinking are noticeable and can be measured on mental status tests, but are not severe enough to disrupt day-to-day life.

Symptoms: Mild cognitive decline. Friends, family or co-workers begin to notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration. Common stage 3 difficulties include:
- Noticeable problems coming up with the right word or name
- Trouble remembering names when introduced to new people

continued
Experts have documented common patterns of symptom progression that occur in individuals with Alzheimer’s disease. Based on these patterns, they developed several methods of “staging.”

Alzheimer’s disease advances at widely different rates. Not everyone will experience every symptom, and symptoms may occur at different times in different individuals. People with Alzheimer’s live an average of eight years after diagnosis, but may survive anywhere from three to 20 years.

Determining which stage an individual has reached helps families and health care professionals make better care decisions. Individuals with the disease and their families can prepare themselves for the progression of the disease. People with dementia can get involved with clinical studies through Alzheimer’s Association TrialMatch®.

**Staging the disease using the Global Deterioration Scale (GDS)**

The Global Deterioration Scale is a system that outlines key symptoms and is characterized by seven stages ranging from unimpaired function to very severe cognitive decline.

**NOTE:** GDS stages correspond to the widely used concepts of mild, moderate, moderately severe and severe Alzheimer’s disease. Also noted are which stages fall within the more general divisions of early-stage, mid-stage and late-stage categories.

### Stage 1 – Preclinical Stage

**Description:** A newly defined stage reflecting current evidence that measurable biomarker changes in the brain may occur years before symptoms affecting memory, thinking or behavior can be detected by affected individuals or their physicians. While the guidelines identify these preclinical changes as an Alzheimer’s stage, they do not establish diagnostic criteria that doctors can use now. Rather, they propose additional research to establish which biomarkers may best confirm that Alzheimer’s-related changes are underway and how to measure them.

**Symptoms:** No impairment (normal function). No experience with memory problems. An interview with a medical professional does not show any evidence of dementia symptoms.

### Stage 2 – Early Stage

**Description:** Mild cognitive decline.

- Difficulty in social or occupational settings
- Friends or family may notice change

**Symptoms:** Very mild cognitive decline (may be normal age-related changes or earliest signs of Alzheimer’s disease). The person may experience memory lapses — forgetting familiar words or the location of everyday objects — but no symptoms of dementia can be detected during a medical examination or by friends, family or co-workers.

### Stage 3 – Early Stage

**Description:** Mild cognitive impairment (MCI) due to Alzheimer’s disease. In this stage, mild changes in memory and thinking are noticeable and can be measured on mental status tests, but are not severe enough to disrupt day-to-day life.

**Symptoms:** Mild cognitive decline. Friends, family or co-workers begin to notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration. Common stage 3 difficulties include:

- Noticeable problems coming up with the right word or name
- Trouble remembering names when introduced to new people

continued
Strategies for Providing Middle Stage Alzheimer’s Disease Care

1. Try to be patient.
2. Speak slowly and clearly, using short sentences. Always repeat instructions the same way. Break down instructions to single actions or steps. Be consistent.
3. Remember you are caring for an adult; do not treat the person with Alzheimer’s like a child.
4. Be calm if the person appears to hallucinate or believes it is a different time or place. Accept what is said pleasantly. Do not argue. If necessary, divert the person with another topic.
5. Conversations about long ago may help the person become involved with what can be remembered. Listen for cues to continue the conversation even if speech is rambling.
6. Try your best to continue social contacts. One or two visitors at a time is important for your mental health and well-being and can provide stimulation for you both without causing distress. Continue to accept any invitations to small parties or low key events.
7. If the person with the disease asks about his or her condition, explain as plainly and simply as possible that the person has a disease that affects memory and that you will work it out together. Many may know that something is wrong. They need to know that you love them and accept them as they are today.
8. Do not “baby” or wait on the person with Alzheimer’s disease unnecessarily. Allow the person to do as much as possible even if it is not done perfectly.
9. Do provide love and a lot of hugs. Touch and closeness is an important need for you both.
10. Select activities that might connect with the person’s talents, history, or experiences. Be willing to try new activities.
11. Discourage driving. If unsuccessful, get the doctor’s help in revoking the driving license. The car may need to be “lost” or the car may need to be sold, moved or temporarily disabled.
12. Place labels, pictures or signs on doors and drawers to help the person locate or put away items on their own for as long as possible.
13. “Hide” doors or areas that the person should avoid by “disguising” them with curtains, large plants, strategically placed furniture, etc.
14. Don’t encourage smoking or drinking — these affect health, behavior, and safety.
15. For safety and to prevent injury, be aware of accessibility to stoves, heaters and other heat sources. Check water temperature settings and hot food or drinks.
16. Monitor all access to the outside. Safety locks on outside doors may be necessary to prevent the person from wandering outside.
17. Be aware that with Alzheimer’s disease, a person may be able to find their way along a familiar route on one day and then become lost on the next. Register the person in the Safe Return program.
18. Look for potential hazards for falls or accidents - low footstools, area rugs, excess clutter, firearms, tools, etc.
19. Continually assess the overall safety of the person’s environment. Remember that the person will continue to change - abilities and judgment will decline. Plans for future care should be addressed ahead of time.
20. Remember to use observation to find clues for the reasons for difficult behaviors. Look for patterns in time of day, location, people involved, weather, etc. as possible “triggers”.
How to Contact the Alzheimer’s Association – Heart of America Chapter

1.800.272.3900 • alz.org/kansascity

<table>
<thead>
<tr>
<th>Main Office</th>
<th>Northeast Kansas Regional Office</th>
<th>Northwest Missouri Regional Office</th>
<th>Southeast Kansas Regional Office</th>
</tr>
</thead>
<tbody>
<tr>
<td>3846 W. 75th Street</td>
<td>3625 SW 29th St. Suite 102</td>
<td>927 Faraon</td>
<td>2601 Gabriel</td>
</tr>
<tr>
<td>Prairie Village, KS 66208</td>
<td>Topeka, KS 66614</td>
<td>St. Joseph, MO 64501</td>
<td>Parsons, KS 67357</td>
</tr>
</tbody>
</table>

The Heart of America Chapter provides programs and services in 66 counties in Kansas and Missouri. These programs and services are made possible thanks to generous donations from individuals, corporations, and foundations. Contributions and donations allow the Chapter to provide supportive services, including care consultations, free of charge to individuals and families.
Telling the Person and Others About an Alzheimer’s Diagnosis

When you learn that someone you care about has Alzheimer’s, you may hesitate to tell the person that he or she has the disease. You may also have a hard time deciding whether to tell family and friends. Once you are emotionally ready to discuss the diagnosis, how will you break the news? Here are some suggestions for talking about the disease with others.

Respect the person’s right to know

- You may want to protect the person by withholding information. But your loved one is an adult with the right to know the truth. It can be a relief to hear the diagnosis, especially if the person had suspected he or she had Alzheimer’s disease.

- In many cases, people who are diagnosed early are able to participate in important decisions about their healthcare and legal and financial planning.

- While there is no current cure for Alzheimer’s, life will not stop with the diagnosis. There are treatments and services that can make life better for everyone.

Plan how to tell the person

- Talk with doctors, social workers and others who work with people who have Alzheimer’s to plan an approach for discussing the diagnosis.

- Consider a “family conference” to tell the person about the diagnosis. He or she may not remember the discussion, but may remember that people cared enough to come together. You may need to have more than one meeting to cover the details.

- Shape the discussion to fit the person’s emotional state, medical condition and ability to remember and make decisions.

- Pick the best time to talk about the diagnosis. People with Alzheimer’s may be more receptive to new information at different times of the day.

- Don’t provide too much information at once. Listen carefully to the person. They often signal the amount of information they can deal with through their question and reactions. Later, you can explain the symptoms of Alzheimer’s and talk about planning for the future and getting support.

Help the person accept the diagnosis

- The person may not understand the meaning of the diagnosis or may deny it. Accept such reactions and avoid further explanations.

- If they respond well, try providing additional information.

- The person with Alzheimer’s may forget the initial discussion but not the emotion involved. If telling them upsets them, hearing additional details may trigger the same reaction later.

- Reassure your loved one. Express your commitment to help and give support. Let the person know that you will do all you can to keep your lives fulfilling.

- Be open to the person’s need to talk about the diagnosis and his or her emotions.

- Look for nonverbal signs of sadness, anger or anxiety. Respond with love and reassurance.

- Encourage the person to join a support group for individuals with memory loss.
Telling the Person and Others About an Alzheimer’s Diagnosis

continued

Telling family and friends

An Alzheimer diagnosis doesn’t only affect the person receiving it. The lives of family members and friends may also drastically change.

- Be honest with family and friends about the person’s diagnosis. Explain that Alzheimer’s is a brain disease, not a psychological or emotional disorder.

- Share educational materials from the Alzheimer’s Association. The more that people learn about the disease, the more comfortable they may feel around the person.

- Invite family to support groups sponsored by your local Alzheimer’s Association.

- Realize that some people may drift out of your life, as they may feel uncomfortable around the person or may not want to help provide care.

- Alzheimer’s disease can also impact children and teens. Just as with any family member, be honest about the person’s diagnosis with the young people in your life. Encourage them to ask questions.

How to Contact the Alzheimer’s Association – Heart of America Chapter
1.800.272.3900 • alz.org/kansascity

The Heart of America Chapter provides programs and services in 66 counties in Kansas and Missouri. These programs and services are made possible thanks to generous donations from individuals, corporations, and foundations. Contributions and donations allow the Chapter to provide supportive services, including care consultations, free of charge to individuals and families.
Ways Friends Can Assist Individuals and Families Going Through Alzheimer’s

1. Learn as much as you can about Alzheimer’s disease. Go to education programs. Ask to join caregivers in attending educational opportunities.

2. Listen without judgment. Both the individual with the disease and caregivers will have a range of feelings. Sharing them often helps.

3. Accept the person with the disease for where they are today.

4. Offer advice to caregivers only when asked and give only in the context of the reality of the situation.

5. Visit on a regular and structured basis for example visiting every Monday from 3 to 5 or taking the person with the disease to lunch every other Tuesday. This will allow the caregiver to look forward to and plan around that time frame.

6. Make a point to tell the caregiver the positives you experienced in this time with the person.

7. If not able to provide direct assistance such as respite, offer to provide non direct assist such as yard care, going to the store, or home repair. Again, it is important that it is regular and consistent so the caregiver can count on it.

8. Be observant. Caregivers often struggle with asking for help. Notice what needs done and do it or help to get it done. Try to predict and uncover needs.

9. Send cards, flowers or food periodically to let them know you are thinking about them.

10. Be liberal in conveying praise and encouragement for what they are doing.

11. Make only commitments you can keep.

12. Assist in connecting caregivers to other resources and supports including support groups.

13. Recognize your own grief. Share your grief feelings with someone other than the caregiver.

14. Respect the decisions of the caregiver even if you do not agree. They are experiencing the needs of the person with the disease at a whole different level than you are.

15. If the person with the disease is in a long term care facility, continue to visit and share positives with the caregiver. Placement is one of the hardest decisions to be made in this disease. Caregivers need to know that friends will not forget about their loved one and will remain a partner with them in loving and supporting the person.
When a Family Member Has Alzheimer’s Disease

1. Obtain as accurate a diagnosis as possible — rule out other possible causes for the changes.

2. Maintain regular contact with a caring physician.

3. Learn as much as you can about Alzheimer’s disease. Understanding the disease is a key factor in coping.

4. Realize and explain to others that your loved one has a disease it is not insanity or stubbornness AND IT IS NOT A NORMAL PART OF AGING.

5. Be open about the symptoms and progression of the disease.

6. Have a family meeting so that everyone can understand what to expect and what may be required. Also, make sure other family members receive disease information material. With a common understanding, planning for care and making decisions should be easier.

7. Address legal issues immediately. Many people with Alzheimer’s disease in the early stage may still be able to complete documents needed for their care. However, this opportunity can be quickly lost. Seek help from an attorney.

8. Accept all that your family member can still do today, but begin to make plans for future care. Collect information, gather resources and prepare so that if additional help is needed, important decisions need not be made under “crisis circumstances.”

9. Make sure your family member’s home situation is as safe as possible. Consider a Safe Return ID bracelet, special door locks or handles, lowering the water heater temperature, eliminating clutter, etc.

10. Try to maintain a regular schedule for the person with Alzheimer’s disease. Familiarity and routine will help the person get through each day more successfully.

11. Don’t forget other health issues. Continue to have regular check ups or treatment for other health problems and encourage appropriate exercise and a nutritious diet.

12. Be prepared to ask for help. Be prepared to accept help. Be prepared to give help if you are not the primary caregiver. The care of a person with Alzheimer’s disease is too much for one person to handle alone.

13. Family members who are not providing direct care should be aware of the health and feelings of the caregiver in the home. Listen to the caregiver and be supportive.

14. Reach out to others who understand — become part of a support group.

How to Contact the Alzheimer’s Association – Heart of America Chapter
1.800.272.3900 • alz.org/kansascity

The Heart of America Chapter provides programs and services in 66 counties in Kansas and Missouri. These programs and services are made possible thanks to generous donations from individuals, corporations, and foundations. Contributions and donations allow the Chapter to provide supportive services, including care consultations, free of charge to individuals and families.
You Might Benefit From Talking with the Alzheimer’s Association if…

- You or your loved one has been newly diagnosed and you want to learn more about:
  - what the disease means
  - ways to manage
  - telling people
  - connecting with others who are have the disease or are care partners

- Your loved one is experiencing behavior or mood changes

- Your family members all see the situation differently

- You feel like something else needs to happen, but you are unsure what options exist or how to figure out what is needed.

- You would like to talk to other caregivers who are going through the same thing

- You are a community professional and would like to know about education programs the Association offers or need material to share with those you work with about Alzheimer’s and other dementias

- You feel heaviness, are overwhelmed or have persistent guilt about your experience as a caregiver of someone with Alzheimer’s disease.

- You want to learn more about:
  - What to expect
  - Strategies to maintain function as long as possible
  - Activities to consider for a person with the disease

- You are concerned about safety issues such as wandering, driving or living alone

How to Contact the Alzheimer’s Association – Heart of America Chapter
1.800.272.3900 • alz.org/kansascity

The Heart of America Chapter provides programs and services in 66 counties in Kansas and Missouri. These programs and services are made possible thanks to generous donations from individuals, corporations, and foundations. Contributions and donations allow the Chapter to provide supportive services, including care consultations, free of charge to individuals and families.
Kansas Support Groups

Support groups are composed of people who meet, share information, and provide support to one another. Support group members report many benefits including:

- Obtaining information about the disease and community resources
- Understanding the behavior of the individual with Alzheimer’s
- Receiving validation for negative or ambivalent feelings
- Feeling “I’m not alone”
- Receiving emotional support
- Learning specific strategies to handle their loved one’s behavior
- Receiving encouragement to maintain or regain their personal lives.

Participation in a support group may help to normalize the experience of caregiving and decrease feelings of burden.

The Alzheimer’s Association encourages all new attendees to contact the support group leader prior to your first visit to assure time and location.

TELEPHONE SUPPORT GROUP
FOR SPANISH-SPEAKING INDIVIDUALS

Grupo de apoyo de teléfono Español
Este grupo se origina en el sur de California, pero está abierto a los cuidadores a través de los Estados Unidos. El cuarto martes de cada mes.

11:00 a.m. – 12:30 p.m. hora del Centro;
1:00 - 2:30 p.m. hora del Pacífico

Para más información y detalles por favor póngase en contacto con Linda Loera en 213-220-0713 o lloera@alz.org

English Translation:
Spanish Telephone Support Group
This group originates in Southern California but is open to caregivers across the United States. The 4th Tuesday of each month.

11:00 a.m. - 12:30 p.m. Central Time; 1:00 - 2:30 p.m. Pacific Time.

For more information and details please contact Linda Loera at 213-220-0713 or lloera@alz.org.

ANDERSON COUNTY

Parkview Heights Nursing & Rehabilitation Center
101 N. Pine St.
Garnett, KS  66032
Debbie Welsh, facilitator
(785) 448-2434
4th Wednesday, 1 – 2:30 p.m.

BOURBON COUNTY

Breakfast Club
The Breakfast Club is a hometown support experience where people gather in a safe environment and where support is provided in a round table way.

Papa Dons
10 N Main St.
Fort Scott, KS 66701
Angela Decoster, facilitator
(620) 433-2189
3rd Wednesday at 9:00 a.m.

CRAWFORD COUNTY

Breakfast Club
The Breakfast Club is a hometown support experience where people gather in a safe environment and where support is provided in a round table way.

1st United Methodist Church
415 N Pine
Pittsburg, KS 66762
Angela Decoster, facilitator
(620) 433-2189
3rd Thursday at 9:00 a.m.
DOUGLAS COUNTY

West Side Presbyterian Church
1024 Kasold Drive
Lawrence, KS 66049
Gus McClelland, facilitator
Contact: Kim Stein
(913) 831-3888
4th Monday, 3:30 – 5:00 p.m.

JOHNSON COUNTY

Alzheimer’s Association Chapter Office
3846 West 75th Street
Prairie Village, KS 66208
Kim Stein, facilitator
(913) 831-3888
4th Thursday at 10:00 a.m.
This group is for caregivers. During this group time, social engagement and creative activities are available exclusively for individuals whose care partners are attending the support group. Space is limited. If interested, please contact Karen Clond at (913) 831-3888 before attending.

Atonement Lutheran Church
9948 Metcalf Avenue
Sunshine Room, 1st Floor
Overland Park, KS 66212
Theresa Gordon, facilitator
Contact: Kim Stein
(913) 831-3888
2nd Tuesday, 7 – 8:30 p.m.
Does not meet in June

Beautiful Savior Lutheran Church
13145 Blackbob Road
Olathe, Kansas 66062
1st Thursday at 6:00 p.m.
Jeanne Reeder, LMSW, facilitator
(913) 244-1815

For Caregivers
Education Center
3856 W. 75th Street, Prairie Village, KS 66208
Need to call Darcy Letourneau before first attending
(913) 831-3888
1st & 3rd Tuesday at 5:45 p.m.

Frontotemporal Dementia Caregivers
KU Clinical Research Center
Alzheimer’s Disease Center
4350 Shawnee Mission Parkway, Suite 1200
Fairway Office Park, behind Security Bank
Fairway, KS 66205
Tam Smith, facilitator
(913) 645-5254
First Wednesday, 2:00 – 3:30 p.m.
*Note: A caregiver group meets at the same time in another room

Garden Terrace
7541 Switzer
Overland Park, KS 66214
Lindy Griffith, facilitator
(913) 631-2273
3rd Tuesday at 3:00 p.m.

Kansas University Clinical Research Center
Alzheimer’s Disease Center
4350 Shawnee Mission Parkway, Ste 1200
Fairway, KS 66205
(Fairway Office Park behind Security Bank)
Phyllis Switzer, facilitator
(913) 588-6981
2nd Monday at 2 – 3:30 p.m.

Salem Lutheran Church
13402 West 92nd Street, Lenexa, KS
(Corner of 92nd and Haskins)
Courtney Goin, facilitator, (913) 609-1891
2nd Friday 10:00 – 11:30 a.m.
J O H N S O N C O U N T Y  c o n t i n u e d

St. Thomas The Apostle Episcopal Church
12251 Antioch
Overland Park, KS 66213
Margaret Clark, facilitator
Contact: Kim Stein
(913) 831-3888
1st Sunday, 4:00 – 5:30 p.m.

Village Shalom
5500 West 123rd Street
Overland Park, KS  66209
Pat Conway, facilitator, (913) 383-3514
3rd Thursday at 9:30 a.m.

L A B E T T E C O U N T Y

Breakfast Club
The Breakfast Club is a hometown support experience
where people gather in a safe environment and where
support is provided in a round table way.

Four Square Church
98 Main Street, Parsons, KS  67357
Angela Decoster, facilitator
(620) 433-2189
1st Thursday at 9:00 a.m.

L E A V E N W O R T H C O U N T Y

Council on Aging
1830 S. Broadway
Leavenworth, KS  66048
Patty Willmeth, facilitator
(913) 684-0777
4th Monday, 1 – 2:30 p.m.

N E O S H O C O U N T Y

Breakfast Club
The Breakfast Club is a hometown support experience
where people gather in a safe environment and where
support is provided in a round table way.

First United Methodist Church – Fellowship Hall
202 S. Lincoln Avenue
Chanute, KS  66720
Angela Decoster, facilitator
(620) 433-2189
1st Wednesday at 9:00 a.m.
Kansas Support Groups

Support groups are composed of people who meet, share information, and provide support to one another. Support group members report many benefits including:

- Obtaining information about the disease and community resources
- Understanding the behavior of the individual with Alzheimer’s
- Receiving validation for negative or ambivalent feelings
- Feeling “I’m not alone”
- Receiving emotional support
- Learning specific strategies to handle their loved one’s behavior
- Receiving encouragement to maintain or regain their personal lives.

Participation in a support group may help to normalize the experience of caregiving and decrease feelings of burden.

The Alzheimer’s Association encourages all new attendees to contact the support group leader prior to your first visit to assure time and location.

TELEPHONE SUPPORT GROUP
FOR SPANISH-SPEAKING INDIVIDUALS
Grupo de apoyo de teléfono Español
Este grupo se origina en el sur de California, pero está abierto a los cuidadores a través de los Estados Unidos. El cuarto martes de cada mes.
11:00 a.m. – 12:30 p.m. hora del Centro;
1:00 - 2:30 p.m. hora del Pacífico
Para más información y detalles por favor póngase en contacto con Linda Loera en 213-220-0713 o lloera@alz.org

English Translation:
Spanish Telephone Support Group
This group originates in Southern California but is open to caregivers across the United States.
4th Tuesday of each month.
11:00 a.m. - 12:30 p.m. Central Time; 1:00 - 2:30 p.m. Pacific Time.
For more information and details please contact Linda Loera at 213-220-0713 or lloera@alz.org.

ANDERSON COUNTY
Parkview Heights Nursing & Rehabilitation Center
101 N. Pine St.
Garnett, KS 66032
Debbie Welsh, facilitator
(785) 448-2434
4th Wednesday, 1 – 2:30 p.m.

BOURBON COUNTY
Breakfast Club
The Breakfast Club is a hometown support experience where people gather in a safe environment and where support is provided in a round table way.
Papa Dons
10 N Main St.
Fort Scott, KS 66701
Angela Decoster, facilitator
(620) 433-2189
3rd Wednesday at 9:00 a.m.

CRAWFORD COUNTY
Breakfast Club
The Breakfast Club is a hometown support experience where people gather in a safe environment and where support is provided in a round table way.
1st United Methodist Church
415 N Pine
Pittsburg, KS 66762
Angela Decoster, facilitator
(620) 433-2189
3rd Thursday at 9:00 a.m.

continued
Kansas Support Groups

DOUGLAS COUNTY

West Side Presbyterian Church
1024 Kasold Drive
Lawrence, KS 66049
Gus McClelland, facilitator
Contact: Kim Stein
(913) 831-3888
4th Monday, 3:30 – 5:00 p.m.

JOHNSON COUNTY

Alzheimer’s Association Chapter Office
3846 West 75th Street
Prairie Village, KS 66208
Karen Clond, facilitator
(913) 831-3888
4th Thursday at 10:00 a.m.
This group is for caregivers. During this group time, social engagement and creative activities are available exclusively for individuals whose care partners are attending the support group. Space is limited. If interested, please contact Darcy Letourneau at (913) 831-3888 before attending.

Atonement Lutheran Church
9948 Metcalf Avenue
Sunshine Room, 1st Floor
Overland Park, KS 66212
Theresa Gordon, facilitator
Contact: Kim Stein
(913) 831-3888
2nd Tuesday, 7 – 8:30 p.m.
Does not meet in June

Beautiful Savior Lutheran Church
13145 Blackbob Road
Olathe, Kansas 66062
1st Thursday at 6:00 p.m.
Jeanne Reeder, LMSW, facilitator
(913) 244-1815

For Caregivers
Education Center
3856 W. 75th Street, Prairie Village, KS 66208
Need to call Darcy Letourneau before first attending
(913) 831-3888
1st & 3rd Tuesday at 5:45 p.m.

Frontotemporal Dementia Caregivers
KU Clinical Research Center
Alzheimer’s Disease Center
4350 Shawnee Mission Parkway, Suite 1200
Fairway Office Park, behind Security Bank
Fairway, KS 66205
Amy Yeager, facilitator
(913) 945-7663
First Wednesday, 2:00 – 3:30 p.m.

For the Person with Early Stage (not for caregivers)
Church of the Resurrection
13720 Roe Avenue, Leawood, KS 66224
Need to call Michelle Niedens before first attending
(913) 945-7310
4th Tuesday, 2:00 – 3:30 p.m.
*Note: A caregiver group meets at the same time in another room

Garden Terrace
7541 Switzer
Overland Park, KS 66214
Lindy Griffith, facilitator
(913) 631-2273
3rd Tuesday at 3:00 p.m.

Kansas University Clinical Research Center
Alzheimer’s Disease Center
4350 Shawnee Mission Parkway, Ste 1200
Fairway, KS 66205
(Fairway Office Park behind Security Bank)
Phyllis Switzer, facilitator
(913) 588-6981
2nd Monday at 2 – 3:30 p.m.

Salem Lutheran Church
13402 West 92nd Street, Lenexa, KS
(Corner of 92nd and Haskins)
Courtney Goin, facilitator, (913) 609-1891
2nd Friday 10:00 – 11:30 a.m.
JOHNSON COUNTY continued

Village Shalom
5500 West 123rd Street
Overland Park, KS  66209
Pat Conway, facilitator, (913) 383-3514
3rd Thursday at 9:30 a.m.

LABETTE COUNTY

Breakfast Club
*The Breakfast Club is a hometown support experience where people gather in a safe environment and where support is provided in a round table way.*
Four Square Church
98 Main Street, Parsons, KS  67357
Angela Decoster, facilitator
(620) 433-2189
1st Thursday at 9:00 a.m.

LEAVENWORTH COUNTY

Council on Aging
1830 S. Broadway
Leavenworth, KS  66048
Patty Willmeth, facilitator
(913) 684-0777
4th Monday, 1 – 2:30 p.m.

NEOSHO COUNTY

Breakfast Club
*The Breakfast Club is a hometown support experience where people gather in a safe environment and where support is provided in a round table way.*
First United Methodist Church – Fellowship Hall
202 S. Lincoln Avenue
Chanute, KS  66720
Angela Decoster, facilitator
(620) 433-2189
1st Wednesday at 9:00 a.m.
Missouri Support Groups

Support groups are composed of people who meet, share information, and provide support to one another. Support group members report many benefits including:

- Obtaining information about the disease and community resources
- Understanding the behavior of the individual with Alzheimer’s
- Receiving validation for negative or ambivalent feelings
- Feeling “I’m not alone”
- Receiving emotional support
- Learning specific strategies to handle their loved one’s behavior
- Receiving encouragement to maintain or regain their personal lives.

Participation in a support group may help to normalize the experience of caregiving and decrease feelings of burden.

The Alzheimer’s Association encourages all new attendees to contact the support group leader prior to your first visit to assure time and location.

NEW!

**TELEPHONE SUPPORT GROUP FOR SPANISH-SPEAKING INDIVIDUALS**

Grupo de apoyo de teléfono Español
Este grupo se origina en el sur de California, pero está abierto a los cuidadores a través de los Estados Unidos. El cuarto martes de cada mes.
11:00 a.m. – 12:30 p.m. hora del Centro;
1:00 - 2:30 p.m. hora del Pacífico

Para más información y detalles por favor póngase en contacto con Linda Loera en 213-220-0713 o lloera@alz.org

**English Translation:**

Spanish Telephone Support Group
This group originates in Southern California but is open to caregivers across the United States.
4th Tuesday of each month.
11:00 a.m. - 12:30 p.m. Central Time; 1:00 - 2:30 p.m. Pacific Time.
For more information and details please contact Linda Loera at 213-220-0713 or lloera@alz.org.

**ATCHISON COUNTY**

Community Hospital
26136 US 59 Hwy
Fairfax, MO 64446
Brenda Gregg, facilitator
(816) 364-4467
3rd Thursday, 12:30 p.m.

**BUCHANAN COUNTY**

Living Community of St. Joseph
1202 Heartland Road
St. Joseph, MO 64506
Mary Schrom Breese, facilitator
(816) 671-0015
2nd Tuesday, 5:00 p.m.

**CASS COUNTY**

Cass Regional Medical Center
2800 Rock Haven Road
Harrisonville, MO 64701
Shelly Mikuls, facilitator
Contact: Kim Stein
(913) 831-3888
2nd Tuesday, 6:30 – 8:00 p.m.

Foxwood Springs
1500 W. Foxwood Drive
Raymore, MO 64083
Jeanie Parris, facilitator
(816) 331-3111 or (816) 318-2282
3rd Monday, 3:00 p.m.

continued
Missouri Support Groups

CLAY COUNTY
North Kansas City Hospital
Barry Room
2800 Clay Edwards Drive
North Kansas City, MO 64116
Jeanne Reeder, facilitator
(913) 244-1815
3rd Monday, 6:00 p.m

CLINTON COUNTY
Missouri Veterans Home
1111 Euclid Avenue
Cameron, MO 64429
Carol Harkrider, facilitator
(816) 649-1632
3rd Wednesday 1:30 p.m.

GENTRY COUNTY
St. Peter Catholic Church
614 N. Alanthus Avenue
Stanberry, MO 64489
Autum Fisher, facilitator
(660) 582-7447
2nd Thursday, 6:00 p.m.

GRUNDY COUNTY
Dino’s Diner
3027 E. 10th Street
Trenton, MO 64683
Brenda Gregg, facilitator
(816) 364-4467
1st Wednesday, 10:00 a.m.

HARRISON COUNTY
Senior Center
1316 S. 25th Street
Bethany, MO 64424
Brenda Gregg, facilitator
(816) 364-4467
1st Friday, 1:00 p.m.

HENRY COUNTY
Ben Franklin Coffee Shop
106 S. Main
Clinton, MO 64735
Ranae Walrath, facilitator
(660) 492-3486
2nd Thursday at 10:00 a.m.

JACKSON COUNTY
Breakfast Club
The Breakfast Club is a hometown support experience where people gather in a safe environment and where support is provided in a round table way.
Southeast Community Center
4120 E. 63rd Street
Kansas City, MO 64130
Kelly Loeb, facilitator
(913) 327-8278
2nd Saturday, 9:30 – 11:30 a.m.

Christ United Methodist Church
14506 East 39th Street
Independence, MO 64055
Audrey Sloane, facilitator
Contact: Kim Stein, 913-831-3888
2nd Thursday, 7:00 p.m.

First Baptist Church
2 NE Douglas
Lee’s Summit, MO 64063
(west side of Douglas between Maple and 1st)
Jan Horn, facilitator
(913) 831-3888
4th Monday, 6 – 7:30 p.m.

Vesper Hall
400 NW Vesper
Blue Springs, MO 64014
Kim Stein, facilitator
Contact: Kim Stein, (913) 831-3888
2nd Thursday, 2:30 – 4:00 p.m.
Missouri Support Groups

JOHNSON COUNTY

Missouri Veterans Home
1300 Veterans Road
Warrensburg, MO 64093
Angela Boone, facilitator
(660) 543-5064
2nd Wednesday at 10:00 a.m.

LIVINGSTON COUNTY

Bella-Brooke Adult Day Center
1115 Second Street
Chillicothe, MO 64601
Geri Curtis, facilitator
(660) 646-1595
3rd Wednesday, 1:30 p.m.

NODA WAY COUNTY

Oak Pointe Community Room
817 Country Club Drive
Maryville, MO 64468
Jessica Loch, facilitator
(816) 261-2440
3rd Wednesday, 6:00 p.m.

Nodaway County Senior Center
1210 E 1st St.
Maryville, MO  64468
Autum Fisher, facilitator
(660) 582-7447
4th Thursday, 6:00 p.m.

PLATTE COUNTY

Platte Woods United Methodist Church
Room 254
7310 Northwest Prairie View Road
Platte Woods, MO
Karen Clond, facilitator
(913) 831-3888
3rd Thursday, 11 a.m. – 12:30 p.m.

RAY COUNTY

Ray County Library
215 E. Lexington St.
Richmond, MO 64085
Christal Milligan, facilitator
(816) 332-3435
Becky Franklin, facilitator
(816) 217-4152
4th Thursday, 5:30 – 6:45 p.m.

How to Contact the Alzheimer’s Association – Heart of America Chapter
1.800.272.3900 • alz.org/kansascity

The Heart of America Chapter provides programs and services in 66 counties in Kansas and Missouri. These programs and services are made possible thanks to generous donations from individuals, corporations, and foundations. Contributions and donations allow the Chapter to provide supportive services, including care consultations, free of charge to individuals and families.