Banner
Alzheimer's Institute &
Sun Health Research Institute

Driving Guide

An educational guide to help you make informed choices

Hi friend,

Those of us living with early-stage dementia have faced many emotions and life changes which include driving.

This guide was created by the Early-Stage Advisory Council of Banner Alzheimer's Institute, which is composed of people who are walking this dementia journey and are facing decisions about driving. The decision to discontinue driving may make sense logically and legally but carries with it significant emotional weight.

Some of us have voluntarily given up the keys, others are limiting where and when we drive, and others have been told by someone else to stop driving. Our goal is to help you think through the many decisions related to driving and inspire conversations, which can help you to make informed choices.

Bill, Bob, Deb, Kathleen, Karen, Leonard, Mary and Sharon- Living with Early Memory Loss

Barb, Deidra and Heather - Banner Alzheimer's Institute Team

What driving means to me

Driving means different things to different people, but it's safe to say, it means more than simply operating a vehicle.

What driving means to me:

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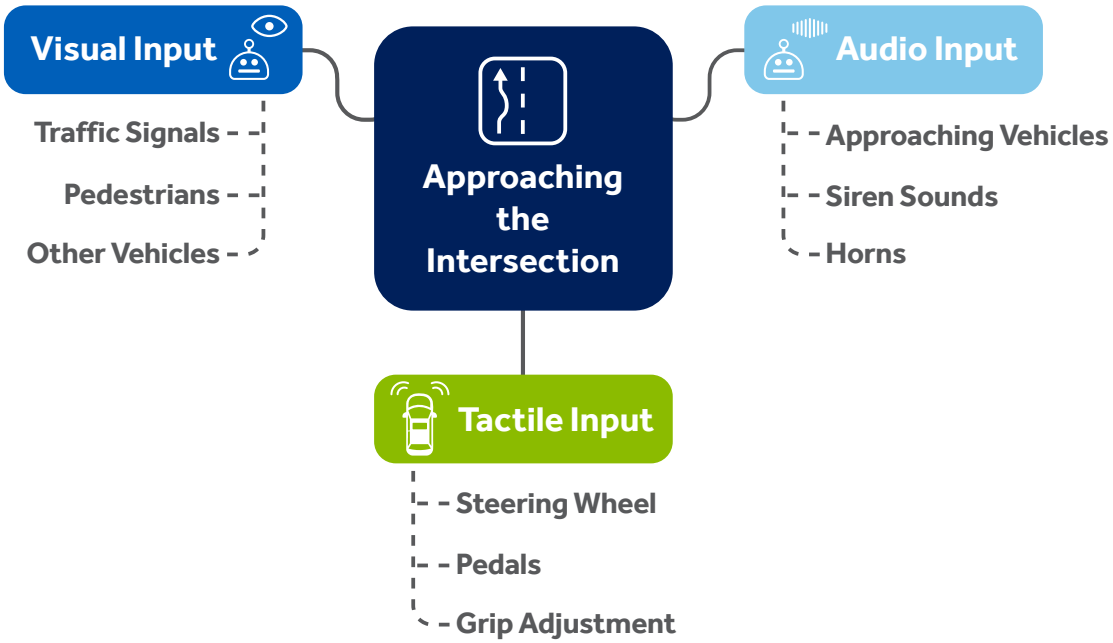
*Compiled by BAI's Early-Stage Advisory Council

Logistics of driving

Driving is a complicated task for the brain that requires multiple areas of thinking to work together. A driver must control and operate the vehicle, have awareness of surroundings, manage distractions, make quick decisions and respond rapidly to the unexpected during every moment of operation. This is a complex task that even the most careful and thoughtful drivers can struggle.

For example, the common driving process of making a right turn:

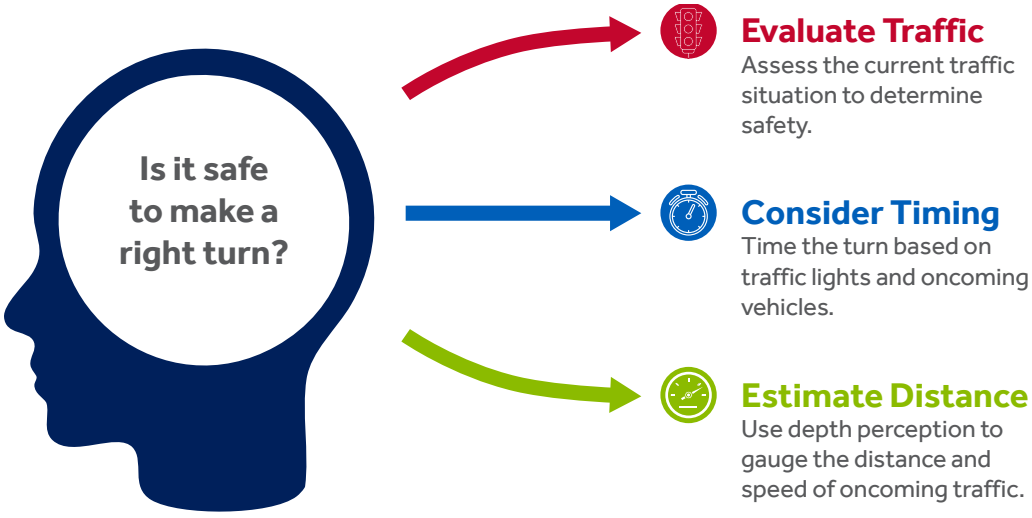


Information Input

As you approach the intersection, your brain is already at work. Your visual cortex is processing information related to the environment such as traffic signals and signs, pedestrians and other vehicles. Your auditory cortex is listening for other vehicles, sirens or horns while physically, you are feeling the steering wheel and pedals and adjusting your grip based on vehicle speed and conditions.

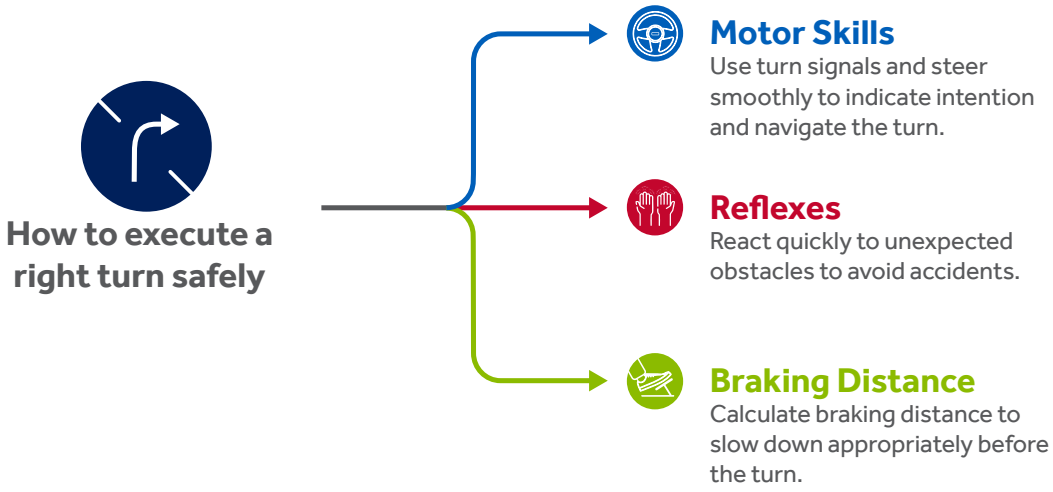
Assessing Safety

Once this information is collected, your brain's judgment and decision-making process are activated. You evaluate the safety and timing of the right turn, and your visio-spatial cortex judges distance and speed to prepare for a safe turn.



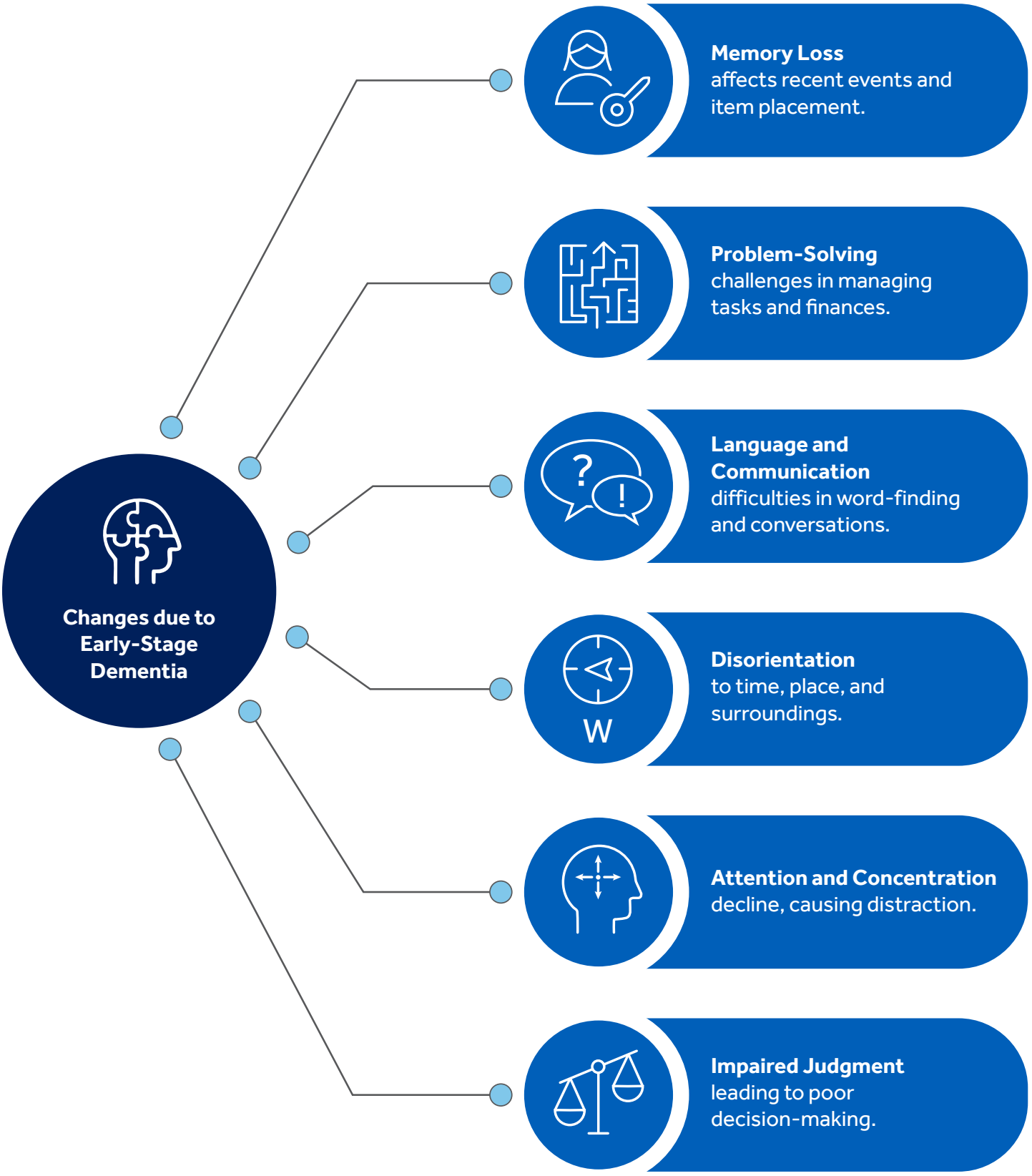
Completing the Turn

Now you're ready to complete the turn! Your motor skills are used to control your arms and feet as they smoothly and safely steer and brake through the turn. At the same time, your reflexes are on standby in case something unexpected happens. All are being told what to do by your brain.



All these areas of the brain work together to complete a common right turn in a motor vehicle- and at the same time make sure you are breathing and blinking and managing the many automatic functions we never even think about. But what happens when someone is developing a memory or thinking disorder, like dementia?

Changes to memory and thinking



Understanding liability

Driving a vehicle carries certain risks and liabilities regardless of cognitive impairment. From your auto insurance to state and federal laws, there are safeguards in place to try to ensure the safest driving experience for everyone on the road. A diagnosis of a dementia creates a new set of legal and financial considerations. Each insurance provider and state can have different laws or regulations, so it is important to do your own research to understand your rights and responsibilities.

"We went to a Memory Café and there was someone talking about driving and their car insurance. It dawned on me that, my dementia diagnosis could hurt us if I were involved in an accident. It is in my medical record now so even if I was not at fault, we may be vulnerable. Very scary. I don't want to give up driving, but I also do not want to put me and my wife at risk like that."

- Early-Stage Advisory Council Member

- Learn potential risk and liabilities:
  - Contact your auto insurance company
  - Visit your state's Department of Motor Vehicles website
  - Speak with a local elder law attorney

Notes

Reflections: Decide when it's time to limit or stop driving

The rest of this guide is designed to help you think through how you function in different aspects of your life. Each section offers questions for you to reflect on to help you honestly assess your abilities. There is space for you to write down your thoughts and ideas so you can reference them again in the future. This section is NOT an assessment of skills, nor should it be used to give permission to continue driving or instructions to discontinue. This is designed for you to reflect and try to come to reasonable conclusions related to driving.

Physical/mood/sensory processing changes

Memory is not the only area of the brain affected by dementia. There are also changes to mood, thinking, processing and even physical changes. You may notice you are more irritable or easily overwhelmed. Maybe it is more difficult to take part in conversations, you find your energy drained more quickly than in the past, or you may feel anxious when doing common tasks.

"Recently, I went to a show choir competition that my granddaughter was performing in. When I got there, it was loud. There were lots of people and I was completely overwhelmed and had to leave. I just can't do constant noise anymore. It is exhausting to use my senses for a long period of time, so when there is noise and chaos, I just must step away. Now I always have an 'escape path' when I'm out in public. I worry when I'm driving because there is no 'escape path'."

- Early-Stage Advisory Council Member

- Decrease in night vision
- Changes in peripheral vision
- Visual 'floaters'
- Changes in mobility
- Increased falls
- Tremors
- Slower reflexes or reaction time
- Increased anxiety
- Easily overwhelmed

What are some of the changes you have noticed in your mood or ability to process information? What concerns do you have?

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Changes at home

Changes in how you function and manage at home can be more noticeable during early dementia. Many of the tasks we do at home to manage our daily lives use skills that are also required when operating a vehicle.

"I have always loved to bake. Since my diagnosis, I have noticed it becoming more difficult. I can't find ingredients like I used to. I have put the flour in the same place in my pantry since we moved into this home, but now I can be looking straight at it and not recognize it! I've also noticed the oven timer doesn't catch my attention like it used to, so I've moved on to other projects while my cookies burn in the oven. I'm finding ways to cope, though. I've started labeling items in my pantry in a way that I better recognize, and I've found that a flashing bike light grabs my attention, so my baking doesn't get burnt."

- Early-Stage Advisory Council Member

Questions for reflection:

- Do you have trouble operating the oven, microwave or other kitchen appliances?
- Do you get disoriented in your home?
- Have you had difficulty recognizing objects?
- Do you leave tasks incomplete because you are getting distracted?
- Have you experienced changes in your ability to manage your household? (pay bills, clean, cook, etc.)
- Have you misused household items or materials? (i.e. aluminum in the microwave)
- What home modifications have you made because of dementia?

What are some of the changes you have experienced at home? What concerns do you have?

Changes at home (cont.)

"I had a morning where I woke up and felt off, but I had things to do, so I pushed through. I couldn't find my t-shirts (they've been in the same drawer for my entire adult life). I ran some errands. When I got back to my car, I couldn't find the keyhole to open the trunk of my car. Luckily, I had left one of the back windows cracked and was able to reach in and unlock the back door. I was glad no one saw me as I crawled into the front seats to get to the trunk release and unlock the car. It wasn't until the next day when I used the key fob to open the trunk that I realized what I had done. I was embarrassed and scared, and I didn't want to tell anyone. I eventually talked to my wife about it, and we use those 'off' feelings as an indicator to take it easy."

- Early-Stage Advisory Council Member

Questions for reflection:

- Have you had trouble getting dressed/ accessorized?
- Have your spending habits changed? Are you more impulsive?
- Are you hiding incidents from your spouse or partner?
- Are you experiencing more difficulty using technology?
- Have others commented on a change in your abilities?

What are some of the changes you have experienced at home? What concerns do you have?

Making quick decisions & dealing with the unexpected

You've thought it through and planned it out, but nothing is certain. Plans change because the unexpected happens and you must adapt. When you're living with cognitive decline, you may find yourself more rigid, less able to problem solve or to make changes. Driving a vehicle is a constant exercise in monitoring for and anticipating the unexpected and having to make quick decisions to maintain safety.

"I have used air travel for my entire career. Moving through check in and security, arriving to the gate— it was all second nature to me. You would think I would have noticed that even though my flight was leaving shortly, the gate I was sitting at was empty. My husband called to check if I had boarded. I realized my mistake and I panicked. It wasn't a panic where I took action, solved the problem or asked for help. It's like my brain was a computer and it just shut down. I didn't know what to do."

- Early-Stage Advisory Council Member

Questions for reflection:

- Are you able to respond quickly when necessary?
- How do you feel when you need to respond quickly?
- If things aren't going as expected, can you pivot to a new solution?
- How do you feel in unexpected situations?
- Do you get overwhelmed easily?

What are some of the changes you have noticed in your adaptability? What concerns to you have?

Changes in driving

Finally, let's consider your recent experiences driving.

"I am selective about where I drive now. I don't drive in the city, or during rush hour, or in unfamiliar places. If I'm planning on driving somewhere, I make sure I am prepared. I have to be well rested and know the route ahead of time. My wife is there with me when I drive to help me navigate. I got pulled over recently and was so glad to have her there. When the officer asked for my license and registration, I couldn't remember where we kept it."

- Early-Stage Advisory Council Member

- Have you started limiting where/when you drive? (avoiding night driving, highways, or high traffic areas)
- Have you been pulled over, or received traffic tickets recently? (speeding, going too slow, driving erratically)
- Do passengers help you navigate more than in the past?
- How do you handle unexpected situations? (traffic jams, road construction, emergency vehicles, traffic stops)

" I have driven the same route to work for the past decade. Recently, I was driving home from work and, when I pulled up to the same stop sign, I see twice a day, I didn't recognize where I was. Nothing was familiar. After a moment of shock, I pulled out my phone and set the map to take me home. Now I don't go anywhere without it on."

- Early-Stage Advisory Council Member

- Have you gotten lost while driving?
- What would you do if you got lost?
- Can you use a navigation system in your car or on your phone?

Space for reflection:

Notes

Conversations with others

While most of this guide has focused on your personal reflections, it can be helpful to ask for feedback from others you trust. Use the following questions to guide conversations:

Family/friends:

- Have you noticed a difference in my driving?
- Do you worry about me when I go out?
- Do you feel safe in the car when I'm driving?

Medical provider:

- Have you noticed any changes in testing that indicate concerns in my driving ability?
- Do you have concerns about how I function related to driving?

Notes

Learn More – Get Connected

***Dementia Untangled Episode: A Roadmap of Driving and Dementia* with Jenny Nordine**

Driving means so many things to us: freedom, independence, responsibility – but is it safe to drive with dementia? Jenny Nordine, an expert with Driving to Independence, helps us untangle the complicated feelings and decisions that must be made when it's no longer a good idea to get behind the wheel. She speaks to evaluating one's cognition and defensive driving techniques to determine one's ability to continue driving after a diagnosis, as well as what steps to take when it's time to give up the keys.

https://cutt.ly/DementiaUntangledEp44

Just Me Support Group

Early Stage/ Mild Cognitive Impairment (MCI) - Person Only

You're invited to a Banner Alzheimer's Institute support group *exclusively for people living with Early Stage Dementia/MCI*. This online group will help you to not feel alone, and connect with others in a safe space while continuing to incorporate good self-care to live successfully with cognitive changes.

If you have any questions, please contact Barbara Johnson, LCSW at 602.839.6510 or via email at Barbara.Johnson@bannerhealth.com

Banner
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DATE
Second Friday of each Month

TIME
1:00 – 2:30PM

LOCATION
Online via Zoom
**registration is required in advance to obtain Zoom access*

COST
Free

REGISTRATION
Barbara.Johnson@bannerhealth.com

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