# Duke Dementia Family Support Program

## Caregiver Connections

### An Educational Webinar Series with the Experts

**The presentation will begin shortly.**

**dukefamilysupport.org**

**919-660-7510**

# The Road Ahead

Driving, dementia, and staying connected



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Duke Dementia Family Support Program · Caregiver Connections

# Where are you on the journey?

- Worried, no diagnosis yet
- Early stage
- Middle stage
- Late stage
- Bereaved
- Professional

**Every module ends with a tip for:**

Early / middle | Late stage | Professionals

TODAY'S FOUR STEPS



Notice



Measure



Talk



Plan

# More than getting around



## Independence

Seeing friends, shopping, and getting to appointments on your own schedule.



## Identity and roles

Being the person who gives the rides and always knows the way.



## A duty to others

Driving is a privilege that carries a responsibility for public safety.

**After driving stops, older adults show more depressive symptoms and spend less time out of the home.**

*Chihuri et al., 2016*

The goal is to plan what replaces the car.

# Why this is hard

WHAT THE DRIVER FEELS

*"I'm fine to drive."*

Often sincere, and still not reliable.

WHAT THE PASSENGER SEES

*"That's the third missed turn to Sarah's."*

Real evidence, not a final answer.

**Self-rating of driving ability is not accurate.** Family observations are valuable evidence. Thoughtful planning beats a crisis.

EARLY / MIDDLE STAGE

Agree now on observable signs that mean it's time for a check.

LATE STAGE

Keep keys and the car out of sight; answer with reassurance, not argument.

PROFESSIONALS

No single indicator is enough; combine several.

# Warning signs from the passenger seat

## Getting around

- Needs reminders for familiar places
- Gets lost on known routes

## Judgment and control

- Slow or poor decisions in traffic
- Too slow or too fast for conditions
- Misses traffic signs
- Poor lane control
- Mixes up brake and gas

## Red flags

- New dents, crashes, or near-misses
- Agitation or confusion at the wheel
- Family or clinician concern

*Source: Alzheimer's Association, Dementia and Driving*

# What predicts unsafe driving

1. **Caregiver concern**
2. **Crashes or citations**
3. **Driving less, avoiding hard situations**
4. **More advanced dementia**

## No single sign decides.

Look at the pattern, then measure it.

*Iverson et al., 2010 (American Academy of Neurology practice parameter on dementia and driving)*

# Your turn

## What have you noticed?

## What worries you most?

## If driving has already stopped: what helped?

**EARLY / MIDDLE STAGE**

Ride along monthly and jot dated notes for the clinician.

**LATE STAGE**

Drive at their best time of day, bring a second adult, and use child locks.

**PROFESSIONALS**

Pair caregiver report with objective data; re-assess about every 6 months.

# Thinking behind the wheel



## Recognize

traffic conditions and destinations



## Process

information and decide in time



## Understand

and operate the vehicle



## Recall

directions and routes

**Dementia can slow how fast the brain takes in and sorts information, even before memory loss is obvious.**

*Hill et al., 2019*

# Seeing the road



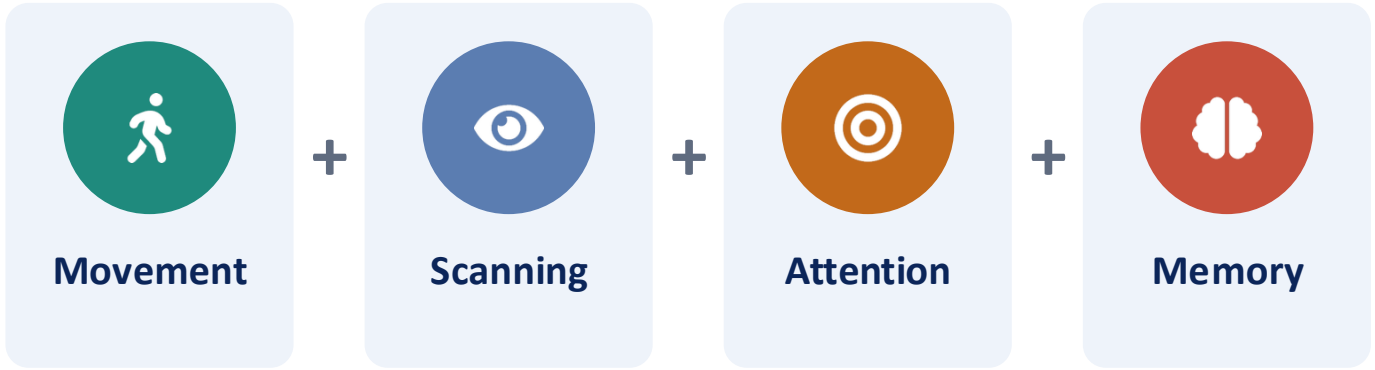
**Most of what we need to drive comes through the eyes.**

- **Other vehicles**
- **Traffic signals and signs**
- **Lane markings**
- **Road conditions**
- **Pedestrians**
- **Equipment and controls**

**Glaucoma, cataracts, and macular degeneration are common and treatable.** Book an eye exam.

# Body and reaction time

- Strength
- Balance
- Range of motion
- Neck flexibility
- Hearing




**= Reaction time**

**A slow Rapid Pace Walk can flag decreased driving ability.**

*Hill et al., 2019*

# Medications and health conditions

## Medications

- Many medications, and new ones, can affect driving
- Sedating medicines need special attention
- Review any new medicine or dose change

***Ask: "Could any of these affect driving?"***

## Health conditions

- **Sleep apnea**
- **Seizures**
- **Diabetes**
- **Stroke**
- **Heart conditions**
- **Eye disease**
- **Psychiatric conditions**

**EARLY / MIDDLE STAGE**

Book an eye exam and a medication review that names driving.

**LATE STAGE**

Vision, hearing, and sedation still affect comfort and safe transfers.

**PROFESSIONALS**

Screen sedative and anticholinergic burden; treat cutoffs as flags.

# An objective third party

## Occupational therapy comprehensive community mobility evaluation

- Performed by an OT or certified driver rehabilitation specialist
- Typically 2–3 hours
- Medical referral
- Objective estimate of crash risk

## From a family argument to a professional measurement.

It can lead to ways to keep driving safely, not only to stopping.

*Ask about current cost and insurance coverage.*

# What is measured, what happens next

## WHAT IS ASSESSED




## WHAT HAPPENS NEXT

- **Drive with no restrictions**
- **Drive with restrictions**
- **On-road evaluation next**
- **Stop driving**

# Who gets the results

**Evaluation** → **Written report** →

- **Referring physician**
- **Patient and family**

An OT can't send results to the NC DMV unless the DMV made the referral.

North Carolina has no mandatory DMV notification of a dementia diagnosis.

**EARLY / MIDDLE STAGE**

Ask the doctor for a referral; call it a neutral expert check.

**LATE STAGE**

A formal evaluation may no longer help. Ask for a written recommendation.

**PROFESSIONALS**

Clinic testing estimates risk; it doesn't replace on-road assessment.

# “We need to talk”

*“Last week we missed the turn to Sarah's. I'm worried because I love you.”*

*“Can we look at this together and ask the doctor?”*

1. **Start early; expect several talks**
2. **Choose a calm time and one trusted messenger**
3. **Name one specific observation**
4. **Re-check about every 6 months**

*Alzheimer's Association; The Hartford and MIT AgeLab, We Need to Talk*

# When the conversation goes badly

1

**Be patient**

Name the loss before the facts

2

**Bring in a neutral third party**

Doctor or driving evaluation

3

**Last resort: remove the keys**

Disable or move the car

4

**Always: a safe ride for every trip**

A car taken away with no replacement means isolation

# Plan a driving retirement



### Start early

Never too early

### Involve family and friends

Include trusted people

### Write the agreement

Sign while the person can take part

### Step down in stages

Daylight, familiar routes, no highways

### Line up rides

Before you need them

**SAMPLE DRIVING AGREEMENT WORDING**

*"If I get lost on a familiar route, or if my doctor recommends it, I'll stop. My family will make sure I can still get to church and the store."*

# Words that help

## Try

- “I've noticed… and I'm worried because I love you.”
- “Let's ask the doctor together.”
- “What would help you keep getting to ____?”

## Avoid

- “You're dangerous.”
- “I'm taking your keys.”
- “Don't you remember what happened?”

**EARLY / MIDDLE STAGE**

Open with a shared goal; plan several short talks and a written agreement.

**LATE STAGE**

Keep it short, calm, and identical each time; a doctor's note can carry it.

**PROFESSIONALS**

Acknowledge the loss, use teach-back, and document the plan.

# Getting around without driving

## Start with the three or four trips that matter most.

Then build a ride for each one.



### Share the driving

Family members and friends take over regular trips.



### Arrange ride services

Ride programs and volunteer drivers. Start with your Area Agency on Aging.



### Reduce the need to drive

Mail-order prescriptions, grocery delivery, and meal delivery.

# Grief, identity, and connection

## Anger is often grief.

Your loved one isn't being difficult. They are mourning a loss.

### Name the loss

"This is a huge change. I'm sorry."

### Keep a role

Co-pilot, navigator, or the person who picks the music.

### Schedule outings

Put recurring trips on the calendar.

### Watch mood

Tell the care team if sadness or withdrawal lasts.

*Chihuri et al., 2016*

# If driving is already behind you

### Keys and car out of reach

Keep keys out of sight. Consider moving or disabling the car.

### Safe rides

Choose their best time of day, bring a second adult, and use child locks if distress appears.

### Be gentle with yourself

Guilt about taking the keys is common. Support groups can help.

**EARLY / MIDDLE STAGE**

Before the last drive, schedule 2–3 outings reachable without a car.

**LATE STAGE**

Short, familiar passenger outings can lift mood.

**PROFESSIONALS**

Screen mood after driving stops; refer to OT for community mobility.

# Driving against medical advice

## Driving against advice can have legal and insurance consequences.

- A person may be held responsible after a crash
- Rules vary by state and change over time
- Written recommendations protect everyone

**DO NOW**

- Get recommendations in writing
- Check your auto policy
- Talk with an elder-law attorney

**EARLY / MIDDLE STAGE**

Learn who can report to the DMV and how insurance treats driving against advice.

**LATE STAGE**

Confirm the car is out of reach; check insurance and ownership details.

**PROFESSIONALS**

Know state reporting rules; document recommendations.

# Where to get help



## Your doctor

Ask for a referral to an OT or certified driver rehabilitation specialist.



## Find a specialist

Association for Driver Rehabilitation Specialists (ADED) directory.



## Local support

Your Area Agency on Aging and your local Alzheimer's Association chapter.



## Duke Dementia Family Support Program

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# Three things to take home



## Notice

Write down what you see.



## Measure

Ask for an objective evaluation.



## Plan

Talk early, often, and kindly, with a ride for every trip.

# Questions?

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**Thank you for joining us today!**

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