

# How an early diagnosis can help caregivers

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25 April 2024



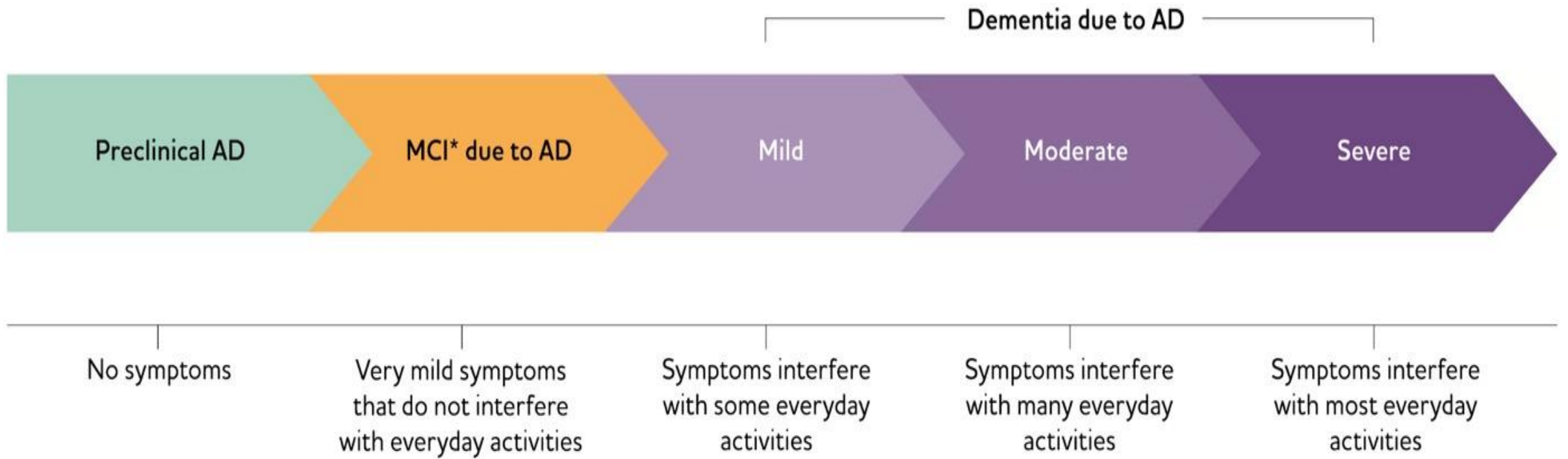
# My inspiration...



# Why diagnose dementia early?

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- Only 60% of people with dementia in the US have a diagnosis – even fewer have been informed of their diagnosis
- A diagnosis is important for accessing specialist treatment and support
- It is hoped that diagnosing dementia earlier in the disease process will lead to better outcomes
- But what is an early diagnosis?



you are  
here



Dementia due to AD



No symptoms

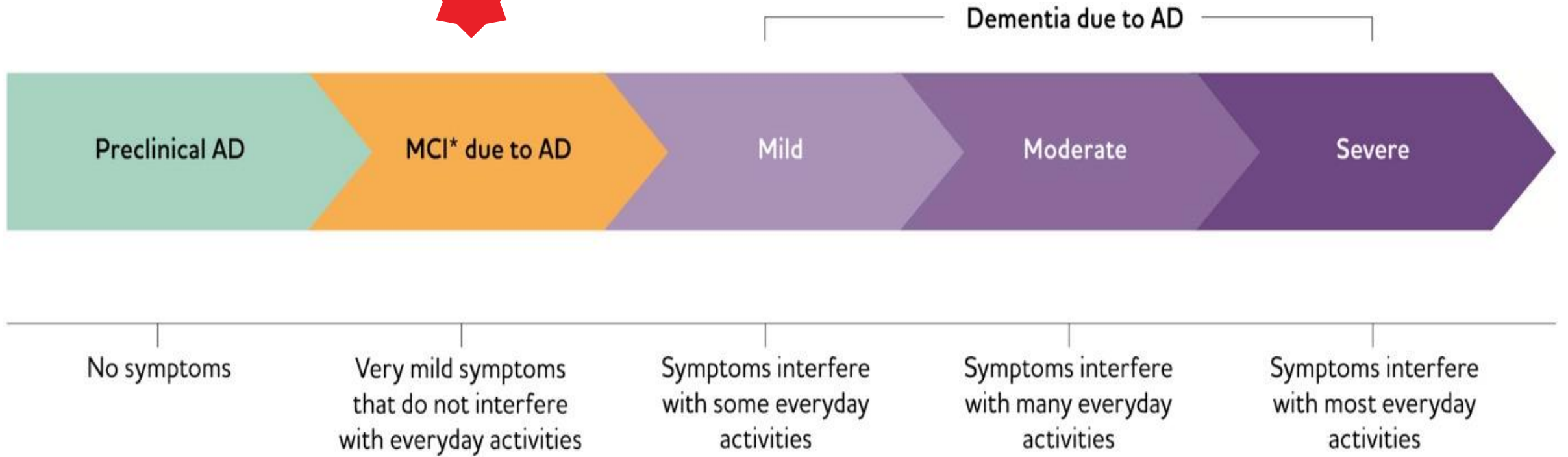
Very mild symptoms  
that do not interfere  
with everyday activities

Symptoms interfere  
with some everyday  
activities

Symptoms interfere  
with many everyday  
activities

Symptoms interfere  
with most everyday  
activities

you are  
here



**An early diagnosis is made close to the onset of symptoms or during a stage called “mild cognitive impairment”**

# Caregiver perspectives of an early diagnosis

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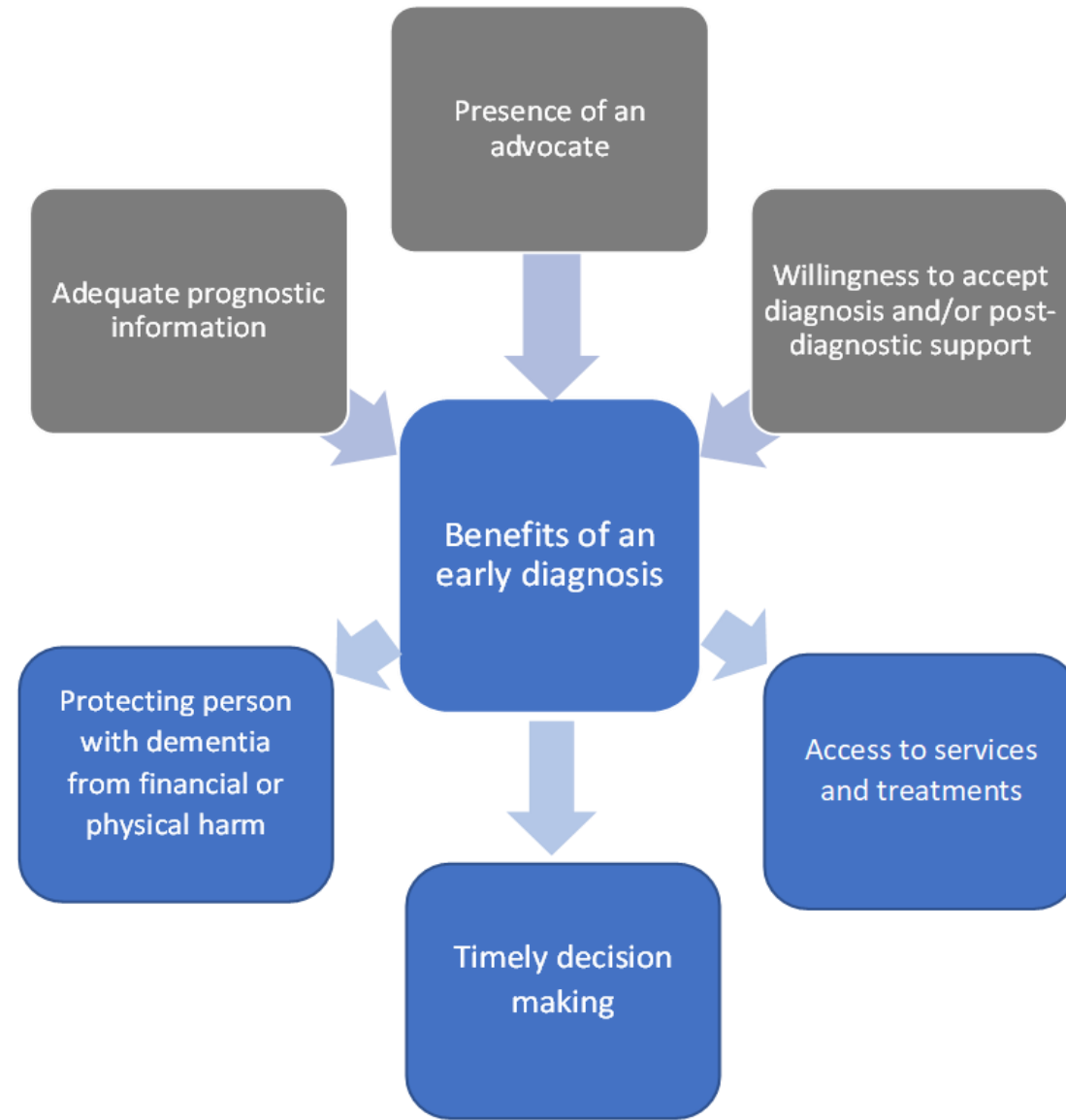
Interviewed 12 UK caregivers

- 10 current and 2 former caregivers
- 2 caregivers to people with MCI
- 9 women and 3 men
- 4 child caregivers, 4 spouse caregivers, 4 caring for multiple people with dementia

Asked questions about

- When they first noticed the person with dementia's symptoms
- Their experiences of diagnosis and follow-up support
- What went well?
- What could have been better?
- How would an earlier diagnosis help?





# Benefit 1: protect person with dementia from harm

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During undiagnosed dementia caregivers said the person with dementia was at risk of:

- Financial exploitation/ scams
- Road traffic accident
- Going missing
- Breakdown of interpersonal relationships

A diagnosis could help prevent these crises

“He was borderline driving, but certainly soon after the dementia diagnosis, after he’d driven through a red light and things, I persuaded him he’d got to stop driving.”

# Benefit 2: timely decision making

A diagnosis triggers conversations about the future.

People with dementia can make plans with their caregivers regarding:

- Nursing home care
- Legal/medical power of attorney
- Estate planning

“we have game plan for the long-term”

“We never had the care home conversation. Not seriously. My view is that if I get old and craggy I want to be in a care home and not be a burden to my family. But I'm not sure he feels the same way, so it's a bit difficult for us now, not knowing where he stands”

# Benefit 3: Access to services and treatments

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A diagnosis is necessary for drug and non-drug treatments

- Drug treatments more likely to be effective during the early stages

Services can help people with dementia cope with the diagnosis

Services can help caregivers adapt to their new role

“She has had quite a lot of support including going to some kind of classes to help for people with dementia and taking medication too”

# Condition 1: Adequate prognostic information

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Participants struggled to find information on how to cope with the person with dementia's symptoms

They wanted single source of information and support

In the absence of support and information, an early diagnosis helped caregivers come to terms with the diagnosis

“But just the anguish of the long goodbye. I think maybe an earlier diagnosis would certainly help you prepare, prepare more, I think. Although it doesn't take the pain away from the length of time. You know. That is something you just have to bear with.”

## Condition 2: Presence of a caregiver

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Caregivers had to fight for support from health care services

They worried about what would happen to people without caregivers

An early diagnosis can be important for people without close family for making plans

I don't think children or marriage are an insurance policy anyway. But you become very aware of the fact that if you start to have Alzheimer's, it's going to be really, really difficult and that you will need to put things in place before you've completely lost the ability to communicate or fight for your rights or feed yourself, all those sorts of things.

# Condition 3: Willingness to accept the diagnosis or support

Some people with dementia did not want to accept the diagnosis

This could make it difficult to access or organize care

Some caregivers did not access support for themselves

“There was probably a period of about six more months, I would say, he didn't want to go to the GP to talk about it. He never in this life acknowledged that he had dementia.”

# Conclusions

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An early diagnosis can help:

- Prevent crisis
- Facilitate making plans for the future
- Access to services and treatment
- Help caregivers to understand the person with dementia better



# Conclusions

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We need to do better at:

- Helping caregivers find information for managing their caregiving role
- Supporting people with dementia who don't have family
- Helping people with dementia to seek help for memory problems or accept their diagnosis
- Helping caregivers to help themselves!

# Future research

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- How biomarker testing affects patient and caregiver experiences of a dementia diagnosis
- Whether outcomes are better for people diagnosed at the MCI stage compared to later stages
- Support and health care needs of people with dementia without close family or friends to act as a caregiver

# Current studies at Brown University

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## LEADS Study

People with cognitive impairment, aged 40-65

## LINE-AD

Emtricitabine for people with MCI or AD, aged 50-85

## US POINTER TRIAL

People aged 60-79 who don't exercise and may be at risk of dementia

Contact the Memory and Aging Program to participate  
[memory@butler.org](mailto:memory@butler.org)

**Thank You**  
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