

The Right to Risk: Clinical and Ethical Challenges of Aging in Place

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Conflicts of interest

None related to this presentation

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Photo credit: A. JOBIN / IUGM outpatient clinics – CIUSSS CCSMTL



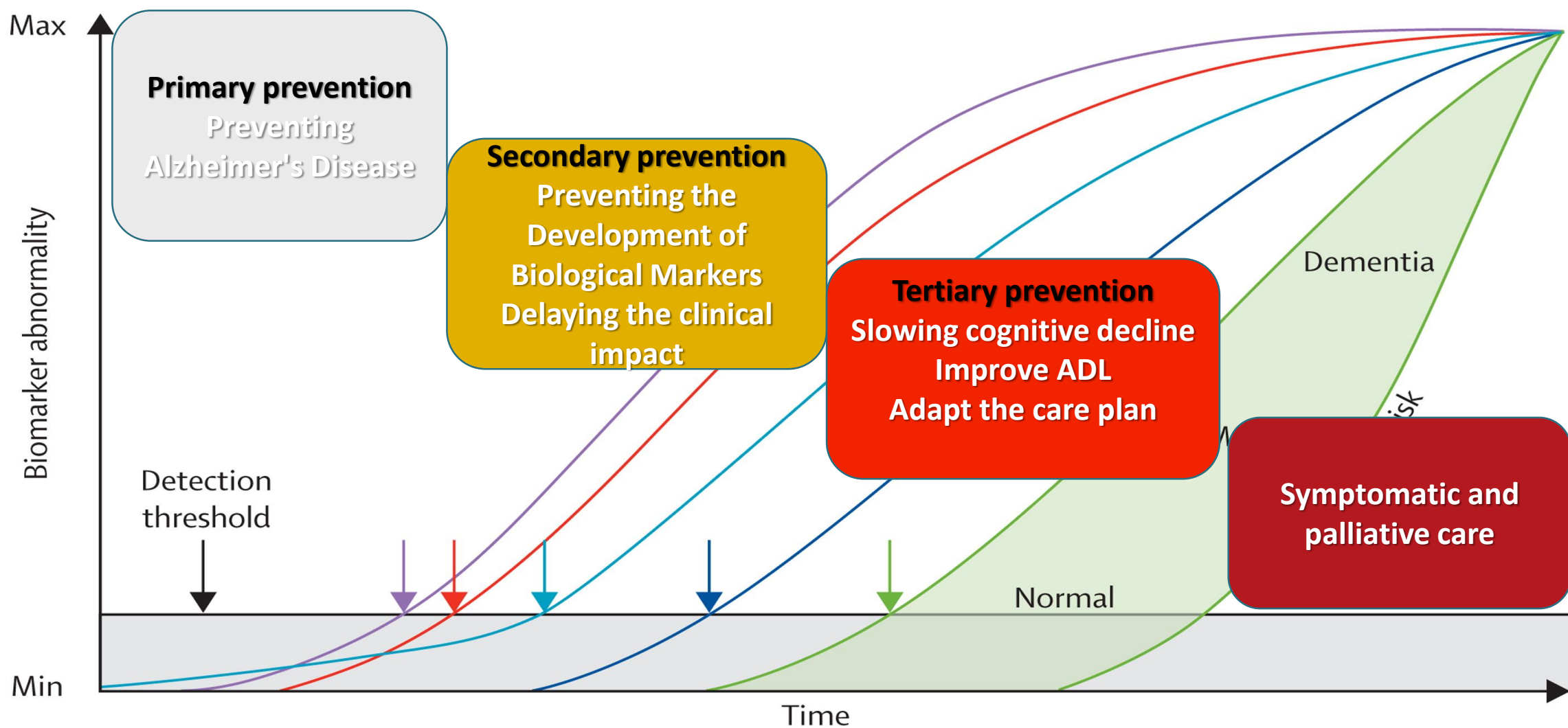
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General topic

How can we support people living with Alzheimer's disease to age in place despite the risks?

The Alzheimer's disease continuum





Approaches to care



Medications

- Symptoms (anxiety)
- Cognitive support (AChE)
- Eliminate unnecessary/excessive medication
- Anti-amyloid therapies

Requiring etiological diagnosis – MRI and ApoE4



Rehabilitation

- Cognitive rehabilitation
- Motor rehabilitation (risk of falling)
- Lexical and language reinforcement.
- Swallowing support
- Incontinence rehabilitation

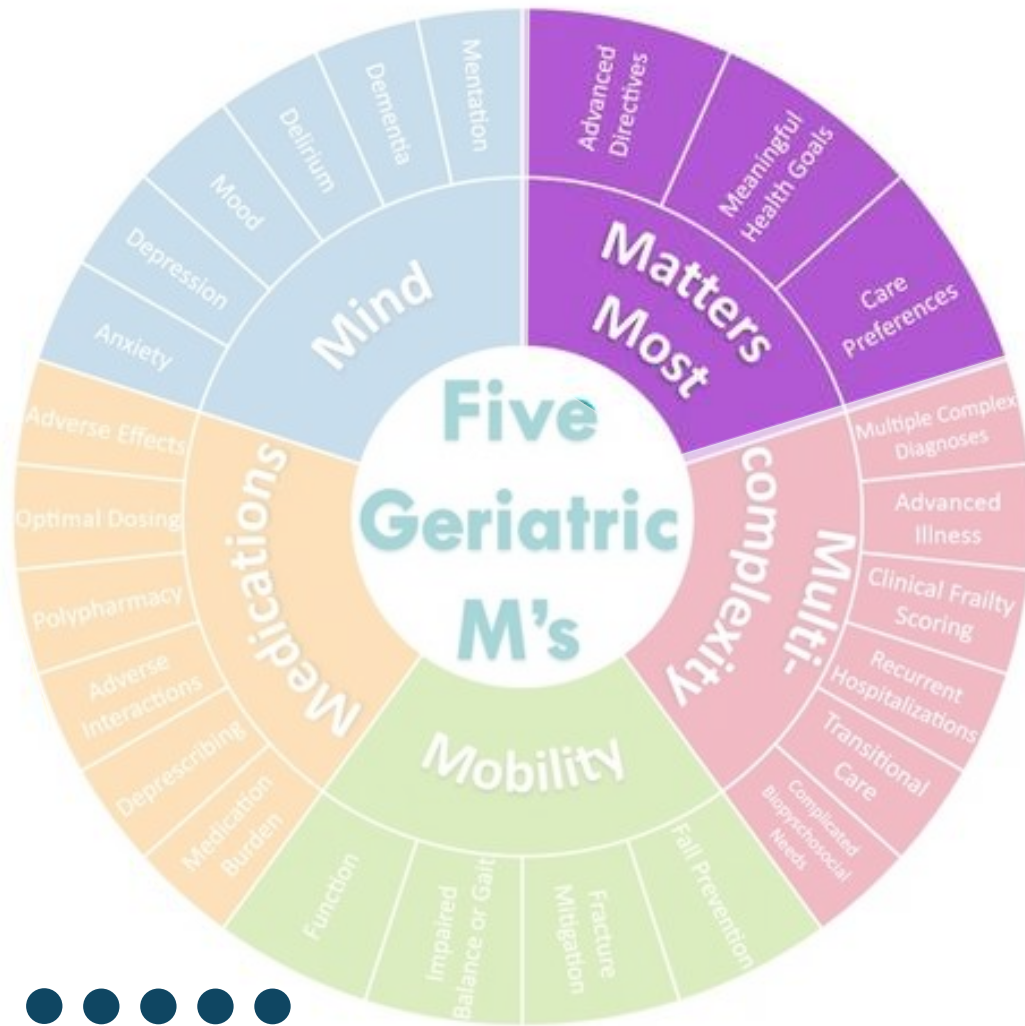


Social support

- Social participation
- Inclusivity
- Gradual implementation of home support
- Integration into support networks and initiatives
- Anticipated Decision-Making



Define care objectives



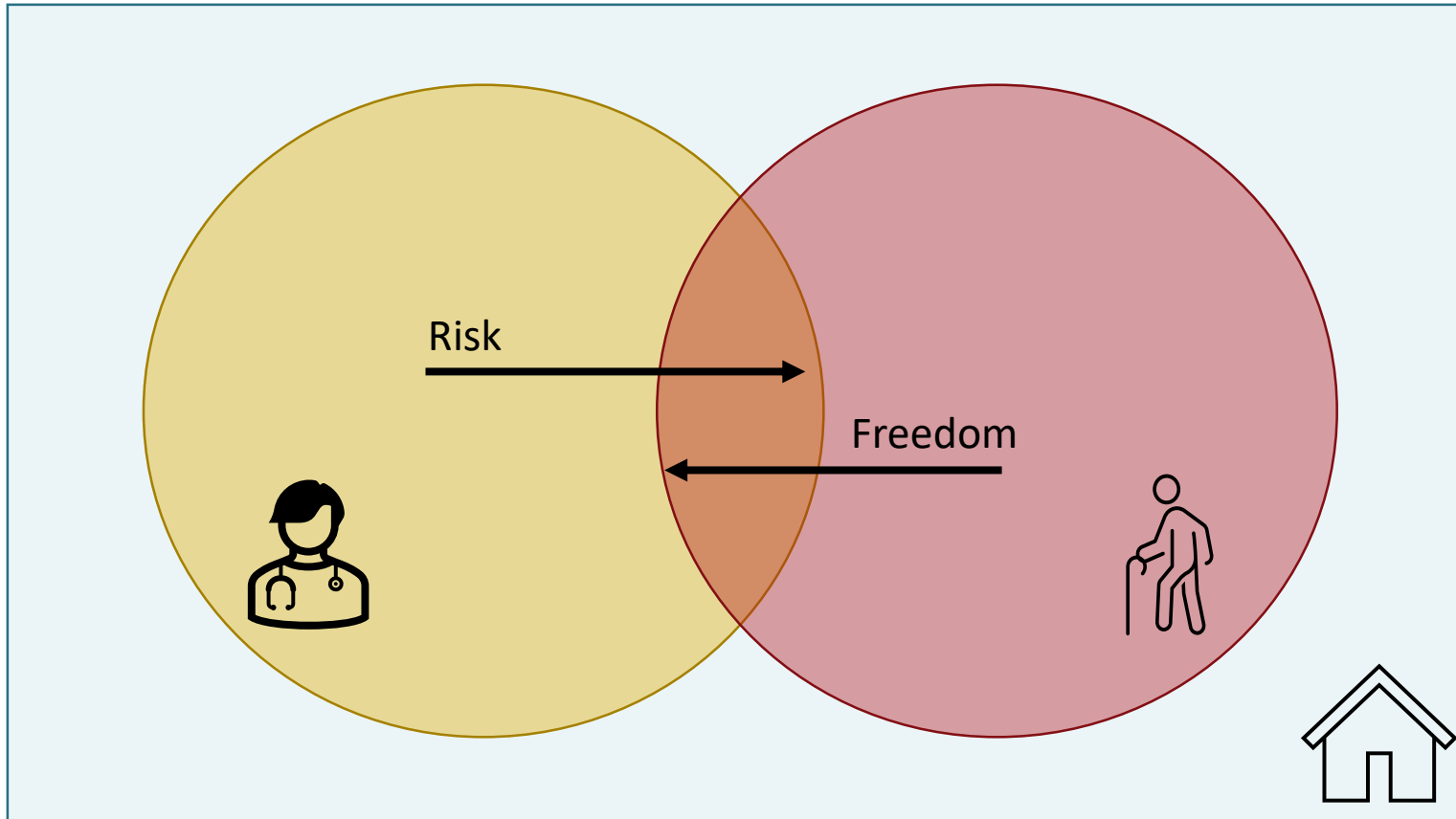
Through access to a multidisciplinary assessment

Requires **coordinated** care

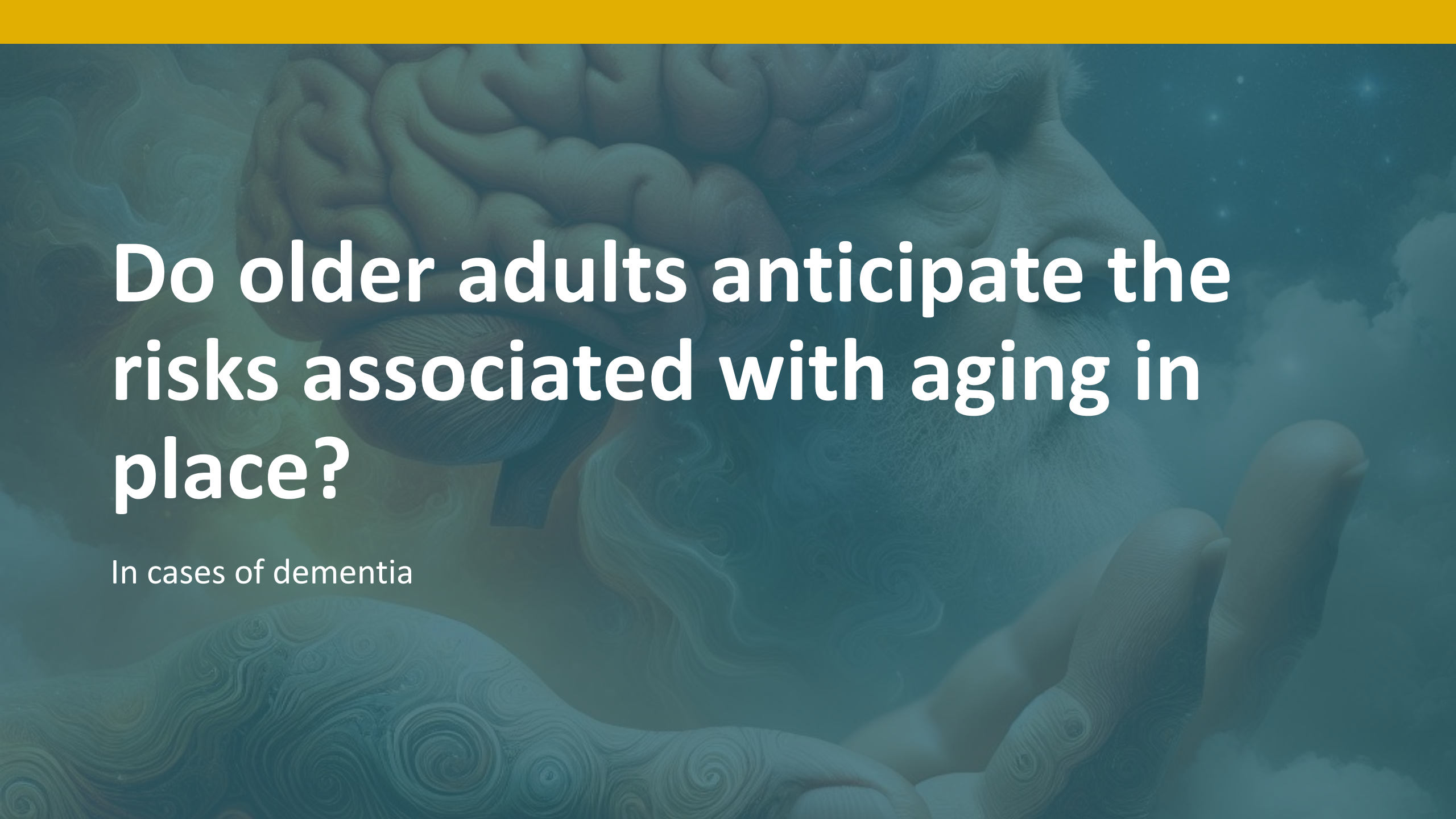
Access to rehabilitation professionals (physical therapists, occupational therapists, speech therapists, neuropsychologists) to **maintain skills**.

Based on a **shared goal** between people living with major neurocognitive disorder and their caregivers, in line with a **person-centered approach** to care.

• The challenges of shared decision-making



Responsibility?



Do older adults anticipate the risks associated with aging in place?

In cases of dementia

A common goal: aging in place

Older adult

Maintaining stability in the environment:
emotional attachment,
points of reference, rights



Caregiver

Maintaining stability in the environment:
emotional attachment,
points of reference, rights

"I've been here for 40 years."

"I hope to be able to stay at home as long as possible."

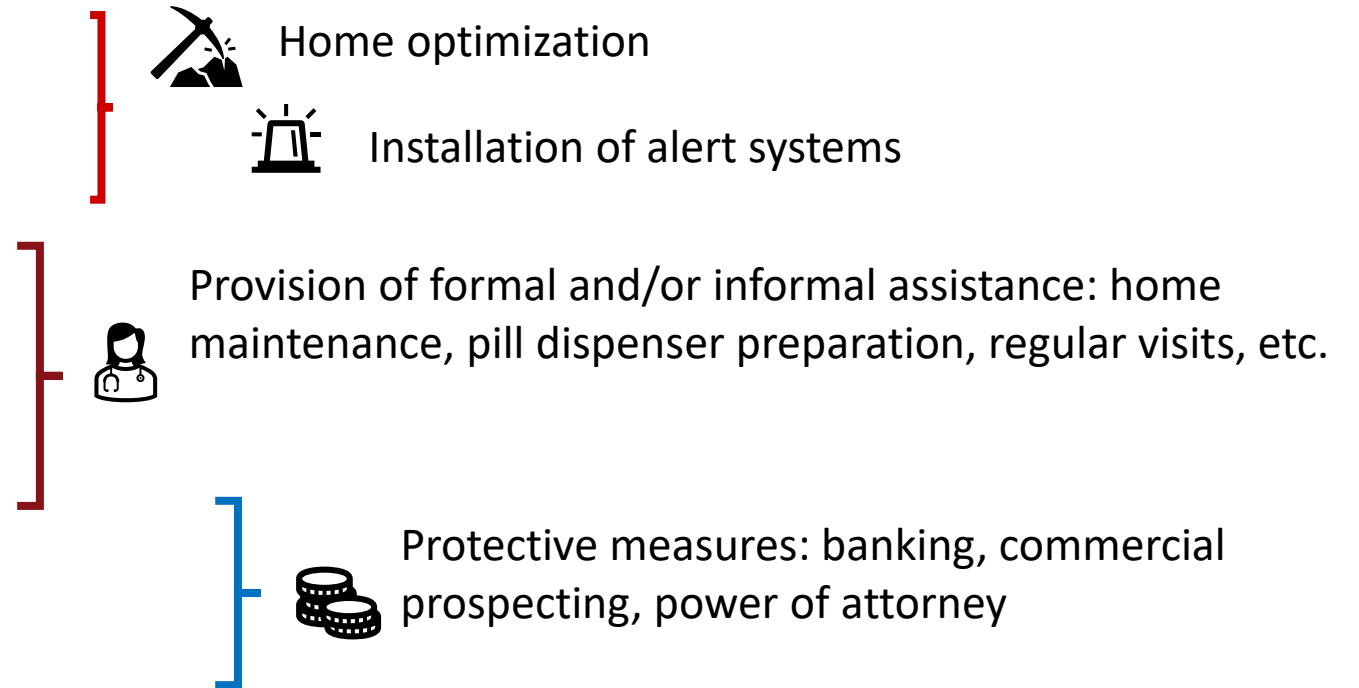
"We have decided to do everything in our power to keep her at home."

"She has her dog, she has all her memories in the house."

Identifies everyday risks

- ❖ Risk within the living environment
- ❖ Food
- ❖ Medications
- ❖ Abuse of weakness/vulnerability

Wants to provide a safe environment.



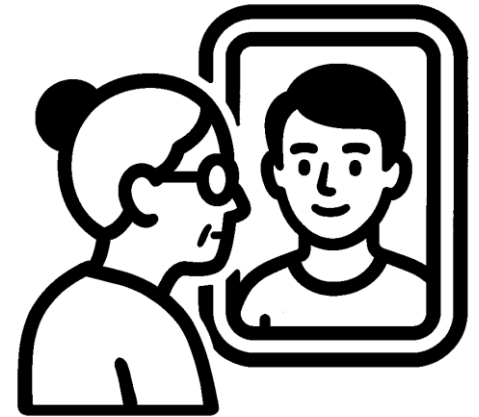
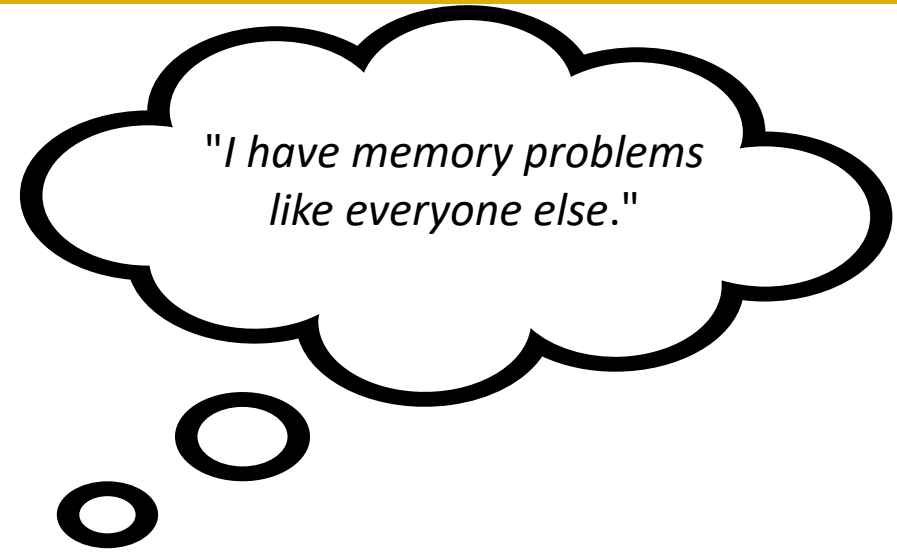


Self-awareness disorders...

What happens... if we forget that we forget?

We think we are the "self" we were before the illness...

...so... we trivialize our needs and resist offers of care and services.



This is known as anosognosia.



Consequences of impaired self-awareness



The importance for older adults of maintaining stability. This relates to their internal security.

(Bonnet and Chopard-Dit-Jean, 2018; Callahan, 2019)



This conflicts with the external risks perceived by loved ones, who believe that adjustments to the environment are necessary.

(Derouesné et al., 1999; Derouesné, 2009)

How to prevent conflicts around aging-in-place?

JOURNAL ARTICLE

Assessing What Matters Most in Older Adults With Multicomplexity FREE

Jennifer Moye, PhD ✉, Jane A Driver, MD, MP, Montgomery T Owsiany, MS, Li Qing Chen, BA, Jessica Cruz Whitley, MD, Elizabeth J Auguste, BA, Julie M Paik, MD, ScD, MPH

The Gerontologist, Volume 62, Issue 4, May 2022, Pages e224–e234,
<https://doi.org/10.1093/geront/gnab071>

Published: 27 May 2021 **Article history** ▼

Oppositional behaviors often reflect unmet needs or lack of adaptation.

We must better understand What Matters Most

What Matters Most – Structured Tool (Revised)

It is important to make health decisions that line up with your priorities, especially when you have many medical concerns. To do so, it is important to know what matters most to you. For some, this can be hard to put into words. This tool may help. Circle **up to 3 things in each column** that **MATTER MOST** to you.

FUNCTIONING	ENJOYING LIFE	CONNECTING
• Think clearly • Walk or move around by myself • Choose where I live • Eat foods I enjoy • Work or volunteer • Make decisions about my finances • Dress or bathe myself • See (or hear, smell, taste, touch) • Drive or be able to get around outside my home • Other:	• Participate in favorite hobbies (like sports, gardening, woodworking, reading, art, etc.) • Attend social events (like movies, concerts, parties, meetings, etc.) • Participate in religious/spiritual services or practices • Spend time outdoors or connecting to nature • Do things to improve myself, learn, or be creative • Have physical touch and / or sexual intimacy • Have quiet time doing nothing in particular • Travel and/or see new places • Exercise • Other:	• Spend time with family and friends • Have good relationships with family or friends • Connect to God or a higher power • Avoid being a burden to others • Take care of my pet(s) • Feel connected to positive aspects of myself • Contribute to my community or neighborhood • Take care of family or friends (like being a caregiver) • Other:

Of all the things you circled, **Which 3 Matter Most** above all? In your own words, what do they mean to you?



Negotiation in aging

Slowing down of information processing speed

Tendency toward **conservative choices**:

- Less appetite for gains
- Loss aversion

Therefore:

- Begin by presenting the **absence of loss/stability**
- Then we present the new advantages
- Finally, we **negotiate the risks**

Key summary points

Aim The complexity of decision-making involves many neurological functions and structures which are potentially altered by cognitive aging.



The use of technology: a tool for risk negotiation in care?

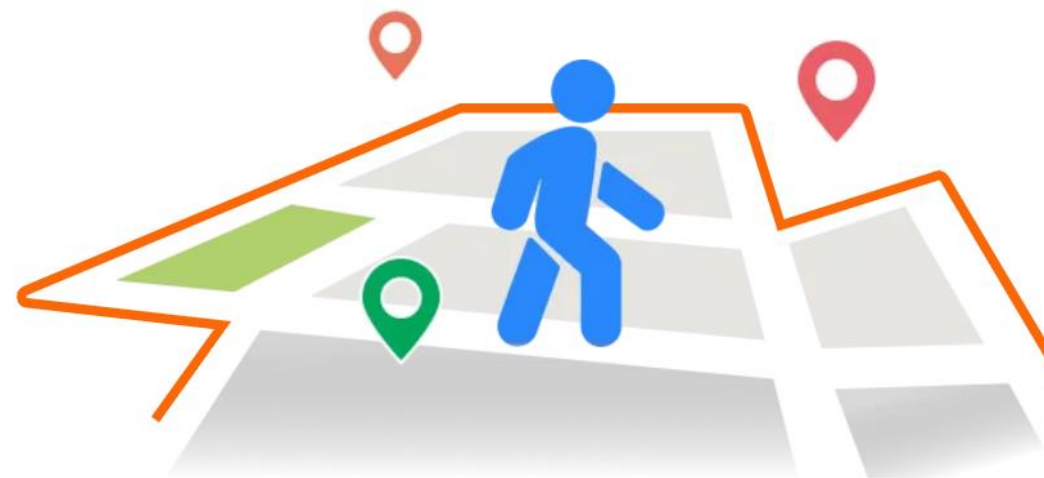
How can social participation be supported despite the risk of wandering?



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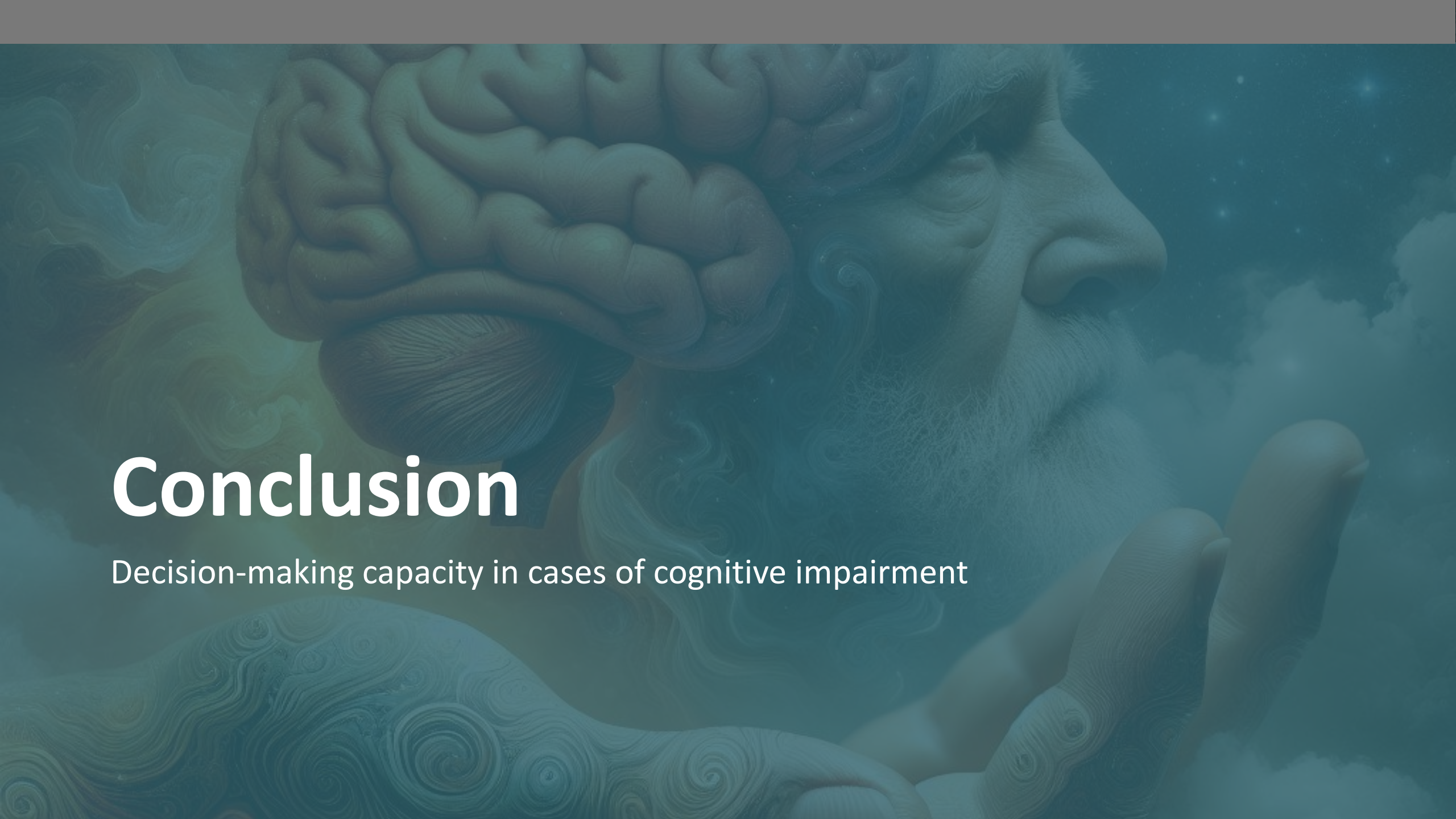
Geo- **Pathing**

Our GeoPathing capability allows caregivers to create custom virtual paths, offering a tailored and realistic safety net beyond traditional geofencing. This precise monitoring ensures safer movements for older adults, enhancing caregiver peace of mind.



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The development of technologies can support risk management and promote social participation, and is an opportunity for research.



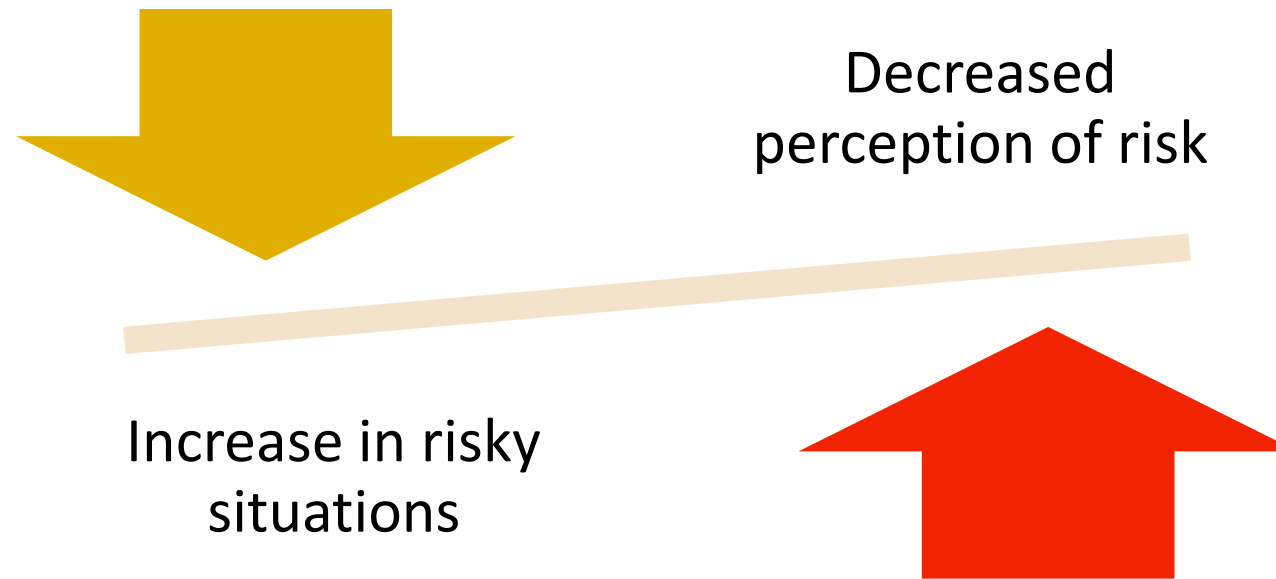
Conclusion

Decision-making capacity in cases of cognitive impairment



Decision-making, between constraints and risk perception

Neurodegenerative diseases: more than just a memory issue, **an issue of adaptability.**



Hypothesis: Leads to a potential impairment of decision-making ability (autonomy) with regard to everyday risk-taking (care, property, and people).



How can we manage the need for shared decision-making?

Conditions to support risky behaviours

1

Degree of risk



2

Level of impairment



3

Persistence of choices
and behaviours



4

Shared decision-making with
the patient's environment



5

Review decision



*The ability to take reasonable risks
defines our liberty.*

When in doubt, rather than safety
concerns, it is the preservation of
human dignity that must guide our
actions, in a spirit of **sharing** and
exchange.



Perspectives:

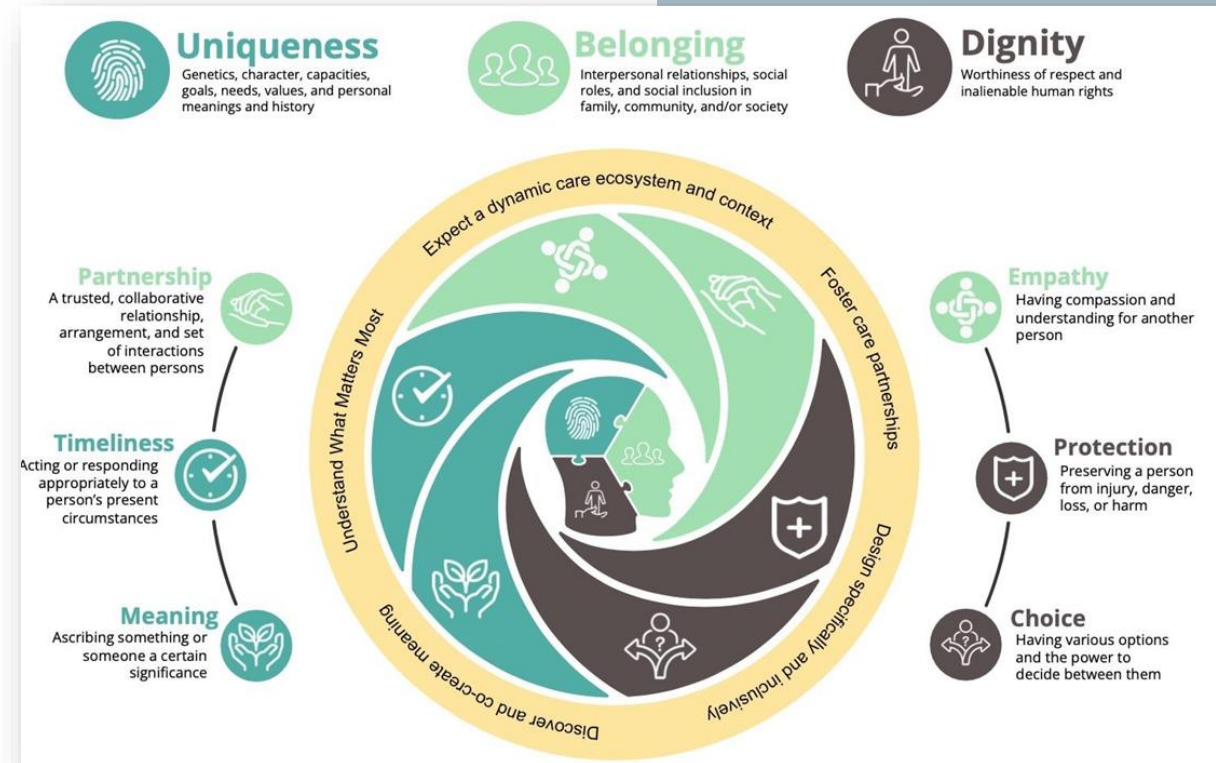
Adapt to the environment...

...or adapting the environment to the person?

Anticipating loss of independence for coordinated, preventive, multifactorial action

Provide adaptable living environments to avoid the need for relocation later in life.

Rely on technological environments to identify needs and target assistance.



Hwang, et al. , Co-creating Humanistic AI AgeTech to Support Dynamic Care Ecosystems: A Preliminary Guiding Model, The Gerontologist, 2024

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