



# Supported Decision Making for Older Pennsylvanians

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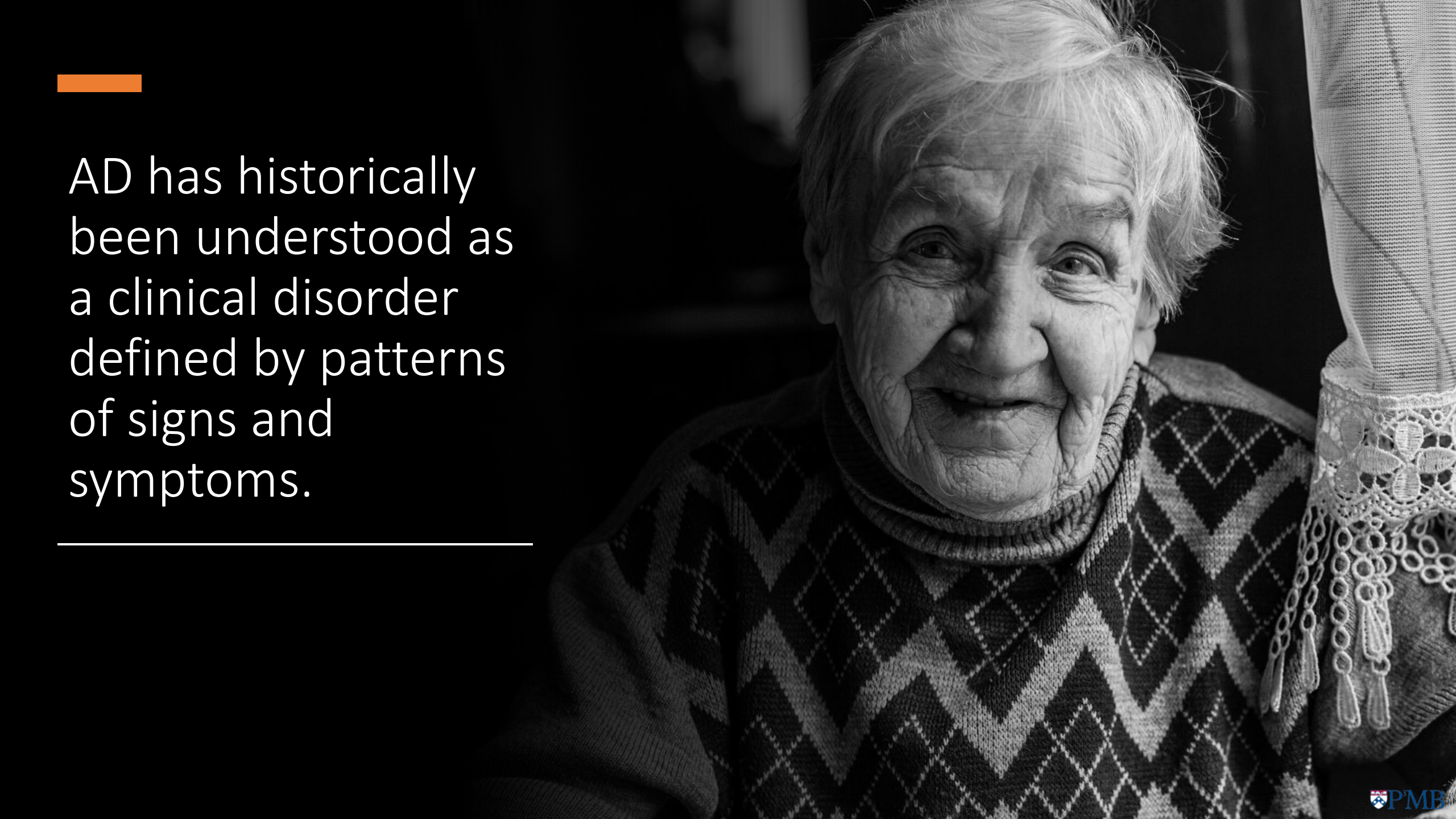
# Disclosures

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- I have grants from the National Institute on Aging and the Greenwall Foundation. The content is solely the responsibility of the author and does not necessarily represent the official views of the National Institutes of Health or Greenwall Foundation.

A photograph of an elderly woman with short, curly white hair, smiling warmly. She is wearing a green turtleneck sweater and a bright orange scarf. She is holding several books, including a red one and a dark green one, in her hands. The background shows wooden bookshelves filled with books, suggesting a library or bookstore. The lighting is soft and warm.

**Why does this  
case matter?**



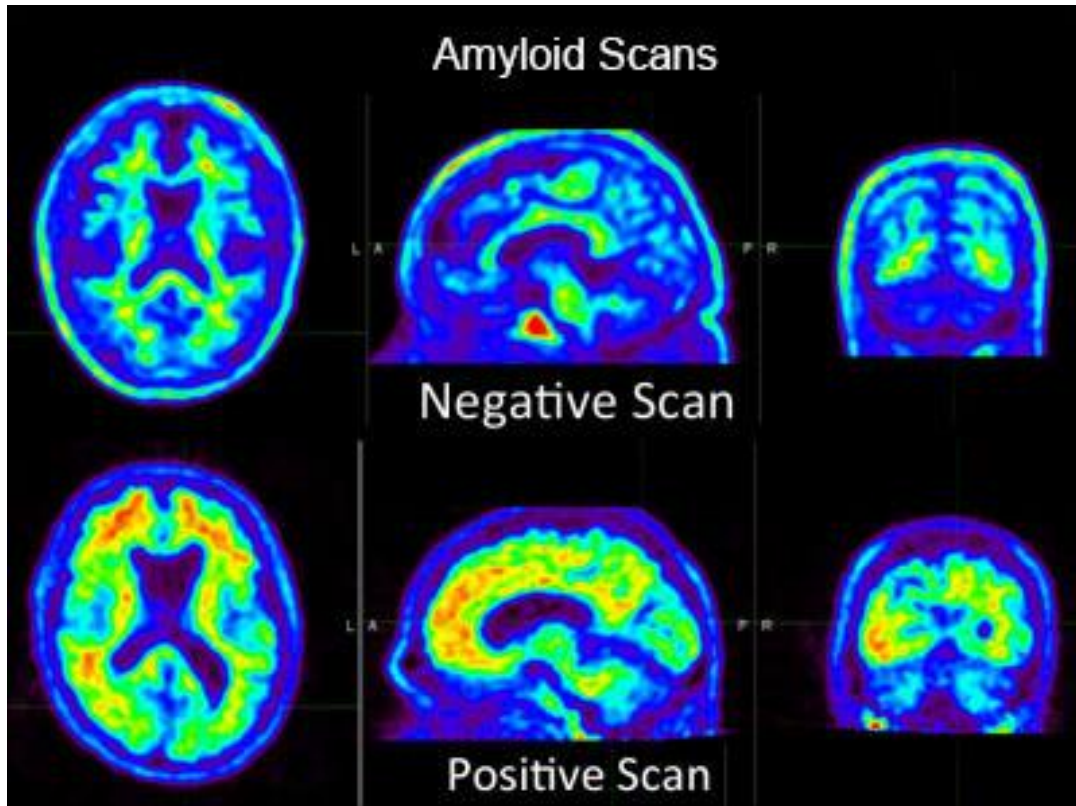
AD has historically been understood as a clinical disorder defined by patterns of signs and symptoms.

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Now, however, we are moving away from a syndromal definition of Alzheimer's disease towards a biological definition.

- Researchers are using biomarkers to identify pathology in vivo.
  - Amyloid, tau, neurodegeneration (A/T/(N))
  - PET, CSF, MRI...plasma





UCSF

Syndromal Cognitive Stage				
		Cognitively unimpaired	MCI	dementia
<b>Biomarker Profile</b>	<b>A<sup>-</sup>T<sup>-</sup>(N)<sup>-</sup></b>	normal AD biomarkers, cognitively unimpaired	normal AD biomarkers with MCI	normal AD biomarkers with dementia
	<b>A<sup>+</sup>T<sup>-</sup>(N)<sup>-</sup></b>	Preclinical Alzheimer's pathologic change	Alzheimer's pathologic change with MCI	Alzheimer's pathologic change with dementia
	<b>A<sup>+</sup>T<sup>-</sup>(N)<sup>+</sup></b>	Alzheimer's and concomitant suspected non Alzheimer's pathologic change, cognitively unimpaired	Alzheimer's and concomitant suspected non Alzheimer's pathologic change with MCI	Alzheimer's and concomitant suspected non Alzheimer's pathologic change with dementia
	<b>A<sup>+</sup>T<sup>+</sup>(N)<sup>-</sup></b>	Preclinical Alzheimer's disease	Alzheimer's disease with MCI (Prodromal AD)	Alzheimer's disease with dementia
	<b>A<sup>+</sup>T<sup>+</sup>(N)<sup>+</sup></b>			

Non-Alzheimer's continuum profiles are not included in table because the risk associated with different combinations of T+(N)-, T+(N)+, T-(N)+ among A- individuals has not been established

- rate of short term clinical progression expected to be low
- rate of short term clinical progression expected to be high

Approval and adoption of disease-modifying therapies in clinical practice will likely mean that individuals live longer with MCI or early dementia—that is, they will live on the AD continuum longer.

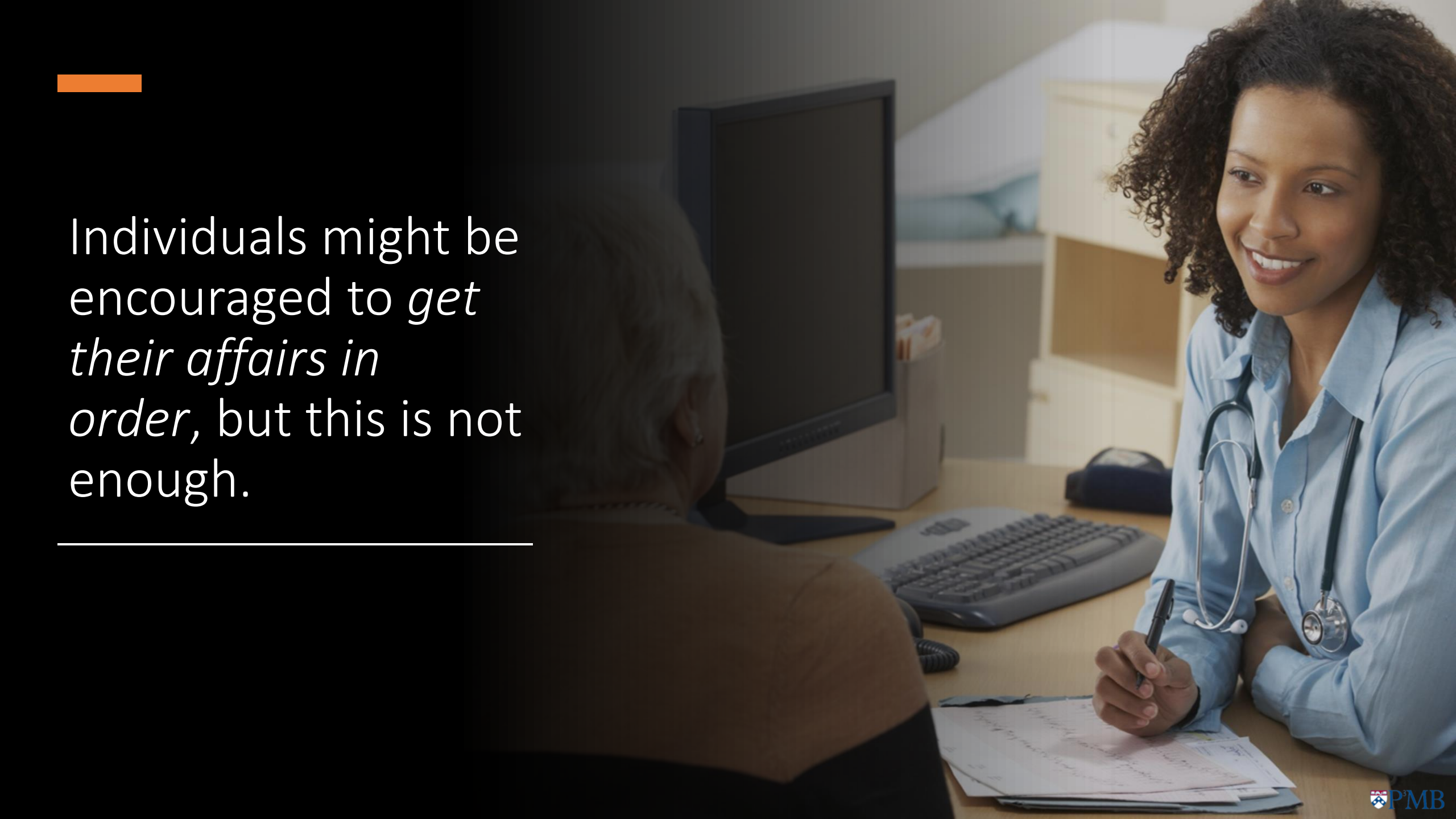


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Understanding AD as a  
continuum disorder suggests  
we need to plan for a  
*continuum of decision making.*

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Individuals might be encouraged to *get their affairs in order*, but this is not enough.

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# Ethical Challenge

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Neurodegenerative diseases,  
like AD, threaten autonomy. We  
don't want to wrest autonomy  
away prematurely.

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## What is capacity?

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The ability to:

- Understand
- Reason
- Appreciate
- Communicate a choice

Individuals who have capacity are *empowered* decision makers. Those who don't have capacity should be *protected*.

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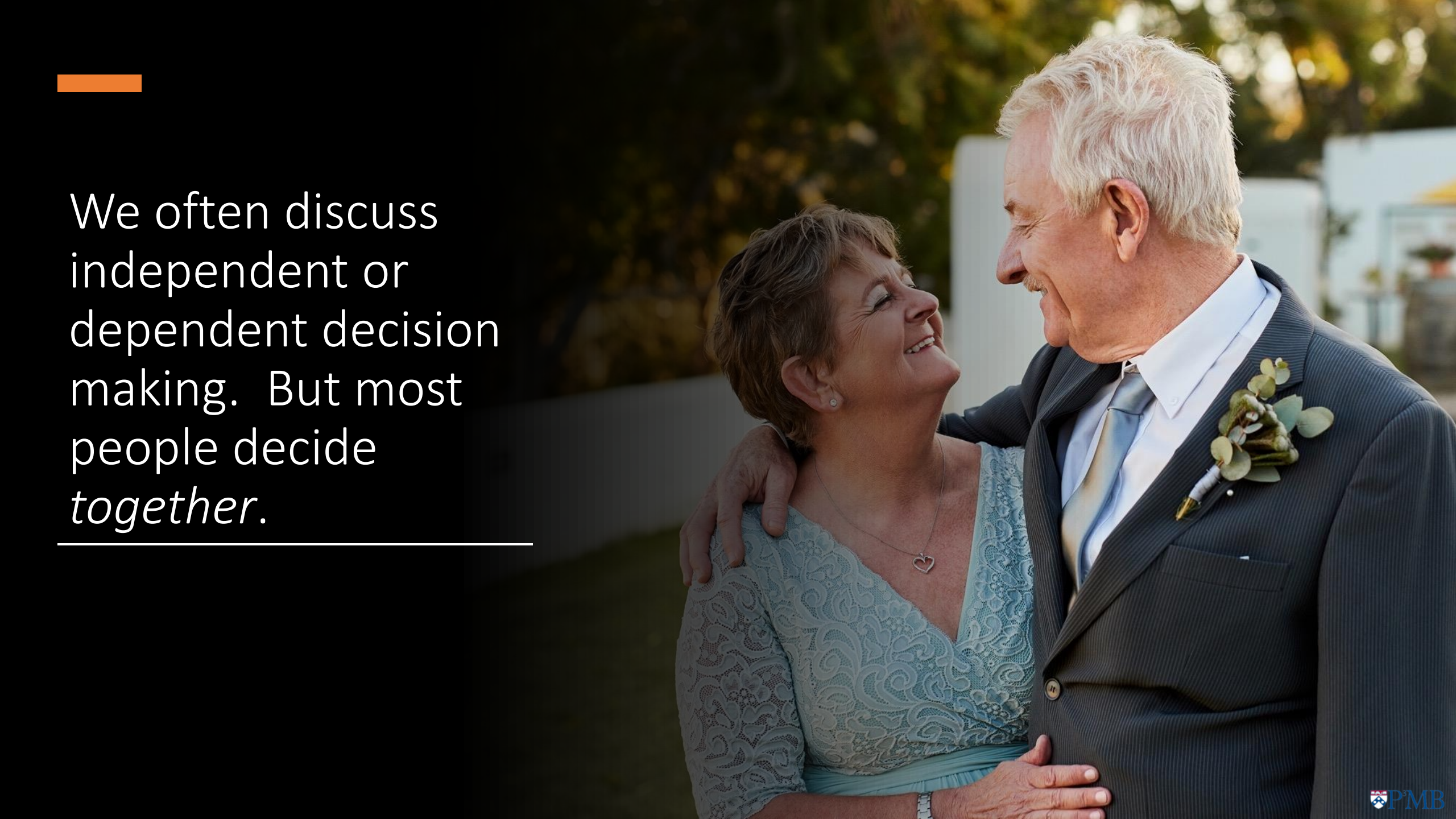
A photograph of two elderly men sitting on a dark brown sofa in a living room. The man on the left has grey hair and a beard, wearing a light-colored cardigan over a collared shirt. The man on the right has white hair and is wearing a patterned sweater over a collared shirt. They are both looking at each other and appear to be in conversation. In the background, there is a white shelf with books and a window with blinds. An orange horizontal bar is located in the top left corner of the image.

We often rely on a capacity-incapacity binary that doesn't always reflect reality—i.e., *marginal capacity*.

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		Truth	
		Has capacity	Lacks capacity
Test result	Has capacity	✓ <i>Correctly grant decision-making authority</i>	✗ <i>Wrongly grant decision-making authority</i>
	Lacks capacity	✗ <i>Wrongly invoke proxy</i>	✓ <i>Correctly invoke proxy</i>






We often discuss independent or dependent decision making. But most people decide *together.*

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# Legal Challenge

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Like ethics, the law recognizes a fundamental right to *autonomy*, though an individual's right to make decisions can sometimes be limited.

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How do we support people  
who have marginal capacity?

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We might think of this as a *goldilocks* problem.

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# Advance Directives

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- Advance directive refers both to a *power of attorney* for health care (identifies a surrogate decision maker) and to *living wills* (gives instructions regarding specific treatments).





# Guardianship

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- A **guardian** is appointed by a court for a person (**ward**) who is legally determined to lack the ability to make decisions autonomously.
  - Limited vs. plenary
  - Temporary vs. permanent
  - Guardian may be relative, friend, professional
- Decision-making authority rests *with the guardian*, though the ward should be consulted whenever possible.



Guardianship can be undesirable for people who have marginal decision-making capacity.





# Supported Decision Making

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- An adult with impaired capacity (**beneficiary**) enters freely into an agreement with a closely trusted person or persons (**supporter(s)**) who assist the beneficiary in exercising and enhancing self-determination.
    - The agreement identifies the domains of support and the means of support.
  - The *beneficiary retains the right to make decisions*, have them recognized by others.
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### Supported Decision-Making Agreement

This agreement is governed by the Supported Decision-Making Act, Chapter 1357 of the Texas Estates Code. This supported decision-making agreement is to support and accommodate an individual with a disability to make life decisions, including decisions related to where and with whom the individual wants to live, the services, supports, and medical care the individual wants to receive, and where the individual wants to work, without impeding the self-determination of the individual with a disability. This agreement may be revoked by the individual with a disability or his or her supporter at any time. If either the individual with a disability or his or her supporter has any questions about the agreement, he or she should speak with a lawyer before signing this supported decision-making agreement.

#### Appointment of Supporter:

I (Name of Adult with Disability), \_\_\_\_\_, agree to this supported decision-making agreement voluntarily.

I choose (Name of Supporter) \_\_\_\_\_ as my Supporter.

Supporters' Address: \_\_\_\_\_

Phone Number: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

#### My Supporters may help me with life decisions about:

- Yes \_\_\_ No \_\_\_ obtaining food, clothing and a place to live
- Yes \_\_\_ No \_\_\_ my physical health
- Yes \_\_\_ No \_\_\_ my mental health
- Yes \_\_\_ No \_\_\_ managing my money or property
- Yes \_\_\_ No \_\_\_ getting an education or other training
- Yes \_\_\_ No \_\_\_ choosing and maintaining my services and supports
- Yes \_\_\_ No \_\_\_ finding a job
- Yes \_\_\_ No \_\_\_ Other: \_\_\_\_\_

My Supporters do not make decisions for me. To help me make decisions, my Supporters will:

1. Help me get the information I need to make medical, psychological, financial, and legal decisions;
2. Help me understand my choices so I can make the best decision for me; or
3. Help me communicate my decision to the right people.

Yes \_\_\_ No \_\_\_ My Supporters may see my private health information under the Health Information Privacy and Accountability Act of 1996. I will provide a signed release.

Yes \_\_\_ No \_\_\_ My Supporters may see my educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g). I will provide a signed release.

This agreement starts when signed and will continue until \_\_\_\_\_ (date) or until my Supporters or I end the agreement or the agreement ends by law.

Signed this \_\_\_\_\_ (day) of \_\_\_\_\_ (month), \_\_\_\_\_ (year)

\_\_\_\_\_  
(Signature of Adult with Disability) (Printed Name of Adult with Disability)

### My Supporters may help me with life decisions about:

Yes \_\_\_ No \_\_\_ obtaining food, clothing and a place to live

Yes \_\_\_ No \_\_\_ my physical health

Yes \_\_\_ No \_\_\_ my mental health

Yes \_\_\_ No \_\_\_ managing my money or property

Yes \_\_\_ No \_\_\_ getting an education or other training

Yes \_\_\_ No \_\_\_ choosing and maintaining my services and supports

Yes \_\_\_ No \_\_\_ finding a job

Yes \_\_\_ No \_\_\_ Other: \_\_\_\_\_



SDM will look  
*different* for  
different people.

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SDM can be used  
alone or in  
combination with  
other legal tools to  
avoid guardianship.

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## Persons with I/DD report favorable outcomes from SDM.

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- More independence
- More dignity
- More freedom
- More confidence
- Happier



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There is growing support  
nationally and internationally for  
supported decision making.

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# U.N. Convention on the Rights of Persons with Disabilities



“States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” and requires that “measures related to the exercise of legal capacity respect the rights, will, and preferences of the person” and are “proportional and tailored to the person.”

# SDM Gaining Traction in US

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- 2015: Texas is the first state to adopt SDM legislation
  - 2022: California is the most recent state to recognize SDM
  - Now: Roughly  $\frac{1}{2}$  of states have or are considering supported decision-making legislation
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“Our state is committed to protecting civil rights and lifting up every Californian with the supports they need to thrive in their community,” said Newsom. *“This measure is an important step to empower Californians with disabilities to get needed support ... while maintaining control over their lives to the greatest extent possible.”*

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# SDM in Pennsylvania


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- PA law does *not* formally authorize supported decision-making
- SDM as been proposed as a legislative reform
- A lot of people would benefit:
  - 3.4 million adults 60+ in PA
  - 280,000 people living with AD
  - Other individuals with cognitive disabilities

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How can we realize supported  
decision making for older  
Pennsylvanians?

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A woman with her hair in a bun, wearing a green t-shirt, is smiling and looking towards a man. The man is wearing glasses and a light blue button-down shirt. They appear to be in a professional or collaborative setting, possibly a meeting or a discussion. The background is softly blurred, showing what might be a window or a bright indoor space.

SDM can happen  
*informally* – and  
often begins  
*naturally* within  
families.

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A woman with blonde hair, wearing a pink cardigan, is shown in profile, looking thoughtfully towards a man whose back is to the camera. They appear to be in a meeting or consultation. The background is softly blurred, showing a window with curtains.


Lawyers can help families understand SDM as an *alternative* to guardianship.

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## Legislation is important.

- Although SDM can be informal, third parties—like health care facilities and banks—sometimes want formal written agreements before they will accept decisions made using SDM.



Clinicians and other  
professionals need  
to know about  
SDM.

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# Why clinicians?

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- Often diagnose and care for people with cognitive impairment
  - Play a role in educating patients and families and connecting them with services and supports
  - Can have a role in guardianship proceedings
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“Who supports you  
when you’re making  
decisions?”

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We don't yet know  
what factors lead to  
successful SDM for  
older adults.



**Conduct modified Delphi Panel to develop a supported decision-making toolkit for older adults with MCI**


**Assess readability and characterize the determinants of intention to use the supported decision-making toolkit**

**Pilot test the supported decision-making toolkit in a RCT at the Penn Memory Center**

We should also  
remember  
*unbefriended*  
older adults.

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Recognition of AD as a  
continuum disorder  
requires consideration of  
ethical, social, and legal  
challenges.

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**Thank You.  
Questions?**