

**Challenges and Complexities in Decision-Making in Dementia Care**

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**Overview:**

- Challenges in decision-making**
- Stages of Dementia and Decision-making abilities** | Strategies for communication and inclusion
- Individual decision-making styles** | Understanding and working with various decision-making styles
- Family communication and collaboration in decision-making** | Structure for family or group meetings

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**Challenging Scenarios**

- Under-estimate abilities of person to participate in decision-making
- Over-estimate abilities of person to participate in decision-making
- Assumption that legal status is based on "all or nothing"

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Participation in decision-making

Have the right to participate in decisions about their care

Importance of:

- Assessment
- Communication approaches based on cognitive abilities

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Decision-Making and Dementia

Mathy Mezey, EdD, RN, FAAN

Hartford Institute for Geriatric Nursing 2016

- Guiding concepts
  - Capacity is not an all or nothing "on-off" switch
  - Decision-making capacity presumes the retention of personal values and goals

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"Decision-specific capacity" assumes the presence or absence of capacity for a particular decision at a particular time and under a particular set of circumstances

Person with dementia may be able to make, or indicate a preference related to daily care but not make a decision about a complex treatment choice

Ability to appoint surrogate vs ability to make complex decision

Encourage participation even if another person makes actual decision

Decision-Making and Dementia

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Helping Families/Caregivers Make the Difficult Decisions for Those Without Capacity

Viki Kind  
<http://kindethics.com/>




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The Framework and Tools

- THE DECISION MAKING FRAMEWORK
- THE SHARED DECISION MAKING MODEL
- THE SLIDING SCALE FOR DECISION MAKING
- THE ASSENT TOOL
- "THE 5 CORE QUESTIONS FLOWCHART"




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Core Questions Along the Path




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**Core Question #1:**

**Does the individual have the ability to make their own decisions?**

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**Core Question #2**

**If the person is not able to speak for themselves, how long will it last?**

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**Core Question #3**

**Does the person want to make their own decisions?**

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**Core Question #4:**

**Who should make the decisions when the person can't?**

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**Core Question #5:**

**What is their capacity?**

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**Decision-  
Making  
Frameworks**

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### Decision-Making Framework

Framework	Ranking	Definition
Autonomy	Best option	Person with decisional capacity allowed to make their own decisions
Substituted Judgment	2 <sup>nd</sup> best option	Person has lost decisional capacity; someone else makes decisions based on patient's values and wishes
Best Interest Standard	3 <sup>rd</sup> best option	Decision maker/health care team who may or may not know the patient will make decisions without benefit of knowing what patient would want.

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### The Sliding Scale for Decision Making

How serious is the situation, and is it safe for the person to participate?

No capacity	A little bit of capacity	Some capacity	Almost full capacity	Full capacity
No decision making	Some small decisions	Daily decisions, some voice in medical decisions, but not life & death	Larger voice in important decisions	Full voice in own decisions, including life & death decisions

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### The Shared Decision-Making Model

Approx Developmental Age	Decision Making Tool	With Adults, who Participates?
Age 0-6 (No Capacity)	Decision Maker's Consent	Decision maker uses Substituted Judgment or Best Interest Standard
Age 7-13 (Some Capacity)	Assent	Decision-maker, with help of provider if needed, talks to patient about the medical decisions and gets patient's assent/dissent. Decision-maker gives final consent
Age 14-17 (Almost Full - Full Capacity)	Consent	If the patient has enough capacity, the patient uses autonomy and makes the decision. If not, you move back up one level and use Assent.

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The Assent Tool

- 1. Evaluate ability
- 2. Allow enough time
- 3. Using developmentally appropriate language, provide information re: issue and options
- 4. If the person says yes, be careful that the person isn't just saying that to make you happy.
- 5. If they don't understand, try again, then use other approach

A blue silhouette of a person is on the left side of the slide.

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Decision-Making Styles



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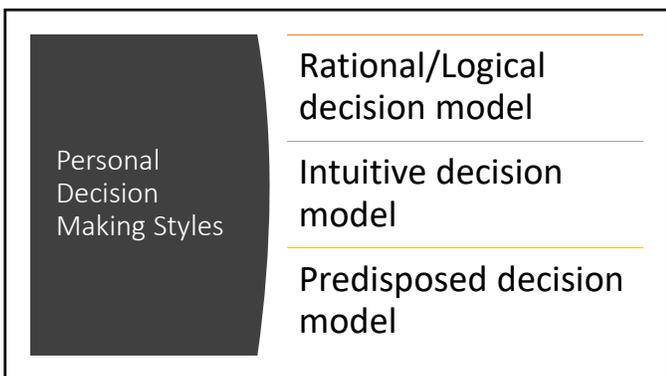
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Personal Decision Making Styles

- Rational/Logical decision model
- Intuitive decision model
- Predisposed decision model

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Personal Decision-making Styles and Long-Term Care Choices

- “Scramblers”
- “Reluctant Consenters”
- “Wake-Up Call”
- “Advance Planners”

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Family Involvement in Decision-Making

- Family communication and collaboration in decision-making
- Structure for family meetings/ decision-making
- Understanding of dementia
- Attitudes & perceptions
- Degree of involvement
- Relationship history
- Personal Styles

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Context

- Context: proactive/ reactive
- Purpose
- Timing
- Composition

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Supporting Family Conversations

- Engaging participants
- Soliciting perspectives
  - Definition of problem
  - Solutions
- Anxieties/worries
- Seeking Solutions

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Wrap-Up

- Assessment of person with dementia re: degree to which they can participate in different types of decisions
- Understanding various decision-making styles of client and family members
- Support family in understanding abilities of person with dementia, and the decision-making process, which may not be linear.

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## Session #306 - Is there a “friendly” fit for your community?

Presenters: Sue Kelley, Marilyn Lange, Miriam Olienses-Torres

List any Age-Friendly and/or Dementia-Friendly Activity Ideas discussed today that might be feasible in your community:

Three things you can do to explore potential interest when you are back in your community:

- 1.
- 2.
- 3.

Five Stakeholders to involve in this:

- 1.
- 2.
- 3.
- 4.
- 5.

- over-

Next Steps:

**Comparison:**

**WHO/AARP Age-Friendly Domains and DFA Dementia-Friendly Sectors**

WHO/AARP Age-friendly Eight Domains	Dementia Friendly America Ten Sectors
<p><b>1) Outdoor Spaces and Buildings</b> Availability of safe and accessible recreational facilities.</p>	<p><b>1) Transportation, Housing and Public Spaces (Local Government)</b> Infrastructure that makes communities more livable for people with dementia and their caregivers.</p>
<p><b>2) Transportation</b> Safe and affordable modes of public and private transportation.</p>	<p><b>2) Businesses</b> Dementia-supportive customer service and environments and policies that support employee caregivers.</p>
<p><b>3) Housing</b> A wide range of housing options for older residents; the ability to age in place; and other home modification programs.</p>	<p><b>3) Legal and Advance Planning Services</b> Legal services that help vulnerable clients express their wishes early and avoid problems such as unpaid expenses.</p>
<p><b>4) Social Participation</b> Access to leisure and cultural activities; opportunities for older residents to participate in social and civic engagement with their peers and younger people.</p>	<p><b>4) Banks and Financial Services</b> Dementia friendly practices that help maintain clients' independence while protecting them from problems.</p>
<p><b>5) Respect and Social Inclusion</b> Programs to promote ethnic and cultural diversity as well as multigenerational interaction and dialogue.</p>	<p><b>5) Neighbors and Community Members</b> Raising awareness to help neighbors and community members understand and support people living with dementia.</p>
<p><b>6) Civic Participation and Employment</b> The promotion of paid work and volunteer activities for older residents and opportunities to engage in formulation of policies relevant to their lives.</p>	<p><b>6) Independent Living</b> Home-based services available to maximize independence and promote autonomy and a high quality of life.</p>
<p><b>7) Communication and Information</b> The promotion of and access to technology to keep older residents connected to their community and friends and family.</p>	<p><b>7) Communities of Faith</b> Faith communities use dementia friendly practices to provide a welcoming, compassionate environment and spiritual connection.</p>
<p><b>8) Community and Health Services</b> Access to homecare services, clinics, and programs to promote wellness and active aging.</p>	<p><b>8) Care Throughout the Continuum</b> Early diagnosis of dementia and ongoing medical care; patient education; and connecting patients and their caregivers with community resources that promote quality of life.</p>
	<p><b>9) Memory Loss Supports and Services</b> A spectrum of settings and services needed by people with dementia - from long term care facilities and assisted and independent living residences, to home care, adult day services, and hospice.</p>
	<p><b>10) Emergency Planning and First Response</b> Community planning and family preparation considers safety, security, and needs of people with dementia in disaster planning and emergency response.</p>