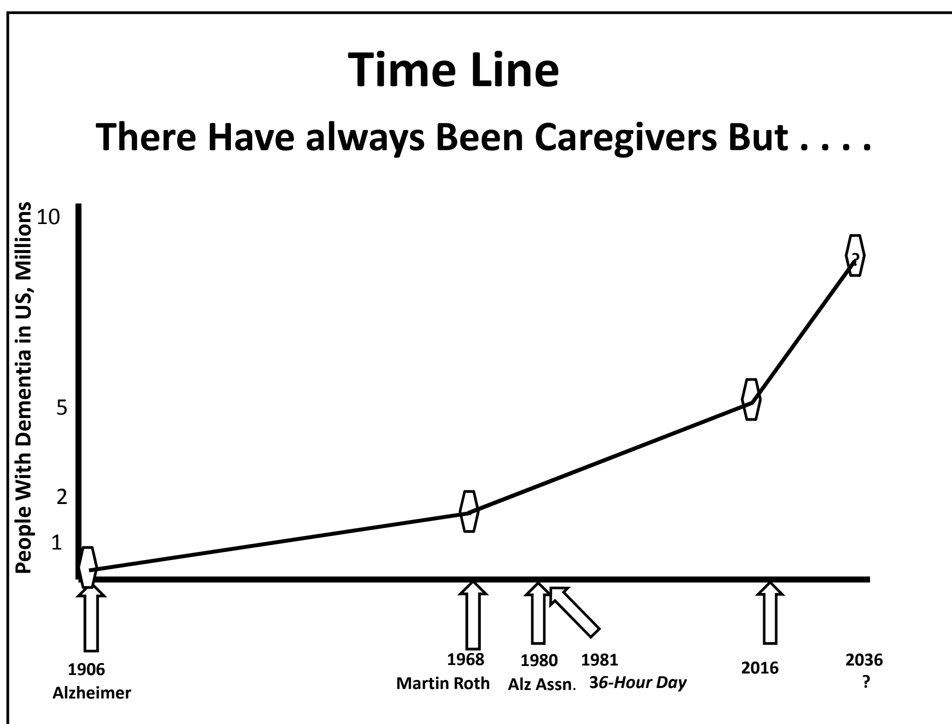
Alzheimer Disease: The Joys and Challenges of Caregiving

Peter V. Rabins MD, MPH
Erickson School, UMBC
Johns Hopkins School of Medicine

Time Line

There Have always Been Caregivers But . . . .

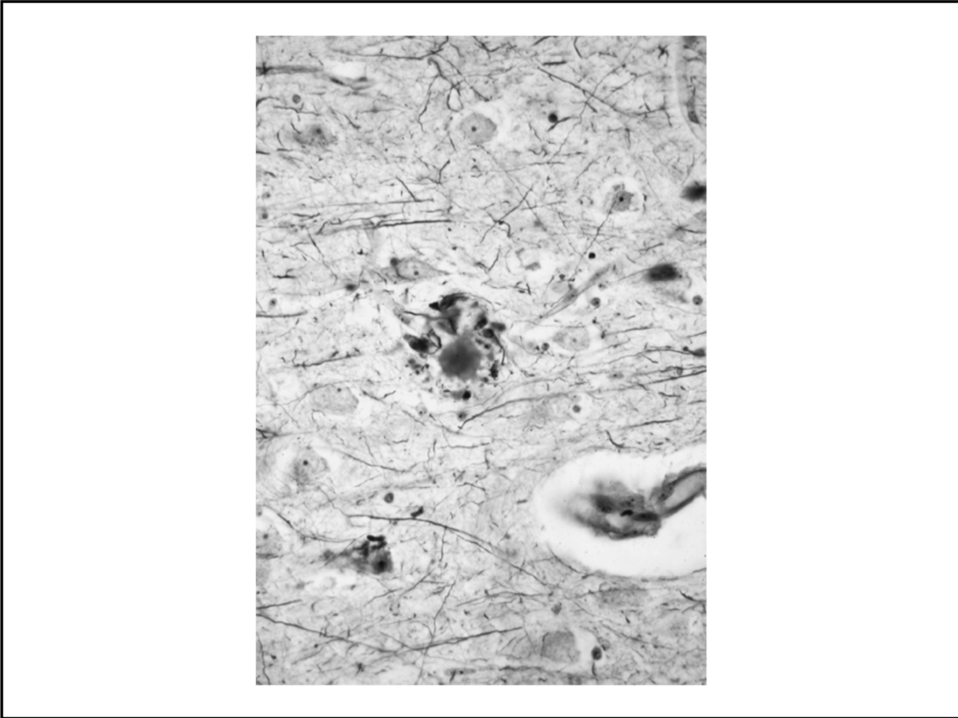


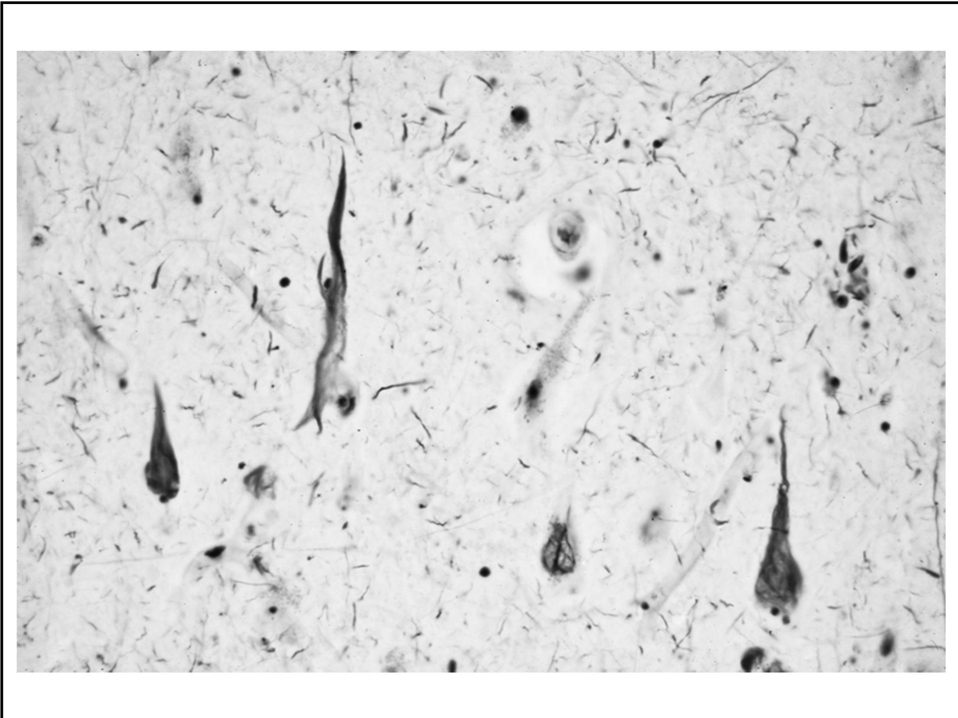
Who Are Caregivers ?

- Two-thirds of persons with dementia live at home, most (>80%) with one or more caregivers
- 70-80% of caregivers are women (spouse, daughter, daughter-in-law)
- Rates of emotional distress are 2-3 times higher in caregivers than in matched non-caregivers
- Adverse health impacts are well documented, including increased mortality in some studies

Dementia Syndrome

- Declines in 2 or more cognitive capacities
- That cause functional decline
- Normal level of consciousness and alertness
- Onset in adulthood

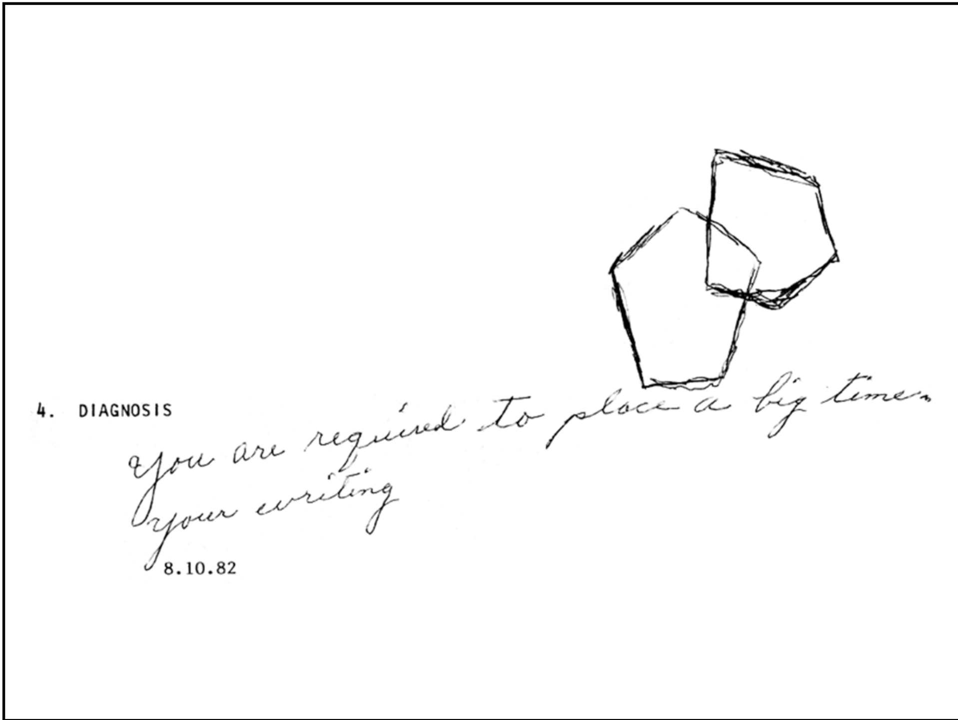




Diagnostic Features of Alzheimer Disease

- **Slowly progressive dementia**
- **No other etiology identified:**
  non-contributory neurological examination, laboratory evaluation and brain imaging
- **Decline in memory plus either:**
  -aphasia
  -apraxia
  -agnosia
  -impaired executive function

THE 4 A's OF ALZHEIMER DISEASE	
	IMPAIRMENT IN
AMNESIA	memory
APHASIA	language
APRAXIA	doing
AGNOSIA	recognition/perception
After McHugh and Folstein	



THE 4 A's OF ALZHEIMER DISEASE	
	IMPAIRMENT IN
AMNESIA	memory
APHASIA	language
APRAXIA	doing
AGNOSIA	recognition/perception
After McHugh and Folstein	

"Honey, am I home?"

3 Stages of Alzheimer Disease
after Sjogren, 1953

- I Memory Impairment
  - -learning new information most impaired
  - -1/3 develop personality change
- II "Cortical" Impairments
  - -language (aphasia)
  - -everyday learned activities (apraxia)
  - -recognizing the familiar (agnosia)
- III Physical Impairments
  - -walking (gait)
  - -mutism (end stage aphasia)
  - -incontinence
  - -swallowing

ALZHEIMER DISEASE

Staging Per Sjogren (1953)

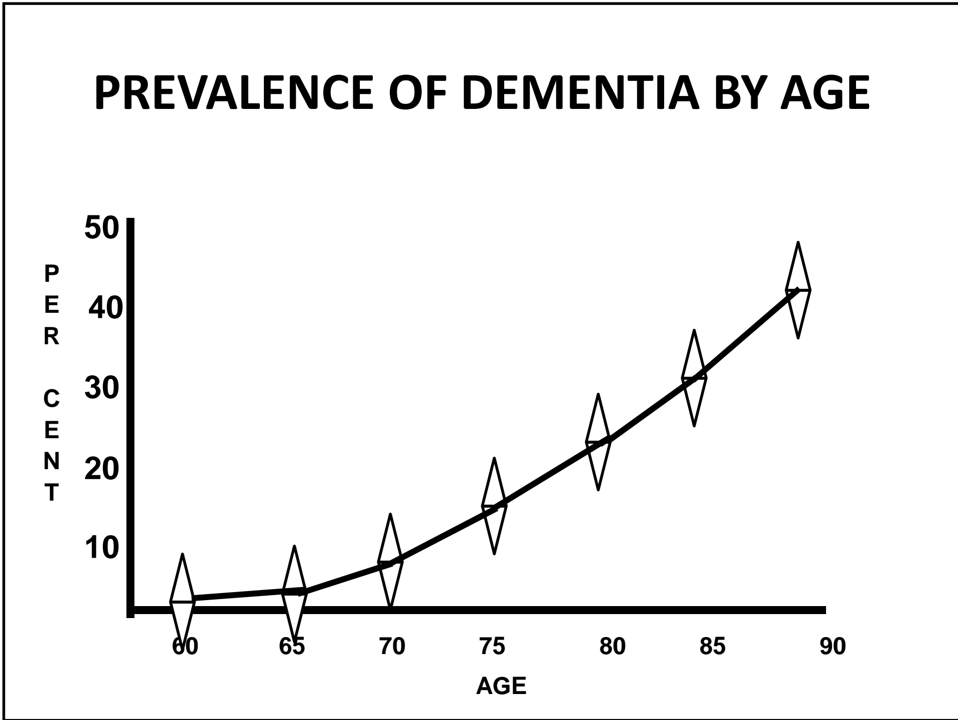
I - Memory impairment
Personality change

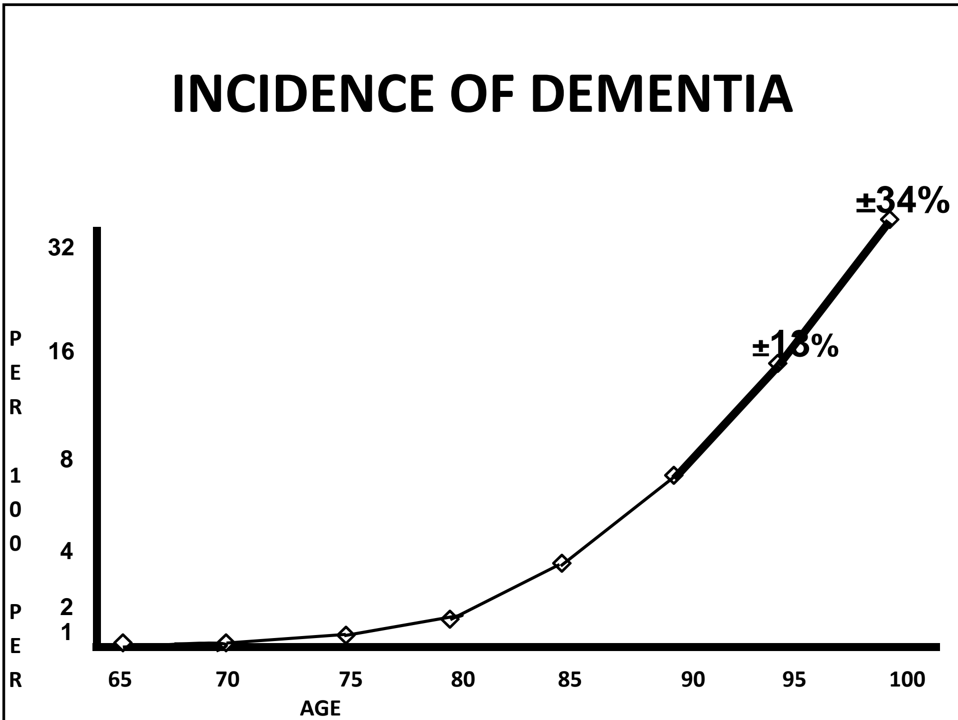
II - Cortical signs - aphasia
apraxia
agnosia

III - Physical decline - incontinence
- gait disorder
- muteness
- feeding difficulty

COMMON CAUSES OF DEMENTIA

- Alzheimer disease 66%
- Vascular dementia 15-20%
- Dementia with Lewy bodies 8-15%
- Fronto-temporal dementia 5%


PREVALENCE OF DEMENTIA BY AGE
50
40
30
20
10
PER CENT
60
65
70
75
80
85
90
AGE


INCIDENCE OF DEMENTIA
±34%
±18%
32
16
8
4
2
1
PER 100 PER
65
70
75
80
85
90
95
100
AGE

Prevalence of Dementia

By Setting

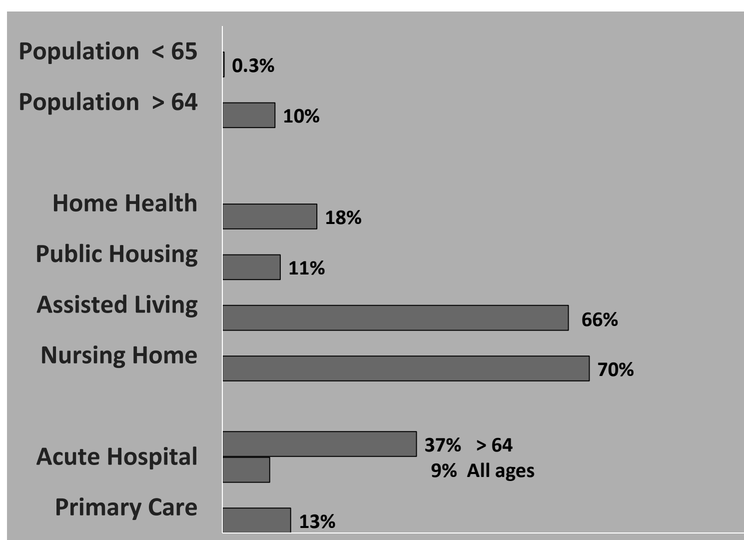


TABLE 1.—BEHAVIOR PROBLEMS OF PATIENTS CITED BY FAMILIES

Behavior	No. of Families Responding*	Families Reporting Occurrence, No. (%)	Families Reporting Behavior to Be a Problem, No. (%)
Memory disturbance	55	55(100)	51(93)
Catastrophic reactions	52	45(87)	40(89)
Demanding/critical behavior	52	37(71)	27(73)
Night waking	54	37(69)	22(59)
Hiding things	51	35(69)	25(71)
Communication difficulties	50	34(68)	25(74)
Suspiciousness	52	33(63)	26(79)
Making accusations	53	32(60)	26(82)
Meals	55	33(60)	18(55)
Daytime wandering	51	30(59)	21(70)

*"Don't know" answers excluded.

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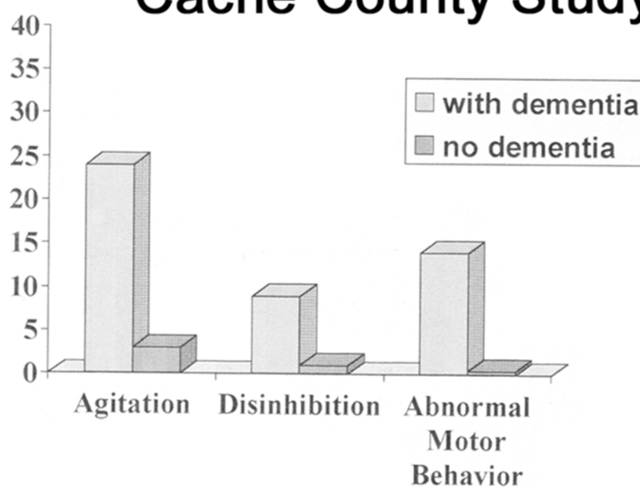
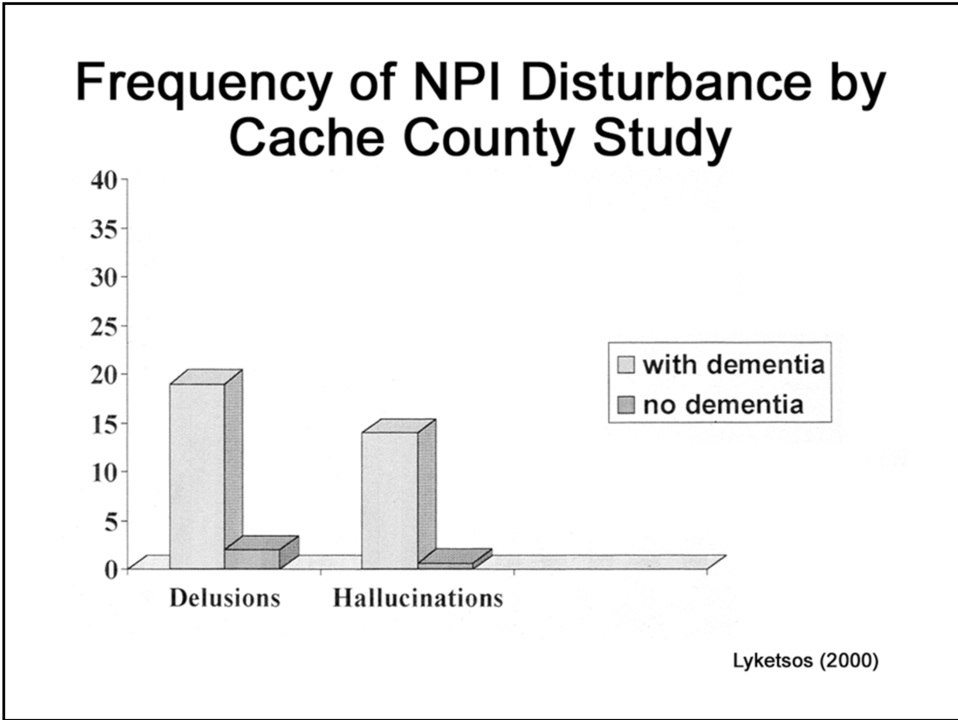
Bathing	51	27(53)	20(74)
Hallucinations	49	24(49)	16(42)
Delusions	49	23(47)	19(83)
Physical violence	51	24(47)	22(94)
Incontinence	53	21(40)	18(86)
Cooking	54	18(33)	8(44)
Hitting	50	16(32)	13(81)
Driving	55	11(20)	8(73)
Smoking	53	6(11)	4(67)
Inappropriate sexual behavior	51	1(2)	0(0)

*"Don't know" answers excluded.

Frequency of NPI Disturbance by Cache County Study



Lyketsos (2000)


Frequency of NPI Disturbance by Cache County Study
40
35
30
25
20
15
10
5
0
with dementia
no dementia
Delusions
Hallucinations
Lyketsos (2000)

SURROGATE DECISION MAKING: ETHICAL AND LEGAL ISSUES

Peter V. Rabins MD, MPH
Erickson School, UMBC
Johns Hopkins School of Aging

DEFINITIONS

COMPETENCY

- Legal concept
- Comprehension
- Choice
- Coercion free

- Binary (categorical)
  "yes/no"

CAPACITY

- Clinical concept
- Multiple functions
  - Memory
  - Language
  - Visuo-spatial
  - Executive

- Dimensional (graded)
  "it depends"

TWO CONCEPTUAL APPROACHES

- CATEGORICAL
- IDENTIFIES DISTINCT ENTITIES
- BINARY OR “DIGITAL” MODEL
- EXAMPLES:
  - DEMENTIA
  - SCHIZOPHRENIA
  - MAJOR DEPRESSION

- DIMENSIONAL
- GRADED, UNIVERSAL CHARACTERISTICS
- “ANALOG” MODEL
- ABNORMALITY IS DEFINED ARBITRARILY USING LIKELIHOOD OF ADVERSE OUTCOME
- EXAMPLES:
  - MENTAL RETARDATION
  - PERSONALITY DISORDER

Questions to Guide Assessment

- What are the impairments?
- What is/are the diagnosis/diagnoses
- Are impairments permanent or reversible? (depends on diagnosis)
- If permanent, is disorder progressive?
- What are potential harms?
- What are potential benefits?
- What is likely time course? (delay sometimes helpful if risk not immanent, recovery possible)
- What is link between impairment and potential harm?

Common Ethical Challenges

(Rabins, Lyketsos, Steele, *Practical Dementia Care, 2nd Ed.* Chapter 13)

- The person who doesn't want to be evaluated
- The person who lives alone
- The person who demands to drive
- The use of medication and restraints to control behavior and protect from harm
- The use of lying to better patient's life and prevent harm
- The person with poor oral intake
- Medical decision making for the severely incapacitated

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The Person Who Doesn't Want To Be Evaluated

- Cannot force medical care upon a 'competent' person
- Encouragement, even nagging, often works
- PRINCIPLE: Unless there is clear evidence of danger, cannot and should not force

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The Person Who Lives Alone

- Seek professional evaluation re dangerousness
- If moving is appropriate, be persistent
- If danger is clear, seek legal solution (obligation to protect the impaired)
- Giving a limited range of options often avoids need to force
- PRINCIPLE: Maximizing choice is desirable but protecting the significantly impaired is a necessity

Making Health Decisions For The Incapacitated

- Person's prior values should be respected
- Family *usually* acts in best interest
- Because the details of medical situations are often crucial but not knowable in advance, a substitute decision maker is more desirable than a document that lists specific requests; however, general guidance is often helpful
- PRINCIPLES:
  - -incapacitated individuals should be protected
  - -a combination of *substituted consent* (prior values) and *best interest* is ideal
  - -family members are usually best representatives of the impaired but may have conflicts of interest

The Use of Medication and Restraints to Control Behavior and Protect From Harm

- Non-pharmacologic approaches are desirable/required *unless* high risk of significant harm or symptom is very distressing
- Pharmacotherapy is minimally effective
- Physical restraints almost never necessary (?falls?)
- PRINCIPLE: Least restrictive intervention is always desirable but when harm/benefit ratio is very undesirable, treatments should only be used in last resort when risk of harm to self or others is high. Restraints severely restrict freedom and severely undermine dignity.

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LYING

- Truth telling is a strong value in our culture
- I believe that terms such as “white lie”, “half truth”, and “not really a lie” diminish the importance of truth telling
- HOWEVER, in some diseases the adult has an illness that makes it impossible for them to “know” the truth
- PRINCIPLE: Lying is justified when the ill person cannot comprehend/remember the truth *and* if telling the truth is harmful to them

Common Ethical Challenges

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- **The person with poor oral intake**
- **Medical decision making for the severely incapacitated**

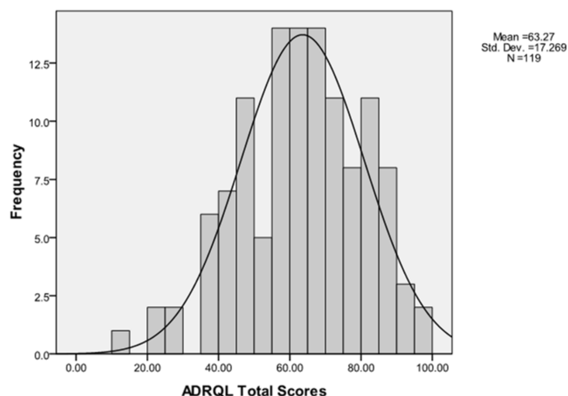
LATE STAGE CLINICAL ISSUES

• GAIT DISORDER • BEDBOUND • RIGIDITY	• Frequent falls • Decubiti
• SWALLOWING APRAXIA	• Malnutrition • Aspiration • Pneumonia
• GAZE PALSY	
• MUTENESS	• Can't report history, depression or pain

UNIQUE ISSUES IN LATE-STAGE DEMENTIA

- End stage patients lack capacity, therefore significant decisions are always made by proxies
- Many patients lack ability to speak, i.e., report pain
- Advance directives precede end stage by years
- Death is most commonly secondary to pneumonia
- Many preconceived ideas: "Aggressive care can burden end-stage patients with iatrogenic complications and discomfort" (Whitehouse, 1996); "When the patient is at the end stage…then comfort care only is appropriate" (Callahan, 1996)
- Hospice criteria used to be unique to dementia

QUALITY OF LIFE IN PERSONS WITH LATE STAGE DEMENTIA



Frequency of Medical Decisions Faced by Caregivers within 6 Months of Death

(n = 72)

Type of Treatment	Faced with Decision N (%)	Only Decided For %	Ever Decided Against %
Hospital admission	38 (**52.8**)	13.1	**86.8**
Blood test/ diagnostic test	29 (**40.3**)	44.84	**55.2**
Feeding tube	25 (**34.7**)	8.0	**92.0**
X-ray	21 (**29.2**)	66.7	**33.3**
Infection treatment	25 (**34.7**)	**64.0**	**36.0**
Respirator/ ventilator	17 (**23.6**)	23.5	**76.5**
Resuscitate	14 (**19.4**)	**--**	100
Surgery	4 (**5.6**)	--	**100.0**

Difficulty with Decision

Decision *To Treat*		Decision *To Limit*	
Not Difficult	Any Difficulty	Not Difficult	Any Difficulty
87.7 %	**12.3 %**	**55.2 %**	**44.8 %**

Satisfaction with Decision

Decision *To Treat*		Decision *To Limit*	
Somewhat Satisfied	Very Satisfied	Somewhat Satisfied	Very Satisfied
28.8 %	**71.2 %**	**80.6 %**	**19.4 %**

Presence of Any Formal Advance Directive

(76 / 125 = 61%)

Sex	**Female** (61%)	**>**	**Male** (39%)	**.05**
Marital Status	**Mar / Wid** (64%)	**>**	**Sep/ Div/ Nev Mar** (42%)	**.07**
Race	**White** (58%)	**>**	**Black** (15%)	**.001**
DNR Order	**Yes** (82%)	**>**	**No** (71%)	**.11**
Age				**.98**

CORRELATES OF HAVING ADVANCEDIRECTIVES

		#	%	YES	%	X^2	p value
SEX	Male	23	29	32	26		
	Female	19	15	49	40	2.60	0.107
AGE	<80	19	15	26	21		
	80-89	17	14	46	37		
	>89	6	5	9	7	2.91	0.226
RACE	African Am	16	13	4	3		
	White	26	21	77	62		<0.001[a]
Education	<High School	24	21	16	14		
	HS or >	16	14	61	52	17.998	<0.001
Marital Status	Mar, Wid	32	26	73	59		
	Sep, Div, Never	10	8	8	7	4.298	0.038
Living Situation at Admission	Lived alone	7	6	3	3		
	Lived with others	35	28	77	63		0.019[a]

[a] Fisher's Exact Test

Barriers to Creating Advance Directive Documents in 20% For Whom Decision Makers Had No Information

- Didn't want to discuss
- Deferred to others
- Didn't believe it was important

BUT

- Having an advance directive was rated as making a decision “easier” and “leading to more satisfaction” for the decision to place a feeding tube.

Making Health Decisions For The Incapacitated

- Person’s prior values should be respected
- Family almost always acts in best interest

- Because the details of medical situations are often crucial but not knowable in advance, *I believe* that a substitute decision maker is more desirable than a document that lists specific requests; however, general guidance is often helpful

- PRINCIPLES:
  - -incapacitated individuals should be protected
  - -a combination of *substituted consent* (prior expressed values) and *best interest* is ideal
  - -family members are usually best representatives of the impaired but there are exceptions
  - -decisions can change over time because information changes

CHALLENGING SITUATIONS

- CONFLICTING GOALS OF MAXIMIZING AUTONOMY AND MINIMIZING HARM
- DEMENTIA AND DRIVING
- RECURRENT MENTAL ILLNESS WITH PERIODS OF RECOVERY
- VARYING CAPACITY
- DELIRIUM AND CONSENT
- ADVANCE DIRECTIVE IN RECURRENT MENTAL ILLNESS

OPERATIONALIZING COMPETENCY/CAPACITY ASSESSMENT

- COMPREHENSION

  CAN THEY REPETE THE OPTIONS?
  CONFIDENCE INCREASED WHEN THEY CAN EXPAND UPON
- CHOICE

  CONFIDENCE **INCREASED** WHEN THEY ARE:
  - CONSISTENT OVER TIME
  -"RATIONAL REASONS" GIVEN
- COERCION-FREE

  ASKED ALONE?
  BEING ILL, ESPECIALLY MENTALLY ILL, IS ITSELF COERCIVE

OPERATIONALIZING CAPACITY ASSESSMENT

- MEMORY
  - -ORIENTATION
  - -RECALL AFTER DELAY OF SEVERAL MINUTES
  - -IN DEMENTIA, REMOTE MEMORY OFTEN BETTER THAN ABILITY TO FORM NEW MEMORIES
- LANGUAGE
  - -NAMING
  - -REPETITION (BEST SINGLE TEST)

- VISUO-SPATIAL
  - -PLACING ITEMS IN SPACE AND IN RELATIONSHIP TO EACH OTHER
  - -TEST BY ASKING TO COPY
- EXECUTIVE
  - -INITIATION
  - -PERSISTENCE
  - -STOPPING
  - -CHANGING "SET" (MENTAL FLEXIBILITY)
  - -ABSTRACTION

B
L **I** F E
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D **E** A T H
T
H
B **I** R T H
C
S

Evaluating Risk, Danger and Safety When Creating a Good Care Plan

Viki Kind, MA
kindethics@gmail.com
KindEthics.com
805-807-4474

1

Should I Step In?

2

Capacity vs. No Capacity

- Capacity for what?
  - To express preferences?
  - To see the dangers?
  - To understand the consequences?
- Can the person connect the dots?
- A person can be very verbal and charming but not be able to understand the dangers

3

Respecting the Decisions of the Person Who Has Capacity

- Autonomy – People, with full capacity, have the right to determine the course of their lives
- **People have the right to make a wrong decision**
- There is a limit to this right – When our actions harm others: "The Harm Principle"
- (People are allowed to harm themselves)
- Is the help/advice you are offering wanted?

4

Why Won't the Senior Use His Walker?

5

Understanding Normal Aging

- Two developmental stages or tasks of seniors: **Control and Legacy**
- **Control:** The senior feels the loss of control over the changes that are happening to his or her body, mind and life
- **Legacy:** The end-of-life work which processes questions such as, "Did I matter?" "Will anyone remember me?" "What is the legacy I am leaving to my family and to this world?"

David Solie, MS, PA

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Continued…

- Slowing down when aging is normal – not always a sign of physical or mental decline
- Seniors – goal is to "**ponder** and **process"**
- Middle-aged – driving force is to get things done quickly
- Creates conflicts regarding speed and timing
- Solution: There is power in backing off and allowing the senior some space and time
- *Be aware of our professional speed and pace*

7

Frame as Short-term Control vs. Long-Term Control

- "*In the short term, of course you can choose to not use your walker, It does worry me (It concerns me) that in the long term, you may be* ***sacrificing long-term control*** *if you break your hip and can't live at home anymore. Then you wouldn't have any control over where you live, what you eat, how you structure your day, etc.*"
- ***"Of course, it is your decision."***

David Solie: How to Say it To Seniors

8

Our Obligations Change When the Person Lacks Capacity

9

I Know I Should Step In But I Feel So Guilty

10

Appropriate Guilt vs. Inappropriate Guilt

- *"Did you actually do something wrong?" "By choosing ____, are you actually doing something wrong?"*
- If answer is yes: *"Then own up, say you are sorry and make it right if you can."*
- If answer is *"No, I just feel badly."* Then say, *"If you didn't do anything wrong, then guilt is the wrong word. The reason people call it guilt is because we don't have another word for it in English. But what you might be feeling in your gut is a combination of regret mixed in with wishful thinking. I understand you may still feel badly but please, don't call it guilt. You haven't done anything wrong."*

11

My Denial About My Dad's Falling

12

Use 5-Step Process to Help the Person Get Out of Denial

At any point in the conversation, you may need to stop and allow the person time to process what you have said. You may need to come back later to finish the 5-steps, if the person is willing.

- **Step 1:** Normalize: *"So many of the people I work with struggle to take in all of this new information. It can be really overwhelming."*
- **Step 2:** Introduce denial gently: *"Especially when we don't want the bad news to be true.*

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- **Step 3:** Introduce the idea of denial being both good and bad:
- *"This wishing it wasn't true can be both good and bad. In the short term, denial can be good because it protects the person from the pain of hearing the bad news. (It keeps the person's brain from exploding.)"*
- *"But in the long term, denial can be really bad because it can keep the person from…"*
  - *Seeing the changes in the person*
  - *Asking for help from family, friends, faith community and professionals*
  - *Getting proper medical care*
- **Step 4:** If the person hasn't shut down and is still listening, you can try option A or B

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- **Option A:** Test the person's denial by asking an "If question." This will also introduce the concept of **disbelief.**
  - *"If ______ were going to die, would he want to go home or stay here in the hospital?"*
  - Alternate: *"Does it ever cross your mind that _____?"*
- **Option B:** *"I wonder if you would be willing to talk about ___ for 15 minutes. Then you can not think about ___ for the rest of the day."*
- **Step 5:** Ask a second "if" question but be careful because coming out of denial is painful and the person will be emotionally fragile: *"If ___ were to help him go home, would you like some information about this now or later today when your family can be here with you?"*

15

But She is Okay Some of the Time!

16

I Don't Want to Accept That Mom Needs Help!

- Do you know which days or times of day she will be fine?
- If there is a fire, will she be able to get out of the house and call for help, even on the days when she isn't doing well?
- I had the sisters repeat to themselves: *"We can't take a chance that the danger will happen on one of her bad days."*
- What really helped were the next two tools

17

Empower and Enable the Person Based on His or Her Mental Age

- These age ranges will help guide you as you use the Shared Decision Making Model

- 0-6 years old?
- 7-13 years old?
- 14-17 years old?

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The Shared Decision Making Model

Approximate Develop-mental Age	**Decision Making Tool**	**With adults, who participates?**
Age 0–6	Decision Maker's Consent	The patient's decision maker uses Substituted Judgment or the Best Interest Standard.
Age 7-13	Assent	The decision maker, with the help of the doctor if needed, talks to the patient about the medical decisions and gets the patient's assent/dissent. The decision maker gives the final consent.
Age 14-17	Consent	If the patient has enough capacity, the patient uses autonomy and makes the decisions. If not, you move back up one level and use Assent.

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The Sliding Scale for Decision Making

How serious is this situation?

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 and some voice in medical decisions, but not life-and-death decisions	Larger voice in important decisions	Full voice in his or her own decisions, including life-and-death decisions

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It is no longer,
"*Should* We Step In?"

The question is now,
"*When* Should We Step In?"

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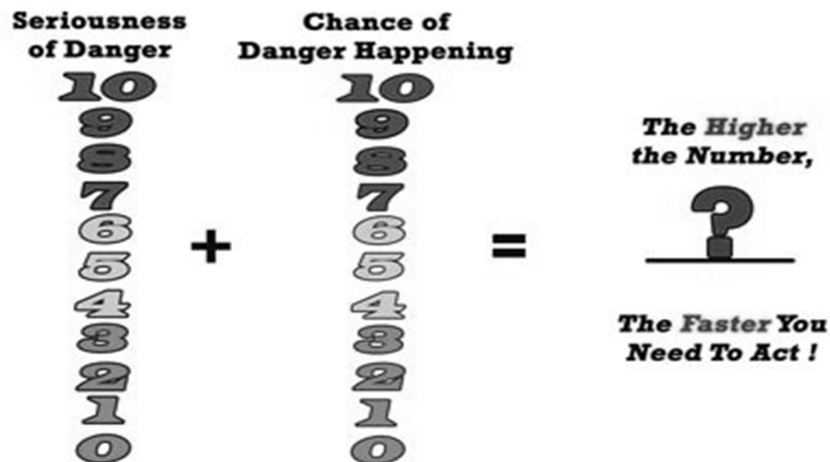
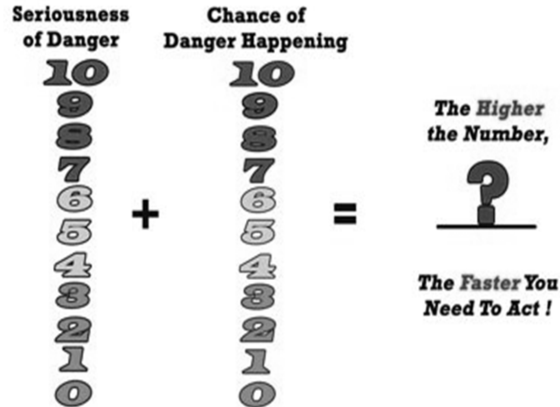
Balancing the Seriousness with the Chance the Danger Will Happen



What is ***this person's*** score when he or she is ***not thinking*** clearly?

- Showering
- Turning on the stove
- Wandering
- Taking medications incorrectly



Short-Term Plan vs. Long-Term Plan

- **Lower Score:** Take some time to develop a good long-term plan which both protects the person and provides a good quality of life
- **Higher Score:** Take action quickly and put a short-term plan in place. Then take some time to create a better long-term plan

- Knew my dad was in danger, so I moved him immediately into a skilled nursing facility
- They placed in restraints to keep him "safe"

24

Have I Really Made My Dad Safer or Are There New Dangers I Should Be Aware Of?

25

Risks With Restraints

- Falls
- Strangulation
- Pressure Sores
- Decreased Mobility
- Loss of muscle tone and stiffness
- Reduced Bone Mass/Fractures
- Increasing weakness
- Incontinence
- Constipation/Impaction
- Infection
- Restricted breathing and aspiration
- Sleep disturbances
- Fear, agitation, frustration
- Loss of hope and internal motivation
- Loss of dignity and humiliation
- Increased boredom, loneliness and helplessness
- Feelings of being punished
- Depression, isolation, withdrawal
- Thoughts of suicide
- Learned dependence
- Diminished staff opinion of resident
- Death

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If I Could Go Back in Time, What Should I Have Done?

27

Solutions for A Restraint-Free Life

- There is no *one-size-fits-all* solution
- Personalize the solution to fit the individual
- If one solution doesn't work, try another
- Here is a partial list of solutions: (email me for 80 more options at kindethics@gmail.com)
  - Fall reduction class
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28

How Do I Step In?

Creating a Plan That Keeps the Person Safe While Providing for a Good Quality of Life

29

Balance Reducing the Risk While Improving Person's Quality of Life

- A life without danger may mean a life without meaning
- What would the person tell us to do if he or she understood the situation?
- Which is worse, the danger or the solution?
- What are the **burdens** of the solution?
  - Emotional, physical, loss of control and dignity?
- **What will it feel like and be like for the person to experience this decision?**

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Using the Worksheet To Develop A Better Long-Term Plan

- Are there experts I can ask for advice?

  www.alz.org toll free # 800-272-3900
- What are the *least restrictive* options available?
- Will this option keep the person safe?
- Will it create any new risks?
- What will it feel like and be like for the person to live with this solution?
- What else can I do to improve this person's quality of life while keeping him/her safe?

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Using the Assent Tool

- 1. Evaluate the person's mental age, maturity level, psychological condition and ability to give assent/dissent.
- 2. Allow enough time to use an alternate method of communication. You may need to slow down and repeat yourself a number of times.
- 3. Using developmentally appropriate language (language the patient can understand), give the person the necessary information about his or her illness. You may want to use pictures, a video or a simply written handout.

- 4. Give the person the details of the proposed treatment, test or surgery. Explain what the experience will be like *from the patient's perspective*.
  - What will it be like for the patient to experience the proposed treatment, test or surgery? Where will the test take place?
  - Will the test hurt? Will the patient be left alone or can you stay with your loved one during the procedure?
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Emotional Memory

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Dr. Annette Swain

35

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Evaluating Decisional Capacity, Danger and Risk: Is It Time To Step In?

Viki Kind, MA

kindethics@gmail.com

KindEthics.com

805-807-4474

Capacity vs. No Capacity

- Capacity for what?
  - To express preferences?
  - To see the dangers?
  - To understand the consequences?
- A person can be very verbal and charming but not be able to understand the dangers
- Can the person connect the dots?

Can the person connect the dots?

Functional Ability Standard

- Recognize there is a decision to be made
- Understand the relevant information about options
- Understand the consequences of each of the different options – risks, benefits and burdens
- Reason how each option using their values and how the decision would affect their life
- Communicate decision

Can the Person Make a Reasoned Decision?

- Evaluating the ability to reason:
  - What factors were important to you in reaching the decision? How did you balance those factors? Why does A seem better than B? How will this choice affect the things or people who are important to you?" (ABA/APA handbook)
- Can they apply their values to the situation? Is their decision consistent with their values? Do you know the person's values?

- Think about what is most important to you in your life. What makes life meaningful or good for you now?
- What is your financial history? Are you in any debt? Do you live week to week? Are you able to plan ahead and save for the future? How do you prefer to spend money?
- Where are you living now? How long have you been there? What makes a home a home for you?
- Who are the family and/or friends that live in your community that are important to you? What about those that live in another community?
- Consider what is important to you in relation to your health. What, if any, religious or personal beliefs do you have about sickness, health care decision-making, or dying? ABA/APA

Culture and Religion

- Who makes the decisions in their culture/religion?
- What are the norms of their culture/religion?
- Waiver of informed consent - Okay because person with capacity is choosing decision making strategy
- Philosopher, Joseph Raz:
  - 1st ordered reason: Patient evaluates the pros and cons directly regarding the action
  - 2nd ordered reason: Patient doesn't decide the action directly, instead provides a formal mechanism for identifying how first order reasons should be evaluated

A More Positive Approach When Evaluating the Situation, Person and Needs

The Cards I've Been Dealt

How the Medical Capacity Evaluation Can Go Wrong

- *"I don't like what the person is deciding so therefore she must lack capacity."*
- *"I don't believe the family when they say she is more confused because she seems fine to me."*
- *"I don't have the time to spend with her to do a full evaluation."*
- *"There aren't enough guardians/conservators so I'll make the decisions for her since I know best."*

Healthcare Professional's Concerns About Legal Documents

- What I have heard lawyers say that concerns me:
  - *"He didn't have capacity but he seemed to like the person who brought him to the appointment so I let him go ahead and appoint the person as his financial/medical POA."*
  - *"She has severe memory loss. I explained simply to her what the power of attorney was all about. I asked if she understood and she said, 'Yes.' I asked if she agreed to the POA and she said, 'Yes.' I asked her to sign and amazingly, she signed very legibly."*

Will the Decision Last Until They Get Home? Until Time to Implement the Decision?

What If They Can't Remember the Decision Later On?

These Next Conversation Tools Are For Those Who Can "Connect the Dots"

Don't Try To Reason With Someone Who Can't

Is the Person Lacking Capacity Or Is It Something Else?

- Is the person in pain and distracted?
- Are their emotions ruling their decisions?
- Are they in a rush?
- Are their hearing aids in?
- Can they read? In what language?
- Education level?
- Could they count backwards from 100 by 7's before?

Is the Person Listening Well?

- 40-80% of medical information that a patient receives is forgotten immediately after a physician-patient encounter
- Nearly half of the information remembered is retained incorrectly

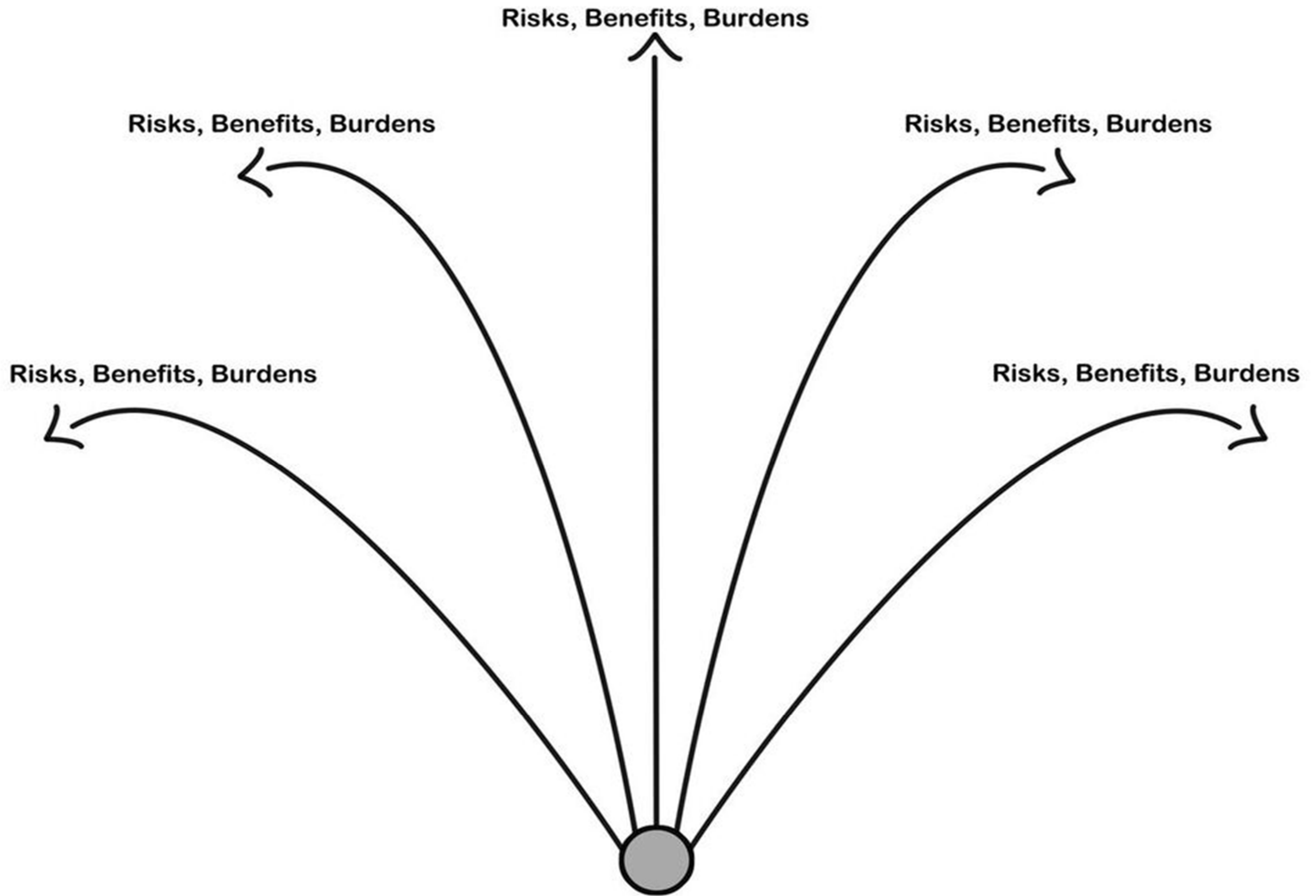
Phrases for Explain Back/Teach Back

- Don't ask:
  - Do you understand? Do you have questions?
- Instead use phrases such as:
  - *I want to be sure we have the same understanding…*
  - *It's my job to explain things clearly. To make sure I did this…*
  - ***When you get home, what will you tell your family about what we have discussed?***

How Do You Learn Best?

© www.f1online.de Bildnr./image no: 1345741

- 65% Visual
- 30% Auditory
- 5% Kinesthetic


Risks, Benefits, Burdens
Risks, Benefits, Burdens
Risks, Benefits, Burdens
Risks, Benefits, Burdens
Risks, Benefits, Burdens
Discussing the Alternatives
Viki Kind c. 2016
www.kindethics.com

Risky Decisions of the Person With Capacity

- Autonomy – People, with full capacity, have the right to determine the course of their lives
- **People have the right to make a wrong decision**
- There is a limit to this right – When our actions harm others: "The Harm Principle"
- (People are allowed to harm themselves)
- Is the help/advice you are offering wanted?

Understanding Normal Aging

- Two developmental stages or tasks of seniors: **Control and Legacy**
- **Control:** The senior feels the loss of control over the changes that are happening to his or her body, mind and life
- **Legacy:** The end-of-life work which processes questions such as, "Did I matter?" "Will anyone remember me?" "What is the legacy I am leaving to my family and to this world?"

David Solie, MS, PA

Continued…

- Slowing down when aging is normal – not always a sign of physical or mental decline
- Seniors – goal is to "**ponder** and **process"**
- Middle-aged – driving force is to get things done quickly
- Creates conflicts regarding speed and timing
- Solution: There is power in backing off and allowing the senior some space and time
- *Be aware of our professional speed and pace*

Frame as Short-term Control vs. Long-Term Control

- *"In the short term, of course you can choose to not use your walker, It does worry me (It concerns me) that in the long term, you may be* **sacrificing long-term control** *if you break your hip and can't live at home anymore. Then you wouldn't have any control over where you live, what you eat, how you structure your day, etc."*
- ***"Of course, it is your decision."***

David Solie: How to Say it To Seniors

Separating The Person From The Problem

- Creates a shared decision making partnership
- *"How are you and I going to solve the _____ problem."*
- The person stops being the problem when you create a third person in the room called, *"The Problem."*
- Allows people to work together to brainstorm possible solutions

My Denial About My Dad’s Falling

Use 5-Step Process to Help the Person Get Out of Denial

At any point in the conversation, you may need to stop and allow the person time to process what you have said. You may need to come back later to finish the 5-steps, if the person is willing.

- **Step 1:** Normalize: *"So many of the people I work with struggle to take in all of this new information. It can be really overwhelming."*
- **Step 2:** Introduce denial gently: *'Especially when we don't want the bad news to be true.*

- **Step 3:** Introduce the idea of denial being both good and bad:
- *"This wishing it wasn't true can be both good and bad. In the short term, denial can be good because it protects the person from the pain of hearing the bad news. (It keeps the person's brain from exploding.)"*
- *"But in the long term, denial can be really bad because it can keep the person from..."*
  - *Seeing the changes in the person*
  - *Asking for help from family, friends, faith community and professionals*
  - *Getting proper medical care*
- **Step 4:** If the person hasn't shut down and is still listening, you can try option A or B

- **Option A:** Test the person's denial by asking an "If question." This will also introduce the concept of **disbelief.**
  - *"If ______ were going to die, would he want to go home or stay here in the hospital?"*
  - Alternate: *"Does it ever cross your mind that _____?"*
- **Option B:** *"I wonder if you would be willing to talk about ___ for 15 minutes. Then you can not think about ___ for the rest of the day."*
- **Step 5:** Ask a second "if" question but be careful because coming out of denial is painful and the person will be emotionally fragile: *"If ___ were to help him go home, would you like some information about this now or later today when your family can be here with you?"*

But She is Okay Some of the Time!

I Don't Want to Accept That Mom Needs Help!

- Do you know which days or times of day she will be fine?
- If there is a fire, will she be able to get out of the house and call for help, even on the days when she isn't doing well?
- I had the sisters repeat to themselves: *"We can't take a chance that the danger will happen on one of her bad days."*
- What really helped were the next two tools

Empower and Enable the Person Based on His or Her Mental Age

- These age ranges will help guide you as you use the Shared Decision Making Model

- 0-6 years old?
- 7-13 years old?
- 14-17 years old?

The Shared Decision Making Model

Approximate Develop-mental Age	**Decision Making Tool**	**With adults, who participates?**
Age 0–6	Decision Maker's Consent	The patient's decision maker uses Substituted Judgment or the Best Interest Standard.
Age 7-13	Assent	The decision maker, with the help of the doctor if needed, talks to the patient about the medical decisions and gets the patient's assent/dissent. The decision maker gives the final consent.
Age 14-17	Consent	If the patient has enough capacity, the patient uses autonomy and makes the decisions. If not, you move back up one level and use Assent.

The Sliding Scale for Decision Making

How serious is this situation?

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 and some voice in medical decisions, but not life-and-death decisions	Larger voice in important decisions	Full voice in his or her own decisions, including life-and-death decisions

What is ***this person's*** score when he or she is ***not thinking*** clearly?

- Showering
- Turning on the stove
- Wandering
- Taking medications incorrectly

EVALUATING RISK FOR THOSE WITHOUT CAPACITY

Seriousness of Danger
10
9
8
7
6
5
4
3
2
1
0

+

Chance of Danger Happening
10
9
8
7
6
5
4
3
2
1
0

=

The Higher the Number,

?

The Faster You Need To Act !

Short-Term Plan vs. Long-Term Plan

- **Lower Score:** Take some time to develop a good long-term plan which both protects the person and provides a good quality of life
- **Higher Score:** Take action quickly and put a short-term plan in place. Then take some time to create a better long-term plan

Have I Really Made My Dad Safer or Are There New Dangers I Should Be Aware Of?

Physical/Chemical Restraints Risks

- Falls
- Strangulation
- Pressure Sores
- Decreased Mobility
- Loss of muscle tone and stiffness
- Reduced Bone Mass/Fractures
- Increasing weakness
- Incontinence
- Constipation/Impaction
- Infection
- Restricted breathing and aspiration
- Sleep disturbances
- Fear, agitation, frustration
- Loss of hope and internal motivation
- Loss of dignity and humiliation
- Increased boredom, loneliness and helplessness
- Feelings of being punished
- Depression, isolation, withdrawal
- Thoughts of suicide
- Learned dependence
- Diminished staff opinion of resident
- Death

Solutions for A Restraint-Free Life

- There is no *one-size-fits-all* solution
- Personalize the solution to fit the individual
- If one solution doesn't work, try another
- Here is a partial list of solutions: (email me for 80 more options at kindethics@gmail.com)
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Using the Worksheet To Develop A Better Long-Term Plan

- Are we trying to create an unrealistic, "no danger zone" that is impossible to achieve?
- How certain are we that these dangers or possible risks will occur?
- Are there options to help lessen or eliminate these dangers?
- Instead of acting out of fear, can we think of options that would minimize or eliminate these risks and/or burdens?
- Are we being reactive or proactive?

- Are we afraid of the actual risk or are we afraid of the legal liability of the risk?
- Are we projecting our fears on the person or are we looking at this situation through the person's eyes?
- Is the person someone who usually takes risks in life, or is he/she a very cautious individual?
- Are these acceptable risks? Based on whose opinion?
- Are there experts I can ask for advice?
- What are the *least restrictive* options available?
- Will option being considered keep the person safe?
- Will it create any new risks?

- What are the known burdens? Emotional, physical, loss of control, loss of dignity, etc.?
- What will it feel like and be like for the person to live with this solution?
- Can we improve the person's quality of life in spite of these burdens?
- Are the benefits worth the risks and burdens?
- Would the person be willing to take the risk and endure the burdens?
- Can we do a trial period and see what happens?
- Can we try watchful waiting?
- What else can I do to improve this person's quality of life while keeping him/her safe?

Steps to Asking for Assent/Dissent

- 1. Evaluate the person's mental age, maturity level, psychological condition and ability to give assent/dissent.
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Dr. Annette Swain

Driving

- Does the person have capacity? If not, what is the person's mental age?
- Is this something I should step in and do something about?
- Do I have the courage to do what needs to be done?
- Are there people in the family that can help or are they in denial?
- If I am going to take away his ability to drive, what can I do to improve his quality of life?

Appropriate vs. Inappropriate Guilt

- *"Did you actually do something wrong?" "By choosing ____, are you actually doing something wrong?"*
- If answer is yes: *"Then own up, say you are sorry and make it right if you can."*
- If answer is *"No, I just feel badly."* Then say, *"If you didn't do anything wrong, then guilt is the wrong word. The reason people call it guilt is because we don't have another word for it in English. But what you might be feeling in your gut is a combination of regret mixed in with wishful thinking. I understand you may still feel badly but please, don't call it guilt. You haven't done anything wrong."*

Assessing and Reporting

- American Medical Association Assessing Older Drivers resources: http://www.ama-assn.org/ama/pub/physician-resources/public-health/promoting-healthy-lifestyles/geriatric-health.page
- Keeping Us Safe: www.keepingussafe.org
- Department of Motor Vehicles – Anonymous reporting form

Resources

- Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists © American Bar Association Commission on Law and Aging – American Psychological Association
- http://www.thecardsivebeendealt.com/

Evaluating the Dangers Worksheet

- **What is the danger? What are the risks?**
- **How certain are we that these dangers or possible risks will occur?**
- **Are we trying to create an unrealistic, "no danger zone" that is impossible to achieve?**
- **Are there options to help lessen or eliminate these dangers?**
- **Are we afraid of the actual risk or are we afraid of the legal liability of the risk?**
- **Are we projecting our fears on the person or are we looking at this situation through the person's eyes?**
- **Is the person someone who usually takes risks in life, or is he/she a very cautious individual?**
- **Are these acceptable risks? Based on whose opinion?**
- **Would the person be willing to take the risk?**
- **Who should be involved in making this decision?**
- **Does the person in danger have enough mental capacity to participate in the decision? In implementing the solution?**
- **If the person could understand the choices that he/she is facing, what would the person say?**
- **What are the known burdens of the possible solutions? Emotional, physical, loss of control, loss of dignity, etc.?**
- **Are the benefits of being safer worth the risks and burdens of the solution?**
-
- **Can we improve the person's quality of life in spite of these burdens?**
- **Can we try this decision for a trial period and see what happens?**
- **Can we try watchful waiting?**
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+

Chance of Danger Happening

10
9
8
7
6
5
4
3
2
1
0

=

The *Higher* the Number,

The *Faster* You *Need To Act !*

ABA/APA Assessment of Capacity in Older Adults

Main page: http://www.apa.org/pi/aging/programs/assessment/

Handbook for Psychologists

http://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf

Handbook for Lawyers

http://www.apa.org/pi/aging/resources/guides/diminished-capacity.pdf

Handbook for Judges

http://www.apa.org/pi/aging/resources/guides/diminished-capacity.pdf

ABA Toolkit for Health Care Advance Planning
http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning.html.

Complete Toolkit:
http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_bk_consumer_tool_kit_bk.authcheckdam.pdf.

ABA Advance Directive App
http://www.americanbar.org/groups/law_aging/MyHealthCareWishesApp.html