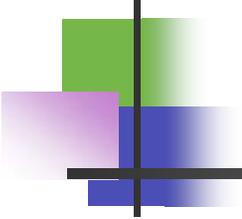


# **Mental Capacity and Competence in Dementia: From Finances, Wills and Voting to Guns**

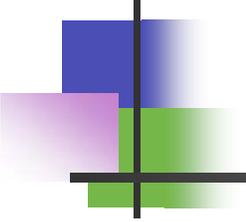


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Barry S. Fogel, MD

Brigham Behavioral Neurology Group

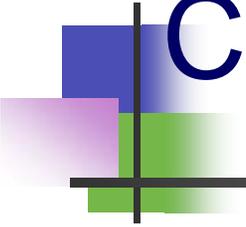
Harvard Medical School



# Themes of This Presentation

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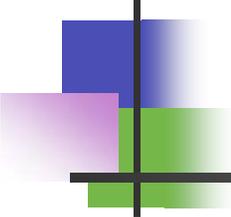
- Organizing Principles
- Executive Function and Metacognition
- Why Assessors May Disagree
- Neuropsychological Testing versus Performance in a Natural Setting
- Specific Issues
  - Driving
  - Financial decisions
  - Healthcare proxies and advance directives
  - Research consent
  - Firearms
  - Voting
- Capacity (a medical judgment) and Competence (a legal judgment)
- Communicating the Findings of an Assessment
- Resources and Advice



# Capacity, Competence, Consent

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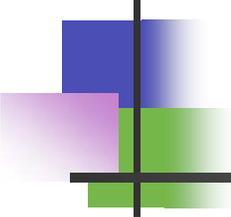
- Capacity is a context-specific medical judgment
- Competence is a legal judgment that should be specific to tasks and situations but sometimes is made in an inappropriately general way
- Valid informed consent is expected prior to medical interventions, but –
  - Consent is *presumed* to be valid in many clinical situations
  - Consent is *deemed implicit* in life threatening emergencies
  - Validity of consent is rarely questioned unless the capacity is blatantly diminished, there is conflict among interested parties, or consent is for research



# Autonomy, Authenticity, Best Interests

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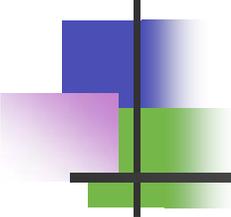
- In America a historical “paternalistic” emphasis on the patient’s best interests (as judged by the clinician) has been replaced by an emphasis on autonomy.
- Nonetheless clinicians will exert themselves to oppose patients’ decisions that they view as against their best interests.
- Authenticity – consistency of a patient’s decisions with his or her personal values and history – should also be considered. Decisions that are neither “authentic” nor in the patient’s best interests should trigger deep evaluation of decision-making capacity.
- Related concepts
  - “Critical interests” versus experiential interests and concurrent desires
  - Intrinsic versus instrumental value
  - Precedent autonomy



# Urgency, Consequences, Conflicts

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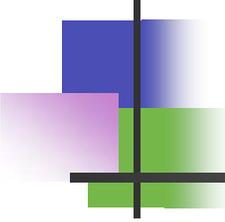
- In true emergencies if there is no advance directive to limit life-sustaining treatment, act to save life.
- In urgent but non emergent situations consent is not implied, but the legal issues should be settled rapidly, drawing upon the hospitals legal, ethical and/or risk management resources.
- When best practice is clear, capacity is diminished, and the patient assents, the trigger for formal capacity assessment is *conflict*
  - Within the family
  - Within the staff
  - Between family and staff
- When best practice is not established, capacity is diminished, and the consequences of the medical decision are major, it's worth the effort to pursue valid consent – either from the patient or a surrogate.



# Understanding, Appreciation, Reasoning and Choice

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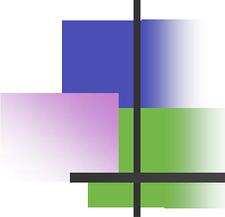
- Appelbaum and colleagues have described four essential capacities needed for valid consent. Their model has wide acceptance and underlies the formal capacity assessments often used in research contexts
- The four capacities
  - *Understanding* what's proposed
  - *Appreciation* of how it applies to one's personal situation
  - *Reasoning* about the situation to reach a decision
  - *Expressing* a clear and consistent choice.



# First Principles – (1)

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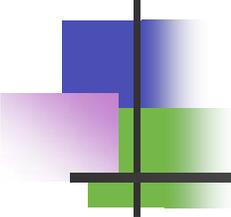
- Capacity is task-specific and context-specific, and can fluctuate over time
- Executive function and metacognition – are essential to instrumental functioning – including competency. They can decline at disparate rates from each other and from memory and language functions
- Criteria for capacity/competency (i.e., validity of a patient's decision) should be more stringent when the patient is making a bad decision
- Clinical observations and neuropsychological testing have complementary roles in assessment of decision-making capacity



## Principles – (2)

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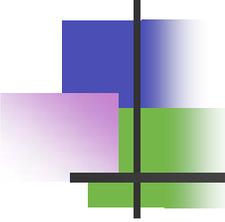
- Competency-related issues should be addressed as early as possible in the course of a neurodegenerative disease – preferably before the patient has even mild dementia.
  - Patients with MCI may (and usually do) already have some diminution of decision-making capacity
- Communication about competency-related issues should be clear, redundant, and multimodal
- Formal legal proceedings to establish incompetency usually are not necessary if the right plans are made early
- Trusts, durable powers of attorney, healthcare proxies and other mechanisms offer more flexibility
- More formality is needed when more is at stake and there is more dissension among stakeholders
- Patients often are competent to choose an appropriate proxy or surrogate decision-maker long after they are incompetent to make a particular type of decision



# Executive Function and Metacognition

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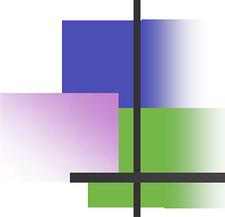
- Executive function is the most important *cognitive* factor determining performance of social and instrumental activities.
  - “Memory loss” is the most frequent presenting complaint – but usually not the biggest problem
- This cuts across diagnoses: True for Alzheimer’s disease, non-Alzheimer dementia, traumatic brain injury, schizophrenia.
- Patients with equal MMSE scores can show substantial differences in functional status.
  - The MoCA, Clock Drawing Test and EXIT are more sensitive to declining executive function



# The Role of Executive Function

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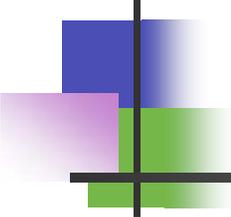
- Executive impairment, measured quantitatively by instruments such as the EXIT or neuropsychological tests (verbal and figural fluency, trail-making B, clock drawing, etc.), explains much of the variance in multivariate models of instrumental function.
- However, education and culture influence scores for particular functions such as driving or managing finances, and current circumstances influence the quality of decision making.



# The Importance of Metacognition

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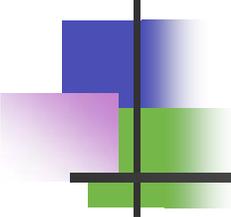
- People aware of their cognitive or sensory impairments will ask others (family and friends) for advice and assistance; people unaware of their limitations won't ask for help, often refuse to accept help when it is offered, and may persist in doing things that have become dangerous.
- People who know their driving abilities are impaired will curtail their driving. Normal old-old people reduce their driving miles per year.
  - Very low annual mileage – less than 3000 per year – is associated with a high risk of accidents



# Metacognition and Awareness of Deficits

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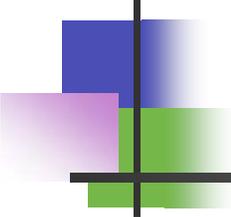
- Awareness of deficits (or, inversely, denial of deficits) is related to the same brain systems as metacognition. Relevant deficits include:
  - Impairments of specific cognitive functions
  - Sensory impairments
  - Somatic diseases and disabilities
  - Behavioral abnormalities
  - Impaired judgment
- Patients with bvFTD typically minimize or completely deny their changes in behavior and judgment.



# Metacognition in Neurodegenerative Diseases

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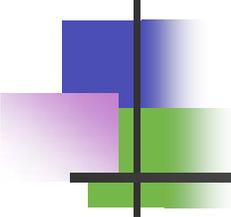
- 2014 study from UCSF: 79 patients with neurodegenerative diseases and 46 healthy older controls
- Self-awareness determined by comparing self- and informant ratings on the Patient Competency Rating Scale (Prigatano 1988)
  - Four domains: IADL, cognitive, emotional control, interpersonal functioning
- Brains imaged with structural MRI, patients statistically compared with controls
  - Confirmed importance of frontal – subcortical circuits, R>L



# Impairments in Metacognition Vary by Disease

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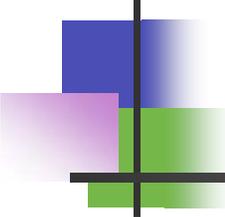
- bvFTD: Overestimated function in all four domains
- AD: Overestimated cognitive function and emotional control
- Right temporal FTD: Overestimated interpersonal functioning
- Non-fluent aphasia: Overestimated emotional control and interpersonal functioning
- Semantic variant aphasia: No overestimation



# Metacognition and Safety

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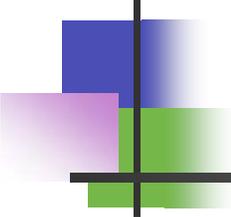
- A recent driving simulator study showed non-demented old people with could improve their driving performance with training. The first step was acknowledging their impairments.
- With adequate self-awareness, cognitively-impaired drivers can avoid situations such as poor lighting, heavy traffic, and fatigue that increase the risk of accidents.
- Of all types of dementia, bvFTD has the strongest association with dangerous driving, and behavioral changes can make driving dangerous at a time when an MMSE might be normal, or only slightly below normal.



# Cognition and Metacognition Are Partially Independent

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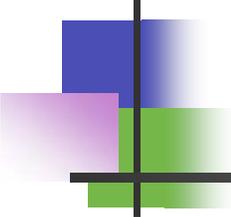
- AD - Patients with relatively more right hemisphere and frontal involvement are more likely to be unaware of their cognitive deficits (or deny their significance)
- FTD varies by type
  - bvFTD: globally impaired metacognition
  - Semantic dementia: relatively preserved metacognition
  - R temporal predominant: overestimation of interpersonal behavioral competence
- Vascular dementia –
  - Metacognition is most impaired with multifocal cortical disease involving frontal or R parietal lobes
  - Deep subcortical small vessel disease less likely to cause disproportionate impairment of metacognition



# Drugs and Metacognition

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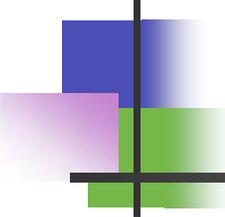
- Some drugs - e.g., benzodiazepines -- may cause cognitive impairment *accompanied by denial of impairment.*
- Other drugs - e.g., anticholinergics -- cause impairment of which the patient usually acknowledges (but doesn't necessarily volunteer, or attribute correctly).



# Initial Clinical Assessment of Metacognition

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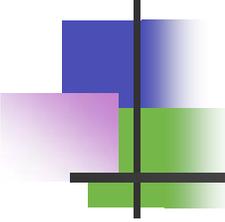
- Before and after concluding clinical or laboratory testing of cognition, hearing, or vision, ask the patient whether they are having trouble in that area, or what they think their tests will show.
- Explain test results, then ask again.
- If the patient initially is reluctant to accept the findings, give them a written report and ask again on the next visit.
- Ask the family if the patient's behavior reflects awareness of limitations.



# Alternative: Comparison of Patient- Informant-Clinician Ratings of Competencies

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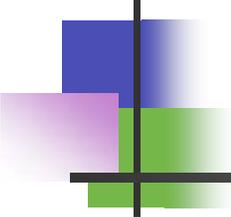
- Comparison of a patient's semi-quantitative self-rating of competencies with an informed observer's ratings permit measurement of metacognitive deficit. PRCS is a practical, no-cost option. Sample questions:
  - How much of a problem do I have in adjusting to unexpected changes?
  - How much of a problem do I have in handling arguments with people I know
  - How much of a problem do I have in accepting criticism from other people?
- Caveats:
  - Family members with their own issues, agendas, or blind spots may overestimate or underestimate patients' deficits
  - Clinician judgments typically are based on small samples of behavior in atypical circumstances



# Increasing Levels of Metacognitive Deficit – (1)

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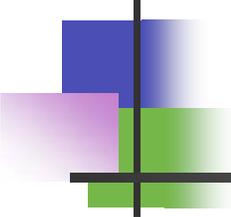
- Acknowledges impairment and appreciates its implications but doesn't act consistently with that awareness and appreciation
- Acknowledges impairment but doesn't appreciate its implications
- Acknowledges impairment upon failing a test, before the results are explained, and then appreciating implications
- Acknowledges impairment upon failing a test, but does not appreciate implications



## Increasing Levels of Metacognitive Deficit – (2)

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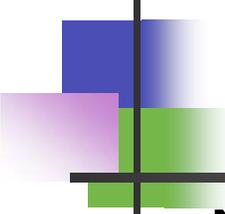
- Acknowledges impairment upon failing a test, but only after results are explained
- Acknowledges impairment when results of a test are explained, but (poorly) excuses the poor performance
- Acknowledges impairment only after repeated explanations
- Acknowledges impairment only after vigorous confrontation
- Denies impairment despite all efforts.



# Denial of Cognitive Deficit is Associated with Impaired Medical Decision-Making

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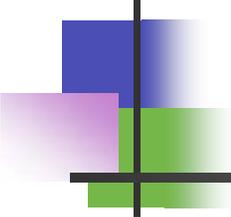
- Gambina et al. (2014) formally evaluated both anosognosia and capacity to consent to research in a population with mild to moderate AD dementia.
- All patients who denied their cognitive deficits lacked capacity to give valid consent to research
- Some (but not all) of the patients with deficits that they acknowledged were judged capable of giving valid consent.



# Formal Testing of Metacognition

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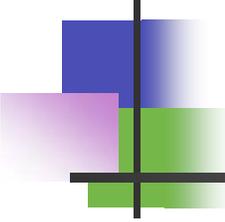
- Neuropsychological testing including metacognitive measures.
  - Formal: Memory tests that ask subjects how sure they are of their answers.
  - Informal: Systematic observations and questions by the neuropsychologist throughout the examination
- Occupational therapy assessment of IADLs, questioning the patient about how they think they'll do and how they thought they did.



# Metacognition Questionnaire (Buckley et al. IJGP 2009)

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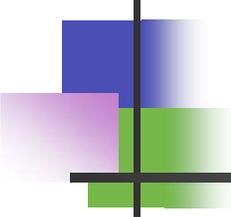
- Ask patient and caregiver to rate change over the past three years in:
  - Remembering recent events, appointments, or where you put objects
  - Remembering the names and faces of friends and relatives?
  - Keeping your train of thought or finding the right words?
  - Finding your way around familiar places?
  - Operating gadgets, appliances, or machinery?
  - Keeping up with household chores, hobbies, and interests?
  - Memory performance in general?
- The MQ does not cover emotional and interpersonal competencies as well as the PRCS



# Why Assessors Disagree About Cognitive Capacity

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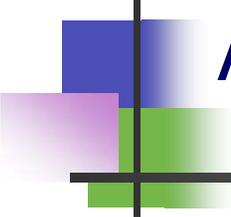
- Different performance criteria or thresholds for determining competence or functional independence.
- Different emphasis on the various dimensions of cognitive performance – e.g. memory versus executive function
- Differences in testing methods.
- Context-dependency of performance, especially when executive function is impaired.
- Fluctuations in performance, especially those related to medical illness or mood.



# Neuropsychological Testing v. Observed Performance

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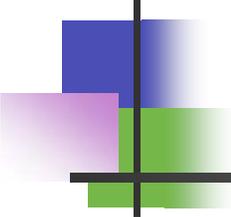
- Comprehensive
- Quantitative
- Normed
- Standardized context
- May disclose unexpected severity of impairment
- Can be used to measure change over time
- Face validity
- Observed degree of benefit from contextual cues is relevant to clinical conclusions
- Results can be more persuasive to family or other interested parties



# Specialized Tests: MacArthur Competence Assessment Tool (MacCAT)

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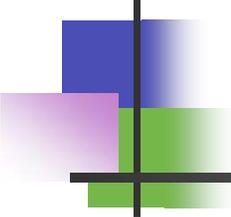
- Focuses on capacity to make a decision about medical treatment or participation in clinical research
- A vignette is presented to the patient that is tailored to the specific clinical decision
- Ordinal ratings of understanding, appreciation of risks and benefits, reasoning, and ability to express a decision; psychometrics OK
- No fixed cutoff for the judgment of competence
- Useful in the clinical trials context – not so useful for clinical practice



# Specialized Tests: Financial Capacity Instrument (FCI-9)

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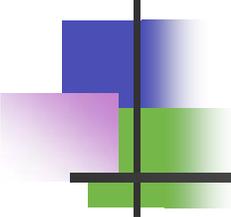
- 18 items in 9 domains assess capacity to make financial decisions
- Broad scope, from making change to reading a bank statement to comparing investment options
- Appealing face validity



# Specific Issues: Financial Capacity

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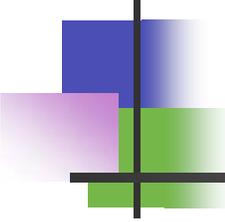
- Financial capacity has been defined as “the capacity to manage money and financial assets in ways which meet a person’s needs and which are consistent with his/her values and self interest” (definition proposed by Daniel Marson, a lawyer/neuropsychologist who has published extensively on the issue)
- Financial capacity is a core element of individual autonomy
- Loss of financial capacity frequently is the first functional change noticed as cognitive impairment develops.
- Financial capacity has two broad dimensions, which can be dissociated
  - Performance – cash transactions, paying bills, filing tax returns
  - Judgment – involving both decision-making and inhibition
- Patients with dementia are at risk both for financial victimization and for self-inflicted financial injuries
- Stakes are high when there is a lot of money .. and where there is very little



# Deconstructing Financial Capacity (Gardiner et al. 2015)

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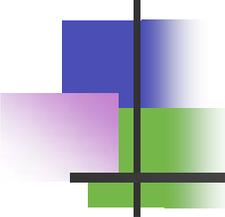
- Basic monetary skills (e.g., naming coins, counting currency)
- Financial conceptual knowledge (e.g., what is interest?)
- Cash transactions (e.g., purchase of single or multiple items)
- Checkbook management
- Understanding bank and credit card statements
- Financial judgment (e.g., recognizing fraud risks)
- Bill payment
- Knowledge of one's assets and estate plan
- Investment decision making



# Financial Capacity Taps Many Cognitive Functions

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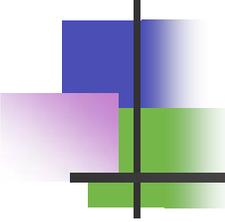
- Conceptual knowledge
- Procedural learning and memory
- Episodic memory
- Visual memory
- Visual attention
- Calculation
- Executive functions
  - Organization and planning
  - Inhibition of impulses/resistance to inappropriate cues.



# Five Roles for the Clinician in Addressing Financial Incapacity

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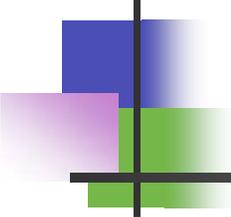
- Education of patients and families
  - Focus on advance planning, especially durable powers of attorney
- Detection of financial impairment
- Assessment of financial impairment
- Supporting financial independence
- Referrals
  - Neuropsychiatric or neuropsychological
  - Legal
  - Financial services



# Warning Signs of Financial Incapacity

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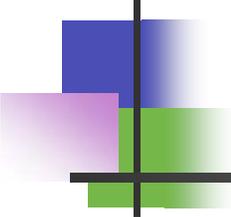
- Memory lapses related to financial mistakes – e.g., paying bills twice
- Disorganization – e.g., losing documents at home
- Confusion about basic financial terms – e.g., mortgage, interest, will
- Impaired everyday math
- Bad judgment: impulsive purchases, foolish investments, falling for obvious scams
- Examination of financial records such as credit card statements, brokerage account records or notices of overdue bills can provide documentary evidence of impairment – and can help establish a rate of decline



# Helping to Preserve Financial Independence: Reduce Executive Demands, Build Backstops

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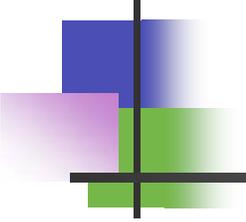
- Durable powers of attorney, and trusts with backup trustees – much more flexible and far less humiliating and guardianship
- Arrangements with the bank
  - Joint checking accounts with two signatures required for large purchases
  - Direct deposit of checks
  - Overdraft protection
  - Third-party notification of unusual activity
- Manual or automated monitoring of credit card transactions
- Automatic payment of recurring bills such as rent and utilities.



# Even Guardianship Need Not Be “All or None”

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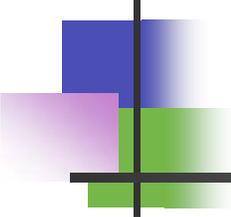
- In many states a guardianship can provide that certain rights are retained by the individual with diminished capacity
- For example
  - Access to pocket money
  - Rights to give gifts or donations (up to a specified limit)
  - Right to modify a will, subject to specified limitations
- Concept is balancing best interests, autonomy, and authenticity (consistency with long-term values and relationships)



# Customizing Management of Decreased Financial Competence: Key Considerations

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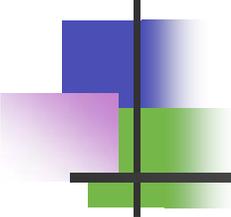
- Stage of dementia and expected rate and pattern of cognitive loss
- Expected needs for care and their cost
- Whether there is someone trusted (and trustworthy) to make financial decisions on the patient's behalf
- Assets and income available for the patient's future care
- Whether the patient is responsible for financial decisions that affect others' welfare



## When There Are Significant Assets

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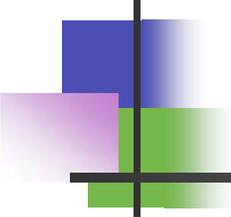
- “Smoke out” issues of trust and trustworthiness
- Be vigilant with respect to potential financial exploitation – it sometimes is subtle
- Involve a “neuro-aware” family therapist or social worker when denial is prominent in the patient or the family
- The estates-and-trusts lawyer should be educated regarding dementia and related neuropsychiatric issues



# Testamentary Capacity: Ingredients

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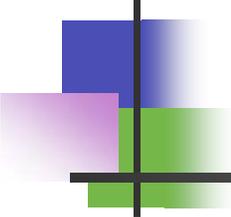
- Know what a will is
- Know what one's assets are
- Know the people who have a reasonable claim to be beneficiaries
- Understand the impact of a particular distribution of the assets
- No delusions that would affect the decisions made
- Ability to express wishes clearly and consistently



# Signs Suggesting Testamentary Incapacity

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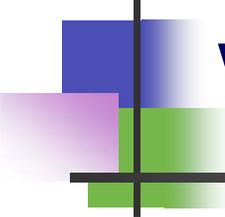
- Radical change from previous will(s) or previously stated intentions
- Disinheriting of “natural” heirs
- Decisions made in context of probable delusions, misperceptions, misunderstandings, etc.
- Choices that disregard one’s personal history and reflect only one’s present circumstances
- Special situations
  - No biological children
  - Suspicion of undue influence



# Reasons to Suspect “Undue Influence”

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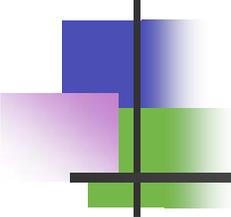
- Physical dependency with caregiver as new beneficiary
- Apparent sexual bargaining
- Change in will instigated by a beneficiary
- Changes made shortly before death



# Undue Influence in Patients with Borderline Capacity

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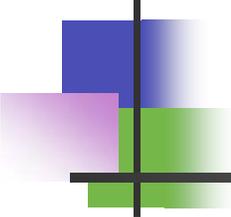
- Some expressions of dementia make patients highly susceptible to immediate circumstances and influences even though they can articulate plausible reasons for their mercurial decisions.
- Such patients are easy prey for self-interested relatives or caregivers
- Evidence of unstable decisions or of marked environmental dependency can help establish testamentary incapacity in a borderline case.



# Pitfalls in the Assessment of Testamentary Capacity

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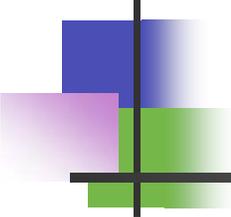
- Focusing on diagnosis rather than functional capacity
- Delusions per se do not imply incompetence
- Poor test performance does not imply incompetence



# Healthcare Proxies, Living Wills, and other Advance Directives

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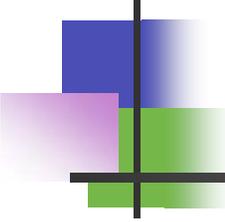
- Advance directives are designations made while a person is competent to decide:
  - Who should make medical decisions when they are incompetent in the future (healthcare proxy)
  - What principles should guide those decisions (living will)
- “Healthcare proxy” can refer either to the document or to the person who functions as the agent or surrogate decision-maker. That is, in this context proxy = agent = surrogate.
- A competent choice of a healthcare proxy may be possible for a patient with quite advanced dementia
- Prior knowledge of the patient and the proposed proxy may be necessary to be confident that the proposed agent is appropriate.



# Special Case #1: Advance Directives for End-of-Life Care

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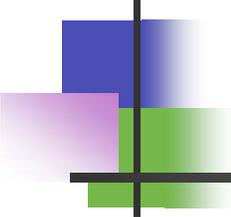
- People's preferences for care at the end of life evolve as they age, actually face illness, and learn more about what their options really entail.
- Revision of advance directives in the face of illness is the rule, not the exception.
- Patients with mild dementia often have the capacity to give the gist of their wishes and to appoint an agent who will fill in the details.



# Capacity to Appoint a Healthcare Proxy – A Recent Meme

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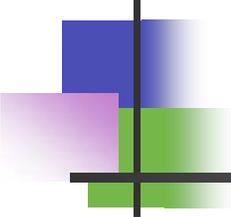
- Some states have a default surrogate consent statute, which gives healthcare decision making authority to the next of kin if the patient lacks the relevant capacity
- For those that don't a valid healthcare proxy is an essential alternative to guardianship – needed for consent when the situation is urgent but not so emergent that the implied consent doctrine is applicable
- Even when states have default surrogates the default surrogate might not be the patient's preference – e.g., patient might prefer a sibling to a child, or a non-spouse same sex partner to a blood relation.
- Since patients often don't do advance directives before the onset of dementia, the question of capacity to appoint a healthcare proxy comes up often – a “concurrent directive” rather than “advance directive”



# Capacity to Appoint a Healthcare Proxy – Minimum Requirements

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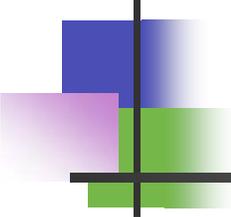
- The patient has a basic understanding of what it means for another person to make healthcare decisions on one's behalf
- Knowing who might be an appropriate choice for a surrogate decision-maker
- Designating a specific individual to be the surrogate decision maker
- Consistently expressed intent to appoint the same person as proxy on multiple occasions
- The choice of agent is consistent with past relationships or, if it isn't, there is a reasonable justification



## Additional Consideration: Understanding of the Proxy Document

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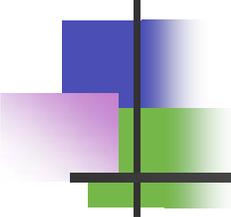
- Patient knows that signing the proxy gives decision making power to another person.
- Patient knows that this could have “life or death” consequences.



# Judging the Appropriateness of a Proposed Surrogate Decision-Maker

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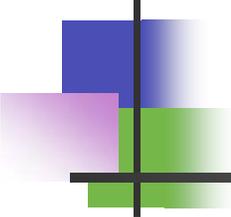
- Does the proposed surrogate have adequate decision-making capacity?
- Will the surrogate be consistently available when needed?
- Does the proposed surrogate show understanding of the patient's general preferences and values regarding healthcare?
- Is there a history suggesting abuse or exploitation by the proposed surrogate, or excessive conflict?
- Do significant others find the surrogate acceptable?



# A Sample List of Questions to Test Capacity to Appoint a Healthcare Proxy (From Moye et al. 2013)

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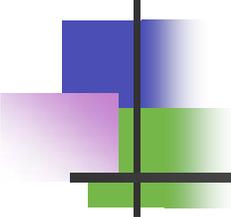
- 1) What is an advance directive?
- 2) What's good about an advance directive?
- 3) What does a healthcare proxy or agent do for you?
- 4) Who would you consider naming as your agent?
- 5) Which of those would you choose as your agent?
- 6) Why would you choose/trust this person?
- 7) (If there is a concern about the proposed agent) Some people would be concerned about appointing X as your agent because of Y. What do you think about that?
- 8) Do you have to fill out an advance directive?
- 9) Why do you want/not want to do it?
- 10) What happens if your illness gets worse and you are unable to make your own healthcare decisions?
- 11) Whom would you choose to be your healthcare agent?



# Special Case #2: Consent to Research – Proxy Consent versus Advance Research Directives

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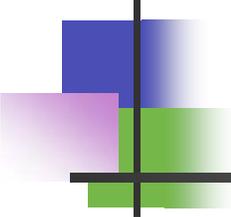
- Not clear that a generic healthcare proxy enables the surrogate decision maker to consent to research that may not directly benefit the patient.
  - Further, living wills cannot anticipate all of the complex choices that might arise with respect to research participation
- If a patient with a neurodegenerative disease wants to participate in longitudinal research he or she ideally should:
  - Sign an advance research directive expressing the desire to participate in research, describing the types of research and level of risk that is acceptable.
  - Sign a healthcare proxy that authorizes the surrogate to consent to research
  - Select a surrogate with the capacity to assess the risks and benefits of participation in research
- Shared decision-making should be attempted even if the healthcare proxy is activated. Patient assent is expected.



# Philosophy Gets Real: Autonomy, Authenticity, or Best Interest?

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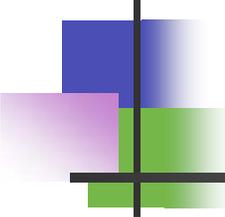
- What is the right basis for making a decision on behalf of an incompetent person:
  - What they thought they'd want under the circumstances when they were still competent? (Precedent autonomy)
  - What would be most consistent with their lifetime attitudes and beliefs? (Critical interests)
  - What a caring and competent proxy thinks would be in their best interest?
- Local law may dictate that clinicians follow the first option, but if not, the second and third options deserve consideration
- And, even incompetent people's wishes should be respected when it's feasible to do so



# Guns and Dementia: Sobering Statistics

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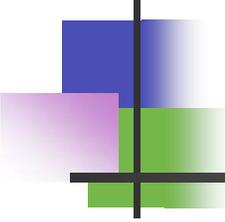
- Older people are more likely to own guns than younger ones.
- As of 2004 27% of Americans over 65 owned firearms.
- 80% of homicides committed by people over 65 are done with guns – most common homicide scenario is a man killing his wife while depressed and/or cognitively impaired
- Men over 85 have the highest suicide rate – 43.6 per 100K per year; and >50% of them use guns. In the population of veterans with dementia, 72% of suicides used guns. Male suicide rates are lower when firearms are less available.
- Patients with dementia are prone to depression – with the risk of suicide – and to paranoia – with the risk of violence in perceived self-defense



# Gun Ownership is Prevalent

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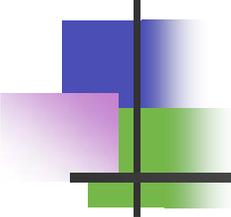
- 21-State VA study: *40% of veterans with mild to moderate dementia lived in homes where there was a firearm.*
  - 21% of those with firearms kept them loaded
  - 61% stored their firearms in an unlocked location
- Study in a university memory clinic
  - 60% of demented patients had a firearm in their home
  - 45% of the firearms were kept loaded
- Gun ownership is more common among men, Southern and Western US, and rural areas.



# America the Exceptional

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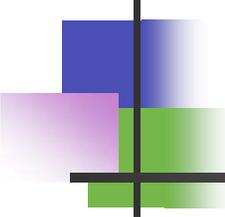
- In Japan gun owners must be licensed, and licenses must be renewed every three years. Civilians may not legally own handguns. Firearm casualty incidence is 0.06 per 100K. The US rate of firearm casualties is 10 per 100K.
- In Australia physicians are expected to inform police if they believe a gun-owning patient may pose a risk, and they are held harmless for the breach of confidentiality.
- In the US there is no national requirement for individuals to be licensed to own a gun legally, though some guns require licenses in some states
- Some states protect gun rights with admirable vigor
  - Iowa – blind people may legally purchase handguns
  - Texas – patients may carry concealed firearms in hospitals
  - Florida – physicians may be fined for recording information about firearms in their medical records if it is “not relevant to the patient’s medical care, or safety, or the safety of others”



# Physician Attitudes Concealed Carry Permits (Goldstein et al. 2015)

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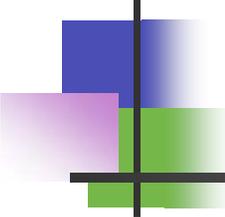
- In North Carolina physicians are sometimes asked to certify that a person applying for a concealed weapon permit is competent to receive one.
- 222 physicians in NC responded to a mail survey (out of 600 sent) on how they relate diagnoses to competency for concealed carry
- Men and gun owners were more inclined to approve permits across all diagnostic categories
- Highest rejection rates were for mild dementia (68%) and Parkinson's disease (42%).
- Remarkably, 10% of respondents would regard a patient with mild dementia as eligible for concealed carry.
- Editorial comment: The specific dementia diagnosis should make a big difference, e.g., bvFTD patients should not be carrying firearms.



# Capacity to Safely Own a Firearm

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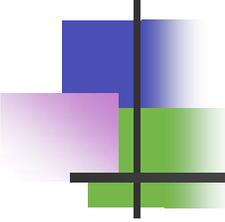
- Understanding the dangerousness of firearms and the risks of firearm ownership
- Knowing how to safely store and handle firearms
- Demonstrable capacity to store, lock, load and unload a firearm – including securing firearms when young children are around
- Adequate physical and sensory ability to handle and use a firearm safely
- Ability to distinguish appropriate from inappropriate use of a gun, and to inhibit impulsive gun use
- No intent to threaten or to harm others
- No suicidal intent



## Like Other Capacities, Firearm-Related Capacities are Contextual and Variable .. and Progressively Lost

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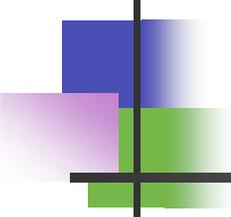
- Capacity to safely own a firearm can be lost early in neurodegenerative disease (e.g., from bvFTD) or relatively late – as in patients with CDR 1.0 Alzheimer dementia whose (appropriate) gun-related behavior reflects crystallized intelligence of diamond-like hardness
- This capacity can fluctuate with physical or mental health, alcohol or drug use, or medications
- Patients with MCI may lack capacity for safe firearm ownership while a few with CDR 1.0 AD may retain the capacity.
- Beyond CDR 1.0 no dementia patient can safely own a firearm



# Giving Up Guns is Like Giving Up Driving

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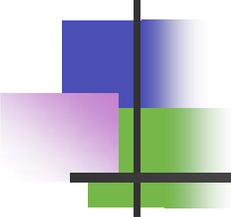
- For many patients gun ownership, like a driver's license, is a critical element of autonomy and self-respect, and for a few it is actually relevant to their safety and security.
- Giving up guns may be easier if:
  - A non-"mental" reason such as declining vision or a tremor is applicable
  - Doing it is framed in terms of prevention and anticipation of potential future contingencies
  - It is required because a home health caregiver won't work in a home with firearms (and NIOSH recommends they don't!)
  - It is related to protecting others – e.g., visiting grandchildren
  - Any realistic concerns related to home security or pest control are addressed by some other means
- Disabling a gun may be necessary in some cases, and may be better tolerated by the patient than confiscating the gun



# Firearm Screening is High-Yield

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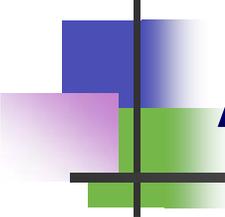
- Incorporate gun-related questions into your standard new patient intake package
  - Is there a firearm in the home?
  - Is it kept loaded? Locked?
- Query family if they are present, or if they are not but the patient consents
- Utilize the usual face-saving maneuvers
  - Talk about potential *future* risks, e.g., those related to gun access during a transient delirium
  - Mention risk to others, e.g., grandchildren, if guns are carelessly left loaded and not secure
  - Take an NRA gun safety course yourself – talk comfortably and knowledgeably whether or not you are personally a gun owner.



# The 5 L's for Geriatric Gun Safety

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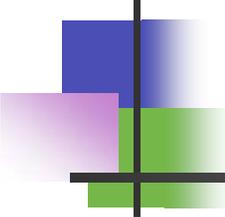
- Locked? (either gun locked up or trigger locked)
- Loaded? (best to keep guns unloaded and ammo stored in a separate locked location)
- Little children? (either living in the same home or visiting frequently)
- Low (mood)? (consider temporary “gun control” while a patient is depressed even if they’re have gun owning capacity otherwise)
- Learned? (Is the owner knowledgeable about gun safety? Does he or she *practice* gun safety? When did he or she last take a gun safety course?)



## When the Right to Bear Arms May Be Abridged by Plaques and Tangles ...

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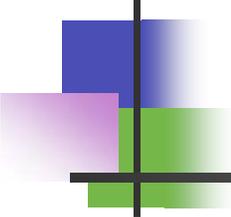
- Deal with guns as with other safety issues such as driving and living arrangements
- Engage concerned family members to lock up, disable, or dispose of guns
- If risk is imminent, hospitalize the patient (involuntarily if necessary) and have family or police remove the weapons from the home while the patient is in the hospital



# Competency to Vote

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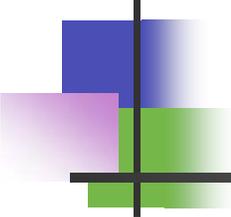
- Relevancy of competency to vote in older voters with mild to moderate dementia has become more politically relevant recently
  - Studied with formal tests by Appelbaum and colleagues
- Understanding of voting and ability to express a choice are preserved in the majority of patients
- Political reasoning and appreciation of personal effects of election results are lost as dementia progresses
- Voting is similar to appointing a healthcare proxy
- Ethical perspective



# Disenfranchisement of Nursing Home Residents

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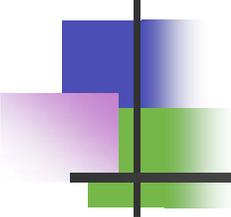
- Most patients with mild dementia remain competent to vote.
- Yet, less than 5% of nursing home residents with mild dementia do in fact vote.
  - Deficits in executive function and mobility may make it necessary for caregivers to transport the patient to the polls or arrange for an absentee ballot
- Political decisions affect healthcare and security in old age – and are personally meaningful to patients with dementia



# Competency to Consent to Sexual Relations

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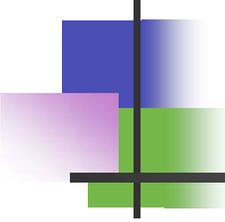
- Sexual relations are a relevant concern for patients with dementia
  - Some desire them appropriately
  - Some desire them excessively, at the wrong time, or with inappropriate partners
  - Some don't want them, and are vulnerable to serious injury from sexual activity because of conditions like osteoporosis and atrophic vaginitis
- Sexual relations between dementia patients and professional caregivers (e.g. nursing home staff) constitute abuse and/or exploitation, because the patient cannot validly consent to them.



# Relations with Spouses or Life Partners are More Complicated

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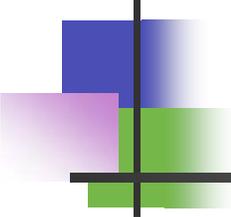
- If a couple has had a consistent sexual relationship throughout the early stage of the patient's dementing illness it may be appropriate for them to continue it even after the patient cannot give affirmative consent.
- However, verbal or non-verbal refusal must be honored.
- Advance directives for conjugal intimacy may be in the offing.



# Legal Competence

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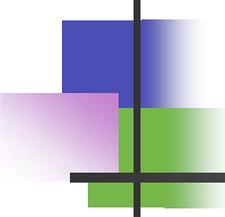
- Competence for what?
  - Deciding on medical procedures (clinical or research)
  - Making or revising a will; establishing, revoking or revising a trust
  - Advance medical directives
  - Making financial decisions
  - Involvement in litigation
  - Consenting to sexual relations
- De facto standard is higher for “unreasonable” decisions.
- Interviews with lay people show that they understand that competence is task-specific and that a person with dementia may be competent to make a healthcare decision but not a financial one, for example.



# Multiple Standards with Different Executive Requirements

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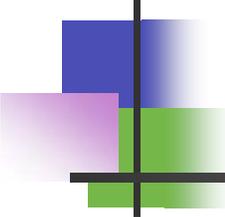
- Ability to understand the question and express a preference
- Ability to reason about the question
- Ability to express rational reasons
- Ability to appreciate context and personal significance
- Ability to conform behavior to expressed intentions



# Why Assessors Disagree About Competency

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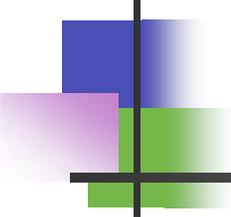
- In practice, assessors of capacity/competence often disagree.
- Assessors disagree least often about patients' capacity to understand the issue at hand.
- They disagree most often about patients' appreciation of context and quality of reasoning. Some assessors put major weight on declarative memory, while others don't.
- Overall judgments disagree for any of these:
  - Disagreement about which dimensions of capacity are important.
  - Disagreement about the measurement of individual dimensions of capacity
  - Disagreement about thresholds or cutoffs for impairment.



# The Bugbear: Disproportionate Executive Impairment

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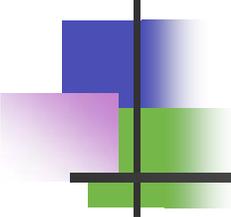
- Disproportionate executive impairment can be found in FTD, Lewy body dementia, dementia of Parkinson's disease, dementia associated with late life psychosis, chronic delirium -- and many other conditions.
- Patients with these disorders can give rational reasons but make irrational decisions because of unawareness of inconsistency, and lack of appreciation of context.
- The problem is especially severe when insight is lost.
- Families, lawyers, and courts may need introduction to the concept of selective cognitive impairment, and executive dysfunction in particular.



# The Problem of Fluctuation

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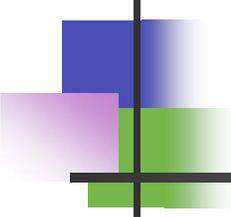
- Fluctuating deficits are the rule in dementia
  - Intercurrent illness
  - Drugs
  - Stressful situations
  - Depression
- They can produce intermittent incompetence including state-dependent treatment refusal
- Consider “Ulysses contracts” for cognitively unstable patients scheduled for high-risk surgery.



# Preventing “Legal Emergencies”

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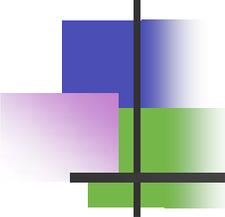
- Gray zones of competency can be anticipated based on the patient’s diagnosis.
- Problems will always be worse in a crisis situation.
- Therefore, durable powers of attorney, living wills, etc. should be done as early as possible in the course of the illness, when the patient still has insight.
- Advance consultation with a hospital’s risk management, counsel or ethics service makes sense if a competency-related problem is anticipated.



# Communicating the Findings of an Assessment

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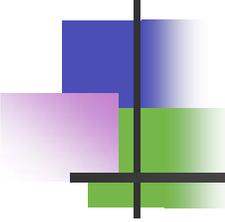
- Identify the interested parties and the key issues -- disability, competence, financial risks, needs for support and assistance, driving safety.
- Get permission to share information
- Estimate the knowledge of the audience and set the stage if necessary -- with an explanation of executive function, need for supervision, course of illness, etc.



# Aids to Communication

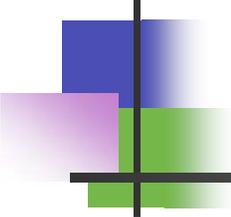
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- Create a “roadmap” for the patient’s expected course, anticipating what practical issues might arise at different points along the patient’s course
- Prepare a written summary of findings and implications.
- Recommend readings, videos, websites, etc.
- Deal early with issues of trust.
- Refer patients and families to specialized resources



# Managing Declining Competency in Dementia Might Require:

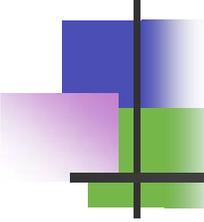
- A family therapist interested in caregiving and legacy issues
- A lawyer with an estates and trusts specialty
- A lawyer with a family law specialty
- An eldercare specialist social worker with broad knowledge of both conventional and unconventional community resources
- A therapist specializing with skill in managing caregiver stress
- A neuropsychologist experienced in competency-related testing and in explaining results to lawyers and judges
- A driving evaluation specialist, preferably one with access to driving simulation and/or telematics
- An occupational therapist who makes home visits
- A financial advisor
- A medical ethicist



# Dialogue Between Physicians and Lawyers

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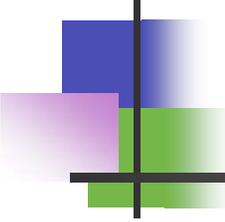
- Physicians – the evaluators of capacity and lawyers – advocates for a determination of competency (or its lack) – come from different traditions and perspectives.
- They can learn from one another through joint engagement with challenging cases.
- The physician will learn what the lawyer needs to know, and the lawyer will gain a more subtle understanding of the diverse ways capacity can be impaired.



# Village-Building Advice

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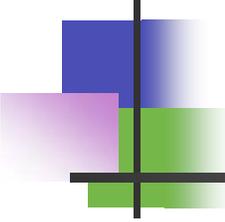
- Practitioners of various disciplines will be more helpful if they understand how executive impairment, loss of self-awareness, fluctuation, context-dependency, and depression and/or psychosis can affect patients' decisional capacity
- They are especially helpful if they're available when you need them
- You can play a role as an educator to build the knowledge of your human resources: Discuss your challenging cases with them
- Introduce your resources to one another, and they'll introduce useful colleagues to you.
- Sharing challenging cases builds trust, and helps you understand your resources strengths and limitations
- Past referrals of rewarding patients open doors to future referrals of difficult ones.



# A Vision for the Future: The “Aging and Brain Health Executive Checkup”

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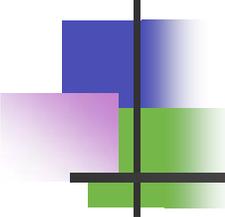
- You might share this vision with patients in their 80s or 90s who:
  - Are intelligent and well-educated
  - Have substantial means
  - Are highly engaged in their own health care
  - Acknowledge that they are aging and that they have “entered the high maintenance phase of life”
  - Are open minded
  - Trust you
- “Let’s make the future happier, healthier and safer by doing a comprehensive inventory now ...”



# What's In the Package - 1

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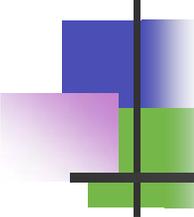
- Formal testing of hearing, vision, and olfaction
- Screening neuropsychological exam
- Testing of gait, balance, reaction time, and useful field of view – with a driving simulator test if applicable
- Review of all medications and supplements
- Nutritional assessment
- Assessment of alcohol and drug use
- Check that all health maintenance items are up to date – immunizations, bone density, cancer screening, etc.
- 24 hour activity monitor; follow up on evidence suggesting sleep disorder or insufficient activity
- Inquiry about firearm ownership and, if applicable, firearm safety issues



# What's in the Package - 2

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- Home visit and full home safety assessment.
  - Does the home need more attention and executive function than the patient can devote to it?
- Comprehensive legal status review
  - Will, trusts, life insurance, etc.
  - Durable power of attorney
  - Advance medical directives/ healthcare proxy designation
  - Provisions for adult dependents if any
- Financial status review
  - Everyday financial arrangement
  - Investments, income and expenses, etc.
- Family assessment
  - Who's responsible for whom and for what?
  - Where are there issues of trust? Capacity? Goodwill? Conflict?



# To prevent needless suffering and find joy and meaning in old age one should:

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- Take care of unfinished business while one can
- Prevent illnesses, injuries, and impairments whenever one can
- Acknowledge and compensate for the inevitable losses that come with aging
- Reduce low-value-added uses of motivation, memory and executive function, reserving those precious assets for the things that matter most.
- Identify one's "critical interests" and plan ahead with those interests in mind.