

# FACULTY GUIDE

## Core Module 11: Ethics and Capacity Issues

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**Slide 1:**

- Module 11 addresses the legal, financial, and ethical challenges that ensue after a person receives a diagnosis of dementia.
- We will also examine the concept of capacity, and how it differs from the legal issue of competency.
- This module also addresses the topic of elder abuse, noting that persons with dementia are at even greater risk than the general elderly population of specific forms of elder abuse.

**Slide 4:**

- In this module, we are going to address how a diagnosis of dementia influences many of the other nonmedical aspects of a person's life, with emphasis on how primary care and health care providers can assist as part of a comprehensive care team.
- This module also focuses on the need for determining a person's capacity to make medical and legal decisions, as well as the ethical challenges faced by care partners and providers.
- Finally, the module explores the issues surrounding the risk of abuse of persons with dementia.

**Slide 5:**

Our goal, by the time we finish with this module, is for you to learn about the following topics:

- Legal and financial considerations associated with a diagnosis of dementia
- Domains that are included in a capacity assessment for persons living with dementia
- Ethical issues related to participation in dementia research
- Signs of elder abuse

**Slide 6:**

- Have a high level suspicion for elder abuse or neglect (physical, psychological and financial).
- Do not underestimate the ability of persons living with dementia to express opinions about their care; older people (including those with dementia) should have a strong say in what they want, but must deal with the reality of limited resources.
- Older people have the right to take informed risks.
- Primary care providers have an important role in determining decision-making capacity – a practical approach to assessment and good documentation can help caregivers and their legal counsel.

**Slide 8:**

- We begin our discussion with an overview of the many different types of challenges facing persons living with dementia, their families and their care partners.

**Slide 9:**

People living with dementia and their families face many decisions during the course of the disease. These decisions include:

- Legal decisions that can encompass giving informed consent, participating in research, voluntarily terminating life, and other end-of-life care issues
- Financial decisions about managing assets and property
- Medical decisions about care and treatment
- Ethical decisions regarding autonomy, safety, and sexuality, as well as issues surrounding abuse and neglect

**Slide 10:**

- Members of the treatment team should help the person living with dementia and the care partner navigate decisions in a way that respects as much as possible the autonomy of the person living with dementia while maintaining Health Insurance Portability and Accountability (or HIPAA) compliance. The values and wishes of the person with dementia can be captured in the early stage of disease in documents including wills, trusts, health care and financial powers of attorney, and advance directives about treatment and end-of-life care.
- Questions from care partners and persons living with dementia regarding financial decisions should be referred to an accountant or other financial advisor.
- If the person living with dementia is not able to afford these specialists, free legal and financial services may be available (see [Resources](#)).
- The primary care provider (PCP) may be called upon to assess the person living with dementia for capacity to make specific decisions.
  - The PCP may choose to refer the person with dementia to a psychologist or psychiatrist for this determination.
  - Decisions regarding “competence,” which is a legal determination, are made by a judge in court.
- What falls under the domain of the primary care provider or health care professional (HCP) regarding legal, financial, and ethical considerations associated with a diagnosis of dementia?
  - All PCPs and HCPs should have a global understanding of the range of issues facing the person living with dementia and family members.
  - They should recommend professional guidance to help patients and their families deal with these considerations and, when possible and appropriate, recommend resources and referrals.
  - PCPs and HCPs should know that difficulty managing finances is one of the early signs of dementia.
  - They should strongly suggest that legal and financial planning be addressed during the earlier stages of dementia, while the patient is still capable of making decisions, is able to participate fully, and can express his or her wishes.
  - Ideally, planning can prevent future family disagreements about the person’s wishes, thus helping the health care team achieve overall quality of care.
  - It is also the (moral) responsibility of all HCPs to know the signs of elder abuse.

**Slide 12:**

- We now begin by looking at the legal and financial considerations that ensue from a diagnosis of dementia.

### Slide 13:

- A careful review and updating of financial, legal, and health care plans should start soon after a diagnosis to allow the patient to participate fully in the process and express and record his or her wishes.
- Once a diagnosis of dementia has been provided, the primary care provider should recommend that persons living with dementia and appropriate care partners meet with specialists for financial planning, assigning power of attorney, wills, and living wills, as long as the care partner and person living with dementia have the financial capability to pay for these services. If, in the determination of the PCP, the person living with dementia and the care partner are unable to afford services, certain free legal services are available. (See [Resources](#) for more information about elder law attorneys and local and state services that can be of assistance.)
- PCPs and other health care providers can inform persons living with dementia and their care partners about legal, financial, and related issues that will need to be addressed in the future—such as concerns regarding driving privileges (and cessation of driving or driving “retirement”), the eventual need for support services (such as in-home or institutionalized care), future treatment plans, and possible research participation.
- Persons living with early-stage dementia are often able to participate in financial decisions, such as applying for Medicaid and arranging finances for long-term care needs.
- Persons with early-stage dementia are often able to participate in developing (or updating) legal documents, such as wills, living wills, advance directives, and trusts.
- Planning allows the person with dementia to designate a person or persons of his or her own choosing (proxy) to make legal or financial decisions on his or her behalf when he or she is no longer able, or is deemed not to have the capacity to make such decisions.
- Planning also allows the person living with dementia to determine how much leeway the identified proxy will have in making decisions. In addition, it should be noted that a person’s wishes may change over time.

### Slide 15:

- An **elder law attorney** can help the family identify and complete the necessary and appropriate legal documents, which may include a will, a trust (if desired), durable power of attorney for finances, durable power of attorney for health care, do not resuscitate (DNR) orders, and an advance directive or living will. Elder law attorneys can also deal with legal issues involving planning for a well spouse, public benefits such as Medicaid and insurance, and veterans’ benefits. Issues involving guardianship are also under the purview of an elder law attorney, as are nursing home claims and resident rights in long-term care facilities.
- An **accountant and/or financial planner** may be contacted to assist the patient and family in making financial decisions for the future. It is especially important to discuss financial issues as soon as a diagnosis is conferred, as the costs of care for a person living with dementia can be significant over time.
- If finances allow, a **geriatric care manager** can be hired to help the patient and family navigate these issues.

**Slide 16:**

- Persons living with dementia need to plan for costs associated with the following:

Ongoing medical treatment for Alzheimer's-related symptoms

- Prescription medications and over-the-counter medicines
- Treatment or medical equipment for other medical conditions
- Safety-related expenses, such as home safety modifications or safety services for a person who wanders
- Personal care supplies
- Adult day care services
- In-home care services
- Full-time residential care services
- In addition, there are costs associated with hiring the specialty team of lawyers, accountants, and a case manager, as well as costs associated with developing the necessary legal and financial documents.
- The predominant costs associated with dementia care concern personal care costs, and not direct medical costs.
- The majority of persons living with dementia may not have the resources to cover all of these costs.

**Slide 17:**

- The Alzheimer's Association, citing information from the Genworth 2015 Cost of Care Survey, noted that the average costs for long-term care services in the United States include more than \$80,000 per year for a semiprivate room in a nursing home and more than \$43,000 per year for basic services in an assisted living facility. Home health aide costs can average \$20 per hour.
  - Many persons living with dementia today likely do not have long-term care insurance, and they may be unable to afford these costs.
- Medicare coverage is limited to a specific duration of time (typically 100 days) following an illness or injury that necessitates a hospital stay of at least 3 days and that requires a skilled level of care that cannot be provided at home or on an outpatient basis. As such, Medicare coverage does not address the needs for long-term care associated with dementia.
- Generally, Medicaid (or medical assistance) benefits are available to elderly people (at least age 65 years) who meet specific low-income and asset guidelines and have disabilities (physical or psychological).
  - The Federal Government establishes guidelines, and each state chooses what specific dollar amount qualifies an individual for Medicaid.
  - Depending upon the state, a person cannot have more than a specific prespecified amount (for example, \$2,000 in the person's bank accounts or \$3,000 for a couple), cannot own rental property or a car worth more than a specific dollar amount, and cannot own any other material assets of substantial value (often excluding a car and home).
  - Persons who live in the community and qualify for Medicaid may need to **spend down** their assets over a period of time to qualify for Medicaid benefits. Each state

has its own Medicaid spend-down process and timeline. Understanding these concerns early will enable the persons living with dementia and their care partners or family to establish a long-range plan that meets their needs. The Estate Tax Reduction Act of 2005, passed by Congress, clearly delineates the stringent divestiture rules, including the 5-year look-back associated with transfers or gifts of assets. The Act mandated that seniors “spend down” their (combined) assets before being able to qualify for Medicaid assistance with costs for a nursing home.

- Current nursing home care is costly and can quickly bankrupt a family.

**Slide 19:**

- A **standard will** is a written legal document that delineates how an estate will be distributed upon death. The will identifies an executor (the person who will manage the estate) and beneficiaries who will receive the assets in the estate. The will must conform to the rules of the state in which the person resides.
- A **living trust** is another document that provides direction about one’s property and assets. It includes instructions about how to handle one’s resources in the event of serious illness or injury. All assets may be transferred to the trust, including titles of property and bank accounts.
- An **advance medical directive** or **living will** is a written set of legal instructions that identify a person’s preferences for medical care in the event he or she is no longer able to make decisions. Advance directives provide information to doctors and care partners in case the person has a terminal illness or serious injury, is in a coma, or is in the late stages of dementia or near the end of life.
- Other components of a living will or advance medical directive include decisions regarding pain management, feeding, and organ donation:
  - Resuscitation, mechanical ventilation, tube feeding, dialysis, antibiotics or antiviral medications, comfort or palliative care, organ and tissue donations, and donating one’s body for medical research
  - Do not resuscitate order
  - Do not intubate (DNI) order
- A **durable power of attorney** for health care (also called health care proxy or medical or health care power of attorney) is a type of advance directive:
  - The person names another person to make medical decisions in the event he or she is unable to.
  - The designated person—who may be a spouse, friend, other family member, or someone else— may be called by several titles: health care agent, health care proxy, health care surrogate, health care representative, health care attorney-in-fact, or patient advocate.
  - This designated person must meet the state’s requirements for a health care agent, cannot be the doctor or part of the medical care team, must be willing and able to discuss medical concerns including end-of-life care issues with the person living with dementia, must be trusted to make decisions that adhere to the wishes of the person living with dementia, and must be trusted to be the person’s advocate if there are disagreements about their care.

- **A durable power of attorney** can also be drawn up for finances, including investments, assets, and income.
- **A research advance directive** is an advance directive delineating interest and willingness to participate in research study.
- **A POLST** (physician [or provider] orders for life-sustaining treatment) or a **MOLST** (medical orders for life-sustaining treatment) can be completed by a physician for persons diagnosed with serious illness to ensure that, in case of emergency, the person's wishes are followed. These forms vary by state.

**Slide 20:**

- Guardianship is not a common occurrence.
- When a person is no longer capable of making his or her own financial or healthcare decisions, the Courts will appoint a **guardian (or conservator)**, depending in which state the person resides) to make decisions on the person's behalf.
- Ideally, a power of attorney will have been identified already by the person while still competent. Only rarely do courts need to appoint a guardian—typically when family members disagree or there are no identified or qualified relatives.
- Supported decision-making is a promising alternative to guardianship. Through supported decision-making, persons living with dementia can confer with their network of care partners and family members, make decisions and have those decisions respected. Supported decision making maximizes independence and promotes self-advocacy and self-determination for persons living with dementia.

**Slide 21:**

- We switch gears from legal considerations to the topic of capacity, which is—probably contrary to many of our beliefs—not a legal issue.

**Slide 22:**

- An assessment of decision-making capacity is necessary when a person living with dementia has to make a decision, particularly a decision that involves notable risks.
- Each state has its own specific laws that define legal capacity.
- Capacity is a functional assessment encompassing four decision-making abilities:
  - The ability to **understand** key facts about a choice, such as risks and benefits and options
  - The ability to **appreciate** the benefits or upsides, the risks or downsides, and the problem or situation—loss of appreciation of disorder is referred to as “loss of insight”— and to appreciate that the choice applies to “me” and is not theoretical
  - The ability to **express** a relatively consistent or stable choice
  - The ability to rationalize or reason

**Slide 23:**

- Primary care professionals are generally capable of making clinical determinations of capacity. As we discuss shortly, there are specific tools that providers can use when assessing for capacity.

- If the PCP cannot easily determine capacity, a formal assessment may be required.
  - Remember that *competency* is a legal determination made by a judge in court.
- In persons living with dementia, memory impairments may influence their capacity to provide informed consent for specific treatments.
- Capacity is not static and may change with fluctuations in a patient’s cognitive status or as the disease progresses. For example, persons living with dementia may be able to make some decisions related to their daily care, but they may not be able to make a more complex decision regarding a treatment choice.
  - A person has the right to make a “bad” or “wrong” decision (as perceived by the care partner or provider)—as long as the person living with dementia has decision-making capacity.
  - Persons living with dementia who have minimal insight into their memory impairments have impaired decision-making capacity.
  - Consequently, an evaluation for capacity may need to be repeated periodically.
- Consider the person’s capacity to receive and understand the diagnosis. If the person is capable and willing, obtain consent to inform family members or others about the diagnosis in a family conference or group meeting.
  - If not, document in the patient record why you feel he or she does not have capacity and why it is in the best interest of the person living with dementia for his or her safety, medical care, etc., to disclose diagnosis to the care partner.
- Clinicians need to determine the person’s capacity to agree to medical treatments.
  - A person living with dementia may have lower decision-making capacity if he or she is unaware of impairments.
- Capacity must be assessed before a person living with dementia can consent to participate in clinical trials.

**Slide 24:**

If the clinician has any questions about a person’s capacity, the person living with dementia should be sent for an evaluation by a psychologist or psychiatrist.

- When the decision-making capacity is called into question—whether by a primary care provider, health care professional, or care partner—an evaluation should be recommended.
- The care partner can alert the primary care provider or health care provider to concerns about deteriorating decision-making capacity and request an evaluation.
- When capacity is not clear, several situations may call for formal assessment, including when:
  - Judicial involvement is expected.
  - Family members and other decision makers disagree on treatment or care planning.
  - A decision about undertaking a risky treatment is needed.
- As discussed in Module 3, throughout the evaluation, language barriers, ethnic and cultural beliefs, and related considerations must be recognized and addressed. If the person living with dementia is determined to lack decision-making capacity, a “proxy” will be identified (most often the care partner) and instructed to make decisions based on what the patient would decide if he or she were able, and to act in the person’s best interests.



**Slide 25:**

- The most commonly used clinical tools for assessing medical decision-making capacity include the following:
  - The MacArthur Competence Assessment Tools for Treatment (MacCAT-T) is considered gold standard for capacity assessment. It involves a hospital (or medical) chart review plus semi-structure interview. It takes 15 to 20 minutes to complete, but it requires training to administer and interpret results. It covers all four capacity domains.
  - The Capacity to Consent to Treatment Instrument (CCTI) includes hypothetical clinical vignettes, covers all four domains, and takes 20 to 25 min to complete. A potential limitation is that it uses vignettes, rather than patient-specific discussion, so it can lead to false assessment of patient's.
  - The Hopemont Capacity Assessment Interview (HCAI) uses hypothetical vignettes in semi-structured interview format. It takes 30 to 60 minutes to administer, and it is not as effective in assessing appreciation and reasoning as MacCAT-T and CCTI.
- As we discussed in Module 2, providers should be aware of possible copyright issues and costs associated with many of these tools.

**Slide 27:**

- Switching gears again, we now turn to how to provide ethical care to persons with dementia.

**Slide 28:**

- Ethics refer to human values and understanding what constitutes a good and moral life. They are often considered within a particular cultural context (Whitehouse, 2000).
- Four primary ethical considerations should guide decision-making on behalf of a person living with dementia:
  - Beneficence (do good; act in the person's best interests): shared responsibilities persons have for one another
  - Nonmaleficence (do no harm)
  - Respect for autonomy (respect a person's wishes and values): preserving an individual's rights to make decisions about his or her own life
  - Privacy and confidentiality
  - Privacy refers to the right of a person to limit access by others to aspects of their person – thoughts, identifying information, medical information.
  - Confidentiality refers to the process of protecting a person's privacy.
  - A systematic literature review identified 56 ethical issues in clinical dementia care across the following major categories: Diagnosis and medical indication,
  - Assessing patient decision-making competence
  - Information and disclosure
  - Decision-making and consent
  - Social and context-dependent aspects
  - Care process and process evaluation
  - Special situations for decision-making

### Slide 29:

- There are ethical issues associated with each stage of dementia. During early-stage dementia, providers must address ethical issues associated with providing a diagnosis. Middle-stage diagnosis may need to address competency issues and possibly issues regarding participation in research. End-stage ethical issues might involve the use of physical or chemical restraints, the use of feeding tubes, specific medications such as antibiotics, and suicide-related considerations.
- Ethical decisions about safety (e.g., remaining at home, continuing to cook, driving) should ideally be made with the person living with dementia and care partner in a way that protects the person while respecting his or her wishes and feelings as much as possible, but also protects others (such as driving). During earlier stages of dementia, “respect for autonomy” may clash with concerns about safety to the person living with dementia and others. However, as the dementia progresses, the person living with dementia will lose the ability to make these decisions, and the care partners (if available) will become responsible for these ethical and safety decisions.
- Other situations in which ethical considerations might arise include the use of global positioning systems (GPS) and other monitoring techniques, indications for brain imaging or genetic testing, and the use of medications.
- Ethical concerns are particularly pertinent during late-stage dementia. Concerns range from tube feeding to use of antipsychotic or antibiotic drugs, to suicide and other palliative care/end-of-life decisions, and will be discussed in detail in Module 12. Care partners are often faced with challenging ethical decisions—such as choosing between two less-than-ideal options (driving) and balancing personal needs versus the needs of the person with dementia (Hughes, [Hope, Reader, & Rice, 2002](#)). Care partners may feel torn between the need to protect neighbors from possibly dangerous behaviors of the person with dementia—or protecting the person with dementia from inquisitive or intrusive neighbors. Perhaps the greatest ethical dilemma is the choice between considering what is in the “best interests” of the person living with dementia versus the needs of the care partners themselves. There often are no easy answers.

### Slide 30:

- The ability to provide sexual consent is of particular concern in long-term care facilities, and it may also be of concern among persons with dementia who still reside at home.
- Sexual consent is determined by the mental capacity of the person with dementia.
  - Most states define “capacity” as the ability to understand the nature of sexual conduct, including physiological aspects and potential consequences. The challenge, however, is the absence of any clear standard or recommended tool to assess capacity to consent to sexual relations.
- Institutions and providers need to individually assess (and continuously reassess) a person’s capacity for sexual decision-making; this is not a static determination, so capacity may need to be reassessed on a frequent basis.
- Each patient’s ability to consent must be established, and patients must be protected from coercion. While expression of sexuality in care facilities can be difficult for both care partners and staff members, residents’ rights to make decisions about intimacy and physical relationships

must be respected once their ability to consent has been established. However, as the neurodegeneration of dementia progresses, the person's capacity to provide consent will diminish, such that consent will need to be continuously reevaluated.

**Slide 32:**

- Research, such as clinical studies and clinical trials, is used to better understand dementias and how to diagnose and treat them more effectively. Observational or cohort studies compare changes over time in people with dementia. Clinical trials assess the effectiveness of interventions (e.g., drugs, devices, and diet or lifestyle changes) in people with dementia. Some persons living with dementia and their care partners might be open to participating in these studies or trials; it is important to ensure that the patients have the **capacity** to consent.
- Clinicians can discuss the opportunity to participate in research with persons who are interested and capable of consenting and their care partners.
- It is important to always mention both the pros and cons of participation. It must be emphasized that there is no way to promise that the intervention is better than the current standard of care, or that the person living with dementia will be in the trial intervention arm. As such, the person living with dementia and the care partner must understand that there may or may not be any direct observable benefit to participation. However, they should all be assured that there will be medical oversight throughout the trial and that the findings may help people in the future.
- Participants also need to be able to understand that there may be risks from the intervention or control arm, and that there may be travel requirements or time commitments involved. Participants will not know during the study which arm they are in. For certain studies, there may need to be a study partner, such as a family member, who would need to take the person to the study site or participate in the research study by answering questions.
- The study partner will also need to provide consent to participate.
- When discussing clinical trials with persons living with dementia and their care partners, the provider should explain that the investigator needs to clearly discuss the type of trial, safeguards, possible risks and benefits, right to refuse or withdraw, informed consent, and protection of privacy.
- Informed consent describes the voluntary choice of a person who has adequate capacity following adequate disclosure. It must be provided in language that meets the person's level of health literacy, and in whatever language is used by the person with dementia. In other words, a person with an elementary school level education who speaks Spanish must be given information on that education level and in Spanish. The researcher needs to assess whether the patient clearly understood the information about the study and the informed consent language.
- Persons who do not have the capacity to provide informed consent may still be able to provide assent, that is, affirmative agreement, to participate. In this case, the person's proxy may provide consent for clinical care, as may a person designated in a research-specific advance directive. However, it is important that the proxy is aware of the patient's desires, as one study found 13 percent of patients who had completed a research advance directive were not willing to participate in future research if they lost the ability to consent.

**Slide 33:**

- Our final topic in this module concerns the topic of elder abuse.

#### Slide 34:

- Elder abuse can occur in any setting: in the home, adult day care, nursing home, long-term care facility, etc.
- Actual definitions of abuse vary by state, but generally, types of elder mistreatment encompass physical abuse, emotional abuse, sexual abuse, neglect, abandonment, financial exploitation, and fraud.
- Each state has its own specific laws delineating who is mandated to report suspicion or evidence of elder abuse. Acts such as the (state-specific) Older Adult Protective Services Acts and the Elder Justice Act (part of Patient Protection and Affordable Care Act) provide guidance, but there are variations with regard to:
  - Who has to report
  - What has to be reported
  - When it must be reported
  - To whom it must be reported
- Consequently, it is imperative that all clinicians be aware of the state and Federal laws and regulations that affect their individual practice.
- Elder abuse is common, yet underreported. An estimated 1 to 2 million older Americans are affected each year.
  - The most recent major studies on elder abuse incidence reported that 7.6 to 10 percent of community-residing study participants experienced abuse in the prior year.
  - A recent literature review found psychological abuse is the most common form, affecting up to 62 percent of the elderly. However, this review reported that up to 23 percent of persons with dementia are victims of physical abuse.
- A U.S. Department of Justice-sponsored survey in 2015 reported emotional mistreatment was reported by 4.6 percent of participants, physical mistreatment by 1.6 percent, and sexual mistreatment by 0.6 percent. However, 5.1 percent suffered potential neglect, and 5.2 percent experienced current financial exploitation by their family.
- Considering only emotional, physical, and sexual abuse, and potential neglect—and excluding financial mistreatment—11 percent of persons reported at least one form of abuse in the prior year.
- Most studies do not include financial abuse from their estimations, but it may in fact be the most common form of elder abuse.

#### Slide 36:

- The U.S. Department of Justice (DoJ) study identified the following risk factors for elder abuse: low household income (46 percent), unemployment or retirement, poor health (22 percent), experiencing prior traumatic event, low levels of social support (44 percent), and needing assistance with activities of daily living (ADL) (38 percent).
- Evidence indicates that people living with dementia are at even greater risk of elder abuse than the general elderly population.
  - Two recent studies indicate that approximately half of people living with dementia experience some kind of abuse, often by their caregivers.

- U.S. DoJ research involving a telephone survey of nearly 6,000 elderly individuals found that a majority (57 percent) of perpetrators of physical abuse were partners or spouses.
  - Half of the perpetrators were using drugs or alcohol at the time of the mistreatment.

**Slide 37:**

- Possible discussion questions:
- How might you help prevent something like this from occurring?
- How might you recognize signs that a person living with dementia might be a victim of this kind of elder abuse?
- What would you do about this?
- It is relevant to note that the MMSE is no longer the automatic tool-of-choice for primary care providers, despite the fact that research programs have used it as the standard for 30 years. Copyright issues now require the payment of more than a dollar for every patient to whom the MMSE is administered. This cost has stimulated the development of other tools that are free to use and are now commonly used in clinical practice, as well as in research protocols. For additional information on what those recommended tools are, please see Module 2.

**Slide 38:**

- Signs of possible elder physical abuse or neglect include:
  - Unexplained weight loss or dehydration
  - Unexplained bruises, burns, scars, or fractures
  - Undetectable or elevated levels of prescribed drugs
  - Dirty clothing or hair, other signs of inattention to hygiene
  - Social isolation
  - Dehydration
  - Malnutrition
  - Pressure ulcers
- It is more challenging for a provider to recognize signs of financial abuse. More often, a care partner or friend or family member will bring his or her concerns to the notice of a primary care provider or health care provider. Red flags that might indicate possible financial abuse can include an observation or statements suggesting that:
  - The person is not being allowed or is unable to spend money the way he or she wants to.
  - Bills are not being paid, or not being paid in a timely manner.
  - The person must sell property or assets.
  - The person's financial situation changes suddenly.
  - The person is making financial decisions that he or she is not otherwise capable of making.
  - The person is receiving care well below what his or her means could afford.
  - The person is afraid or hesitant to speak in front of his or her care partner.
- Of note: Dementia can make it far more difficult to identify elder abuse, as many of the signs of abuse are potentially signs of dementia.

**Slide 40:**

- Different ethnic and cultural groups have their own definitions of elder abuse, but little is known regarding elder abuse of persons with dementia across diverse populations.
- Mistreatment of Black/African American elders is most likely to involve financial exploitation. Studies have shown that financial exploitation disproportionately affects Black/African American older adults versus non-Black/African American older adults. In these cases, the financial abuse is most often perpetrated by someone other than a family member or trusted other, and studies suggest elderly Black/African Americans may be more vulnerable to stranger-initiated scams.
- There are a limited number of studies regarding the mistreatment of Hispanic/Latino elders. One survey found that 40 percent of participating Hispanic/Latino elders had experienced at least one type of abuse and 21 percent experienced multiple types. The study noted that psychological abuse was the predominant form; as such, only 1 percent of survey participants had reported abuse to any kind of Adult Protective Services. Hispanic/Latinos are less likely to report verbal or financial mistreatment compared with non-Hispanic whites.
- Elder persons in the lesbian/gay/bisexual/transgender (LGBT) community are at increased risk of abuse, neglect, blackmail, or financial exploitation by a caretaker because of homophobia. They are also more vulnerable to prejudice and hostility in long-term care facilities.

**Slide 41:**

- There are many patient and provider barriers to reporting:
  - Persons living with dementia may hesitate to report care partner abuse out of fear of the consequences—punitive action for the care partner and possible institutionalization for themselves.
  - Care partners and providers may not be able to identify what actions constitute “abuse”.
- Each state has a law regarding who is required to report suspected elder abuse, neglect, abandonment, or exploitation of the elderly—as well as how much time the clinician has to report potential abuse after becoming aware of it. Failure to report in a timely manner can be associated with monetary fines assessed against the provider. Intentional failure to report can be associated with larger fines and a possible misdemeanor charge along with imprisonment. Generally, all primary care providers and many health care providers are required to document and report suspected elder abuse.

**Slide 43:**

- Two ethical dilemmas:
  - What is the goal? To stop further abuse? Or to punish the abuse?
  - How do you balance confidentiality and trust with need for patient safety?
- Strategies depend on the type of abuse and whether or not the judicial system is involved. Once alerted to possible elder abuse of a person living with dementia that does not require police or judicial intervention, the provider has a few options:
  - Help arrange for respite services for the care partner.
  - Recommend support groups for the care partner (and family) and for the person living with dementia during the early stages of the disease.

- Facilitate the use of home help services.
- Connect the care partner with elder care specialists to help him or her look into adult day care services or possible nursing home placement.
- Recommend counseling to help the care partner learn strategies for safely living with a person with dementia.
- When necessary, the provider should contact adult protective services.

**Slide 44:**

- Numerous ethical, legal, and financial considerations may arise while treating persons living with dementia.
- In many cases, providers—whether primary care providers or health care providers—will not have primary responsibility for comprehensively addressing such issues. But they should alert patients and their families to the need for and importance of obtaining professional legal and/or financial advice.
- When discussing possible participation in a clinical study or trial, it is important for clinicians to objectively review legal and ethical considerations with the patient and his or her care partners.
- All professionals have the responsibility to be alert to the possibility of elder abuse and to properly report any suspicions to appropriate state authorities.

**Slide 45:**

- These items are provided to allow faculty to evaluate what students have learned. The items can be used in several ways including given at the end of the lecture to assess knowledge or as a pre-posttest to assess knowledge gain. These items have face validity. Psychometric testing was not conducted on these items.

**Answers:**

1. c. **Proxy**
2. c. **The ability to make the right decision**

**Slide 46:**

**Answers:**

3. d. **Respect for cultural beliefs**
4. d. **All of the above**