Providing Person-Centered Care:
Can Bioethics Resources Help?

Presented by:
Christine J. Wilson, RN, JD, MS(HCE)

Tyler & Wilson, LLP
5455 Wilshire Boulevard, Suite 1925
Los Angeles, CA, 90036
Tel: (323) 655-7180 Fax: (323) 655-7122
Email: cjw@tyler-law.com

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Meet Alice

- Alice is a mentally competent nursing home resident.
- She has difficulty swallowing during meals, and is prescribed a pureed diet.
- Alice finds the texture of pureed food unappealing and prefers to eat foods of regular texture.
- She would rather risk choking than "having to eat pureed foods the rest of my life."

Meet the Lawyers

- Alice may be competent, but she has choked before, takes a long time to chew food, and often coughs after swallowing.
- Her decision to choose a diet that increases her choking risk may be seen in hindsight as poor judgment indicative of incompetence should there be a negative outcome.
- Alice may understand and accept the risk, but if she should die, it is her family members who could potentially bring a lawsuit.

Meet Bill

- Bill is a mentally competent nursing home resident.
- He likes to have a glass of scotch prior to dinner each night.
- This has been a routine for most of is adult life, and he doesn't want to give up something he truly enjoys just because he moved to a nursing home. His wife agrees that Bill hasn't been himself.

Meet the Lawyers

- Although Bill is competent, alcohol could lead to a serious accident by interfering with his concentration and ability to use his walker.
- Bill may understand and accept the risk, but if there is an adverse outcome, the facility will be on the defensive to prove this in hindsight.

Meet Claire

- Claire is a mentally competent nursing home resident. Subsequent to a mild stroke, she has a history of falling and uses a walker.
- She wants to spend time outside in the fenced-in patio, unsupervised, whenever she desires. She wishes to go for short walks and sit in the sun.
- Claire does not want to be watched "like a small child."

Meet the Lawyers

- Accommodating Claire's request creates potential risks of a fall or a sunburn.
- Staff need to know where all residents are in case of fire or emergency.
- Claire may not be able to notify staff of a fall or medical event if she were outside alone.
- Ultimately, the facility is accountable for Claire's care and safety.

How do we reconcile this tension between quality of care and quality of life?

Consider Claire's desire to spend time outside:

- Traditional approach:

  "Resident will remain free from falls for the next 90 days and will not be permitted to go outside unsupervised."

- New approach:

  "I have a history of falling, but I enjoy being outdoors. I will wear sturdy high-top shoes to assist in walking, and a wide-brimmed hat to avoid sunburn. I will use a sturdy walker and will carry a portable call button."

Patient-Centered Care

- A philosophy that emphasizes the ethical principle of autonomy
- View resident as a member of the care team and focus care around his/her desires and choices
  - In care-planning process, resident is the center of control, not a passive and compliant recipient of care that is deemed best by healthcare professionals
- Relevant at all levels of decision-making
  - Minor issues, like what time to eat dinner
  - Major issues, like decision to decline medical treatment in spite of physician's advice

42 CFR § 483.21 (F 655-661) "Comprehensive person-centered care planning"

Overview:

- LTC facilities must "develop and implement a comprehensive person-centered care plan for each resident, consistent with the resident rights…that includes measureable objectives and timeframes to meet a resident's medical, nursing, and mental and psychosocial needs…"
- Structure
  - (a) Baseline care plans (Phase 2- 11/28/17)
  - (b) Comprehensive care plans
    - (b)(3)(iii) Trauma-informed care (Phase 3- 11/28/19)
  - (c) Discharge planning

42 CFR § 483.21 (F 655-661) "Comprehensive person-centered care planning"

Summary of Significant Developments:

- Facility must develop and implement a baseline care plan for each resident within 48 hours of admission
- IDT must develop and implement a comprehensive, person-centered care plan for each resident within 7 days after a comprehensive assessment; IDT members expanded to include a nurse aide and a member of the nutrition services staff
- Facility may develop a comprehensive care plan instead of an initial baseline care plan and a subsequent comprehensive care plan, but it must be done within 48 hours of admission and meet the same requirements of a comprehensive plan developed later
- Discharge planning should begin early in the care planning process and focus on the resident's discharge goals

42 CFR § 483.21(a) (F 655) Baseline Care Plans

Requirements:

- Include instructions needed to provide effective, person-centered care
- Develop within 48 hours of admission
- Minimum information necessary may include, but is not limited to:
  - Initial goals based on admission orders • Physician orders • Dietary orders • Therapy services • Social services • PASARR recommendation, if applicable
- Provide resident and/or representative a summary including, but not limited to:
  - Resident's initial goals • Summary of resident's medications and dietary instructions • Services and treatments to be administered • Updated information based on the comprehensive are plan, as necessary

42 CFR § 483.21(a) (F 655) Baseline Care Plans

Recommendations:

- Think about how to obtain this information, and how to incorporate the IDT
- IDT participation, although not required, is extremely important
  - An MDS coordinator alone won't have enough time to complete, and can't provide certain helpful insights
- Revise and update plan to meet resident needs until comprehensive care plan is developed
- Consider having care conference with resident and/or representative at admission or within 24 hours

42 CFR § 483.21(b)(2) (F 656 + 657) Comprehensive Care Plans

- Develop within 7 days of completing comprehensive assessment
- Prepared by IDT that includes, but is not limited to:
  - Attending physician
  - RN with responsibility for resident
  - CNA with responsibility for resident
  - Member of food and nutrition services staff
  - "To the extent practicable," resident and resident representative(s)
    - Medical record must include an explanation if IDT deems their participation impracticable, or if they choose not to participate
  - Other appropriate staff or professionals; determined by resident needs or requests
    - Examples: Mental health professional • Chaplain • Pharmacist •. Social worker • Activity professional
- IDT must review and revise plan after each assessment

42 CFR § 483.21(b)(1) (F 656) Comprehensive Care Plans

- Develop person-centered care plan that is consistent with resident rights and includes measureable objectives and timeframes to meet medical, nursing, and mental and psychosocial needs; Plan must describe:
  - The services provided to attain/maintain resident's "highest practicable physical, mental, and psychosocial well-being…"
  - Any services required [by other sections] but not provided due to exercise of resident rights, including right to refuse treatment
  - Any specialized services provided because of PASARR recommendation; if facility disagrees with PASARR findings, indicate rationale in medical record
  - Resident's goals for admission and desired outcomes
  - Resident's preference and potential for future discharge; must document whether facility assessed desire to return to community, and any referrals to appropriate agencies for this purpose
  - Discharge plan, as appropriate

42 CFR § 483.21(b)(3) (F 658 + 659) Comprehensive Care Plans

- Services provided must:
  - Meet professional standards of quality
  - Be provided by qualified persons in accordance with resident's written care plan
  - Be "culturally-competent and trauma-informed" (Phase 3)
    - Goal: minimize triggers and re-traumatization
    - Included to address unique needs of holocaust survivors, war survivors, persons who have experienced disasters or other profound traumas

42 CFR § 483.21(c)(1) (F 660) Discharge Planning

- Discharge planning is incorporated into the comprehensive care planning process (42 CFR § 483.21(b)(1)(iv))
  - Goal: Considering discharge as early as possible helps ensure residents have "every opportunity to attain the highest quality of life"
- Discharge planning process should focus on:
  - Resident's discharge goals
  - Preparing residents to be active partners and effectively transitioning then to post-discharge care
  - Reducing factors that lead to preventable readmission
- Must include resident and/or representative(s) in planning process and inform them of final plan
  - Helpful to include MDS or care plan coordinator

42 CFR § 483.21(c)(1) (F 660) Discharge Planning Process

- Regular re-evaluation or resident to identify changes; update or modify plan as needed
- Involve IDT in the "ongoing process" of developing a discharge plan
- Consider availability of a caregiver or support-person, and capacity and capability of resident and caregiver to perform required care
- Document that resident was asked about interest in returning to community
  - If interested, document any referrals to appropriate agencies
    - In compliance with *Olmstead v. L.C. ex. Rel. Zimring* (1999) 527 U.S. 581, facility and community partners are encouraged to strive to serve individual in preferred setting, when feasible
  - Update discharge plan and comprehensive care plan with any information received from referrals
  - If discharge is infeasible, document who made that determination and why
- SNF only: for resident transferred to to another SNF, or discharged to another level of care, assist in selecting post-acute care provider using standardized assessment data, quality measures data and data on resource use to the extent available

42 CFR § 483.21(c)(2) (F 661) Discharge Summary

Provide resident a discharge summary that includes, but is not limited to:

- Recap of stay, including: diagnoses • Course of illness/treatment or therapy • Relevant lab, radiology, and consultation results • Other relevant information, as appropriate
- Final summary of resident's status that is available (with resident's permission) to receiving care provider; summary should include items described in 42 CFR § 483.20(b)(1)
  - Contact information of practitioner, resident, and representative • Advance directive information • Special instructions/precautions • Comprehensive care plan goals
- Reconciliation of pre-discharge medication with post-discharge medication (prescribed and OTC)
- Post-discharge plan of care developed with resident and representative; must indicate:
  - Where resident plans to reside • Any arrangements for follow-up care • Any post-discharge medical and non-medical services

42 CFR § 483.21 (F 655-661) Implementation

Section 483.21 was implemented in Phase 1 (11/28/16) with the following exceptions:

- § 483.21(a) (F 655) Baseline care plan
  - Implemented in Phase 2 (11/28/17)
- § 483.21(b)(3)(iii) (F 659) Trauma informed care
  - Implemented in Phase 3 (11/28/19)

Care Planning Process

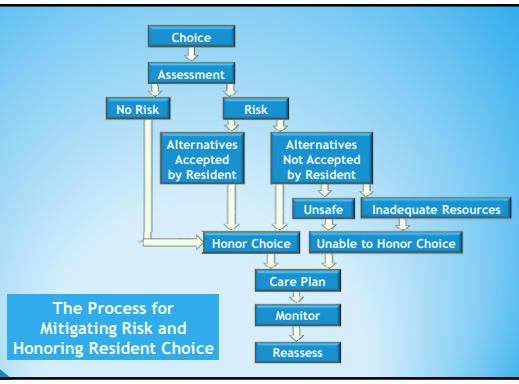
- Goal:
  Honor resident choices that influence quality of care and quality of life, while mitigating risks
- Purpose:
  Documentation shows facility performed its due diligence with respect to:
  - Assessing the resident's functional abilities and decision-making capacity
  - Weighing potential outcomes (positive and negative) of respecting and aiding the the resident in pursuit of choices
  - Reviewing potential outcomes (positive and negative) of preventing the resident from acting on a choice

Care Planning Process Culture Change

- Balanced, person-centered approach to assessing risk
  - Consider potential positive and negative outcomes
  - Consider quality of care issues and quality of life issues
  - Respect resident's right to self-determination as equal to facility responsibility for safety
- CMS encourages facilities to explore ways to allow resident or resident representative to access care plan regularly using technology
- Consider an "I" care plan:
  - "I have trouble with…"

Suggested Care Planning Process

1. Identify and clarify the resident's choice
2. Discuss choice and options with the resident or representative
3. Determine how to honor the choice
4. Communicate the choice through the care plan
5. Monitor and revise the plan
6. Quality Assurance and Performance Improvement (QAPI)



Care Planning Process
1. Identify and clarify the resident's choice

- Interview and observe
  - Over coffee, not over a clipboard
  - Staff to resident ratio:
    - It's not a firing squad
    - Who needs to be present?
  - Facility may become resident's home
  - Environment:
    - Temperature
    - Distractions
    - Privacy
    - Comfort
- Suggested questions:
  - What is your normal routine?
  - What relationships are important in your life?
  - What activities do you enjoy?
  - What are your preferences regarding medication administration? lighting? noise?
- Try to learn context/motivation for individual preferences
  - Example: Ms. A prefers a cane to a walker because walkers make her feel old and disabled; she would rather risk a fall than have such a negative self-image.

Care Planning Process
1. Identify and clarify the resident's choice

- Repeat back key information to confirm that both parties understand each other, that resident understands concerns and likely outcomes of choice, and that resident exhibits process of reasoning coupled with information that supports informed decision
- Discuss resident's goals with family/representative; if unavailable, staff can step in
  - CNAs and floor nurses know routine and what works
- Cognitive impairment/difficulty communicating
  - Capacity assessment is not all or nothing
  - Even major neurocognitive impairment is insufficient alone to justify restriction of rights, absent finding of significant functional impairment of reasoning process
  - Emotional responses and actions are a form of communication and expression of preference
  - Use simple, direct language, gestures, pictures, or written words to determine if an unmet need drives a specific behavior

Documentation
(Adapt to your form or adapt your form)

1. Identify and clarify the resident's choice		Date	Date	Initials
What is resident's preference that is of concern?	Alice prefers to eat foods of regular texture rather than the recommended puree texture. She would rather risk choking than "have to eat pureed foods the rest of my life."	9/5		AB
Why is it important to the resident?	Texture/taste of pureed food is unappealing. Especially since she retired, having healthy, nicely prepared and presented meals has been a high priority for her. Pureed foods don't fit into that preference.	9/5		AB
What is the safety/risk concern?	Alice has choked once, takes a very long time to chew food, and often coughs after swallowing.	9/5		AB
Who representing the resident was involved?	Alice, son and daughter-in-law. Son has durable POA for health care; feels Alice should follow the advice of professionals. Alice, who is competent, disagrees.	9/5		AB
Who on care team was involved in these discussions?	Director of Nursing (DON); daytime RN; primary CAN; SLP; Dietician	9/5		AB

Care Planning Process
2. Discuss choice and options with the resident or representative

- Potential positive and negative outcomes of each alternative
- Explain that resident may still have legal right to make choices and refuse treatment
- Accommodating risky requests:
  - Reducing frequency
  - Alternative with fewer potential adverse consequences (context key)
  - May still want original choice
  - May choose not to do original choice
- Example: Ask Ms. A to agree to use a walker to get to a more distant destination where a cane is not feasible, then switch to her cane once there.
- Great opportunity to assess decision-making capabilities
- Cognitive impairment/difficulty communicating
  - Simplify information; present in multiple forms (written, verbal, picture); ask simple questions to assess understanding of material
  - Example: Ask Ms. A to explain potential consequences if she continues with cane; does she comprehend risk?
    - May need to repeat, clarify, modify, reassess multiple times
- Reassessment
  - Resident can change preference
  - Capacity may fluctuate over time
  - Reassessment frequency should be individualized

Documentation

2. Discuss choice and options with the resident or representative		Date	Date	Initials
What are potential benefits to honoring choice?	Increased caloric consumption, greater satisfaction, higher quality of life, and liberalization conforms to current standards of practice.	9/5		AB
What are the potential risks to honoring the choice?	Risk of choking during meals.	9/5		AB
What alternative options were discussed?	1) Working to improve flavor and presentation of pureed food. 2) Trying a modified texture vs pureed process level. 3) Working w/ SLP and dietician to identify: preferred foods that are safer w/o being pureed; which foods are deemed very unsafe if texture not modified; foods Alice prefers from those options. 4) Teach Alice the universal sign for choking, so she could get help quickly if needed. 5) Alice will participate in dysphagia therapy to improve chewing and swallowing. 6) Always have at least one soft "preferred" food, such as a cream soup, available.	9/5		AB

Documentation

2. Discuss choice and options with the resident or representative		Date	Date	Initials
What education about the potential consequences of the choice, alternative actions/activities was provided?	Asked Alice to discuss with staff the risks of eating regular textured foods, so they ensure she understands. Social worker explained to son that POA for HC doesn't allow him to make choices for mom while she's capable to choose. Care community is responsible for determining and meeting Alice's preferences. Social worker explained to son that Alice still retains decision-making authority and is working with staff to come up with diet that honors most choices while eliminating the most dangerous foods. Son agreed it's important to honor choices as long as staff think mutually-agreed plan will be okay.	9/5		AB
Who was involved in these discussions?	Son; DON; Daytime RN; primary CNA; SLP; Dietician; Social worker	9/5		AB

Care Planning Process
3. Determine how to honor the choice

- Many requests can be honored by making a plan to mitigate risks or offer similar activity
  - Example: Ms. A agrees to use walker for long distances, but will have a cane left in the activity room so that she can use it while there.
- Compare resident choice to resident condition to determine potential risks
- Clearly explain why you cannot honor a choice that poses a significant danger, or requires significant resources
  - Example: Resident who cannot manage alone wants to leave for a few hours regularly to go shopping accompanied by a staff member.
  - Try to accommodate through alternative means, such as arranging for family member to take the resident shopping.

Documentation

3. Determine how to honor the choice		Date	Date	Initials
Of all options considered, is there one that is acceptable to the resident (or representative) and staff? Which one?	(1) Alice will work w/ SLP and dietician to select foods she prefers that are safer to eat w/o being pureed. They will explain which foods are unsafe to eat if texture is not modified. On days when those high-risk foods are being served, staff will ensure that the alternate menu option is something Alice likes and can eat w/ regular or soft texture w/ less risk. (2) Dietician agreed to try to make her plate more appealing in its presentation. (3) Asked family to bring some of Alice's favorite, naturally soft foods. (4) Alice will participate in dysphagia therapy to improve chewing and swallowing.	9/5		AB
If no option is acceptable, what is the reason for denying choice? What are the consequences? What actions will be taken?				
Who was involved in these discussions?	Alice; Son; Daughter-in-law; Dietician; SLP; CNA	9/5		AB

Care Planning Process
4. Communicate choice through care plan

- Mutual decision:
  - Plan out specific steps to support choices
  - Resident or representative participates in care planning process and is aware of steps
- Role of IDT
  - Not practical for all IDT members to attend in-person meeting
  - Can participate via written (email), phone, or video communication
  - Most important to have direct care staff present
  - If pressed for time, try having CNAs attend for 5 minutes but keeping as a goal to have them participate in whole conference

Documentation

4. Care planning the choice		Date	Date	Initials
What specific steps will be taken to assure both resident and staff follow the agreed to option? Document a brief summary of the plan here and put the detailed goal and approaches in the care plan.				
Was care plan updated?	Yes	10/8		AB

Care Planning Process
5. Monitor and revise the plan

- Monitor progress, effects on resident well-being, ongoing desire for particular choice
- Revise as needed and desired by resident
- Plans and staff should be flexible; residents have a right to change their minds
- Monitoring should not be limited exclusively to auditing forms or records
  - Must include observing and assessing at appropriate frequency given resident and choice
- Regular re-evaluation required for discharge plan and care plan
- Be sure to initial and date any changes

Documentation

5. Monitoring and making revisions to the plan		Date	Date	Initials
How often will this decision be formally reviewed (recognizing that informal monitoring may take place on a daily basis)?	Plan is to spend 1 week going through the menus to identify high-risk foods and acceptable alternatives for Alice. This coincided with the beginning of the next 5-week menu rotation. Primary CNA will document Alice's comments regarding food, in addition to routine caloric assessment. SLP and dietician will meet with Alice and CNA each week for the 5 weeks to see how the new menu is working. SLP treatment plan for dysphagia will be initiated.	9/5		AB
Who has primary responsibility for monitoring the implementation?	CNA will track Alice's comments. Dietician to track consumption.	9/5		AB
Was there another option considered to be the "next best step" that would be implemented next?				

Care Planning Process
6. QAPI

- Review trends, especially when a resident is routinely denied a choice, or when QAPI team identifies patterns of care practices that can be improved
- Areas to consider for specific trends:
  - Denial of requests routinely for more than one resident
  - Failure to document assessments of decision-making capacity with respect to considering requests
  - Areas where community can't accommodate preferences and action plans for future growth
  - Feedback from residents and family members
- If several residents routinely make similar high-risk requests, care team may wish to refer to QAPI team to determine a general policy rather than repeatedly make individual determinations

Documentation example for Bill

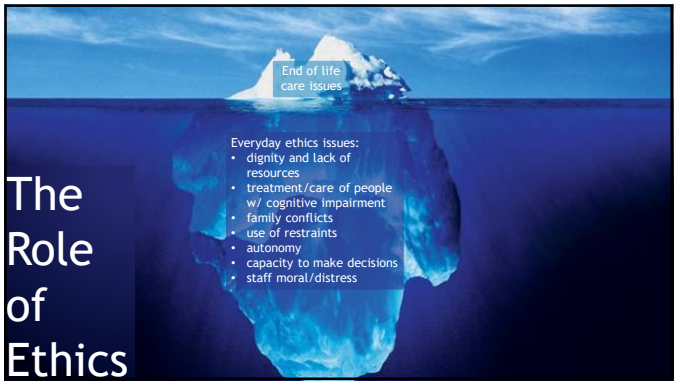
1. Identify and clarify the resident's choice		Date	Date	Initials
What is resident's preference that is of concern?	I want to have a glass of scotch before dinner each night. I want to keep the alcohol in my room and pour myself a drink whenever I desire.	3/25		CD
Why is it important to the resident?	Enjoying an occasional drink at the end of the day has been an integral part or my adult routine and I don't want to give up something I truly enjoy just because I'm living in a nursing home. My wife agrees that I haven't been myself since I was told I couldn't drink when I wanted.	3/25		CD
What is the safety/risk concern?	It may interfere with my concentration and ability to use my walker, leading to an accident. Keeping alcohol in my room may place other residents at risk.	3/25		CD
Who representing the resident was involved?	Bill and his spouse	3/25		CD
Who on care team was involved in these discussions?	Social worker; RN	3/25		CD

2. Discuss choice and options with the resident or representative		Date	Date	Initials
What are the potential benefits to honoring the choice?	Honoring my choice enhances dignity and autonomy. It also allows me to participate in my daily routine.	3/25		CD
What are the potential risks to honoring choice?	Potential for falling; risk to other residents if alcohol kept in room.	3/25		CD
What alternative options were discussed?	Staff store the scotch and pour 1 drink before meals at my request. I could eat a small snack with my drink, so I'm not drinking on an empty stomach. My wife often visits, and suggested I have a drink with her after dinner when she visits; this way I won't be alone and will be less likely to fall on my way to dinner after I've had a drink.	3/25		CD
What education about the potential consequences of the choice/alternative actions provided?	Nurse shared with me her concerns that older adults don't metabolize alcohol as quickly as younger adults do, so alcohol stays in their systems longer and has a greater potential to exacerbate an unsteady gait.	3/25		CD
Who was involved in these discussions?	Bill; His spouse; Social worker; RN	3/25		CD

3. Determine how to honor the choice		Date	Date	Initials
Of all options considered, is there one that is acceptable to the resident/representative and staff? Which one?	Although I don't like the idea of having to ask for a drink and not store the alcohol in my room, I understand the risk to others. Nursing will assess walking safety to dining room after I've had a drink to ensure I am not at risk for a fall. I agree to these recommendations. I also agree to have a snack with the drink and tell the nurse if I want more than one drink.	3/25		CD
If no option is acceptable to all, what is the reason for the denial of resident choice? What is/are the consequences or actions that will be taken?				
Who was involved in these discussions/decisions?	Bill; Social worker; RN	3/25		CD

4. Care planning the choice		Date	Date	Initials
What specific steps will be taken to assure both resident and staff follow the agreed to option? Document a brief summary of the plan here and put the detailed goal and approaches in the care plan.	Alcohol will be stored in the medication room to prevent risk to other residents and so that nursing staff may be aware of what the resident is drinking. Resident will have a snack with his drink to slow metabolism and nursing will assess walking safety.	3/25		CD
Was care plan updated?				

5. Monitoring and making revisions to the plan		Date	Date	Initials
How often will this decision be formally reviewed (recognizing that informal monitoring may take place on a daily basis)?	The plan will be reviewed in 2 weeks after I begin having an alcoholic drink before dinner.	3/25		CD
Who has primary responsibility for monitoring the implementation?	RN	3/25		CD
Was there another option considered to be the "next best step" that would be implemented next?	No	3/25		CD



Ethics Concerns

- Autonomy: Protecting individual rights, self-determination and choice
- Beneficence: The course of action that will give the greatest benefit
- Non-Maleficence: The course of action that will cause the least harm
- Justice: Fairness to the patient with consideration of the needs and rights of others

Ethics and Bioethics Resources

- Ethics committees and lawyers
  - Solve problem before it gets to legal department
  - Create satisfied residents and families
  - Support autonomy, reduce frustration
  - Reduce staff dissatisfaction, distress, and turnover
- Bioethics resources can alleviate consumer and regulatory concerns
  - Outside input
  - Evaluation of specific cases
  - Resource for physicians and facility staff
  - Mediation of family/resident issues
  - Staff and resident/family education

Ethics Committee

- Health providers and others who review ethical issues that arise within nursing facility and make recommendations regarding difficult healthcare decisions
  - Medical Director ● Other MD ● Director of Nursing ● Other nurses ● Social worker ● Clergy/chaplain ● Bioethics consultant ● Community member ● Ombudsman
- Ethics committee may serve as a resource for education and policy advice
- Also a resource to mediate family issues and give an opportunity for all to be heard
- A professional ethics consultant may lend support to person-centered care based upon recognized ethical principles

Ethics Committee vs IDT

- Ethics committee:
  - Not required by statute
  - Educational and advisory; no authority to initiate treatment
  - Functions confined exclusively to ethical matters
  - Recommendations are not mandatory, but are given significant weight
  - Members should include MD, RN other health care providers

Ethics Consultants

- Medical background and training/experience in health care ethics/bioethics
- Consult per facility policies and needs
- Educational programs
- Assist to form and implement ethics committee
- Often a “team” but not always
- May provide written ethics consultation

Additional Resources

- Everything you've ever wanted to know from CMS but were afraid to ask
- Website: https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Nursing-Homes.html
- Contains new State Operations Manual with Interpretive Guidelines, Revised F Tags and more!

Providing Person-Centered Care:
Can Bioethics Resources Help?

Thank you for joining us!

Any questions?

Presented by:
Christine J. Wilson, RN, JD, MS(HCE)
Tyler & Wilson, LLP
5455 Wilshire Boulevard, Suite 1925
Los Angeles, CA, 90036
Tel: (323) 655-7180 Fax: (323) 655-7122
Email: cjw@tyler-law.com

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