

Facing Risk: Care planning for resident choice and self-determination

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TASK FORCE PROJECT

Issue is Choices and Safety How Do These Fit?

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- Federal regulations include:
 - Right to:
 - Participate in planning care
 - Refuse treatment
 - Make choices about things that are important to the person
 - Receive good care from knowledgeable staff
 - Be free from accidents
 - Maintain or improve functioning

The Issues

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- Nursing homes have been “medical model” for decades
- They have seen the care planning process as something they do in behalf of the best interests of residents, in the old way, the residents’ choices are not even sought
- Now culture changing homes are trying to honor choices, and many are afraid the surveyors will punish them with deficiencies

Quality of Life and Quality of Care

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- Are supposed to be equally important in the regulations
 - But in reality quality of life has often been given second place to a home’s desire to focus solely on needed care without regard to preferences and choices
 - Survey teams have to make hard choices when they interview a resident and learn of choices that are “risky.” Does the home honor the choice, do they deny? Do they do something in between? Are they compliant for that resident and for that issue?

What Happens When

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- What a resident wants may lead to a decline or a negative outcome?
- Do people have OR DO THEY NOT HAVE the rights they had in their homes?
- There is not one simple answer to that
- You have a key role in improving quality of life, in bringing culture change values and practices to providers. Even when you are not there, they think of you and fear you.

An Institutional Example

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- A resident wants to refuse his pill
- Nurse becomes worried about consequences and engages in behaviors:
 - Cajole, “come on Walter, just take it this one time, for me”
 - Frighten, “Now Walter, you will get terrible swelling in your legs and it will be hard for you to breathe if you don’t take this pill”

Example (continued)

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- Hide it, crush and add to some food
- Threaten, "Do you want to die? If you don't take this, you might die?"
- What is not often done is have a chat to find out exactly why and what can be agreed to together

Outcomes

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- Emphasis of both providers and regulators is most often on physical outcomes, new weight loss, pressure ulcers, decline in walking, a fall, etc.
- Very little consideration is given to the negative effects psychosocially of having preferences ignored on a daily basis, the effects to mood, self-esteem, dignity.
- WHAT DO WE DO ABOUT IT?

CMS is in favor of culture change

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- Thomas Hamilton applauds it and also "efforts state survey agencies are making to help providers figure out issues of compliance with culture change practices."
- I hear frequently how a survey agency is helping or a survey team is applauding culture change enhancements
- We are here today to discuss care planning for choice and safety

How Much Choice? How Much Safety?

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- Provider must try to balance how much choice and how much safety
- Issue is riskier choices
- Surveyors must come in and evaluate the provider's decision if they are honoring a risky choice – did they do all they reasonably could to mitigate disaster – was this choice so dangerous that it should not be honored

Rothschild Person-Centered Care Planning Task Force

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Providers

Advocates

Surveyors

Associations

Lawyers

Rothschild Person-Centered Care Planning Task Force

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- A group of over 50 stakeholders formed and has been working for two years on the issue of honoring choice and planning care to mitigate risk.
- Includes several nursing groups, lawyers who sue nursing homes, advocates, ombudsmen, survey directors and former surveyors. CMS is interested in this group's work and results.

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The Group's Work

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- Developed a process tool to help providers
- Goal, to figure how to honor choice and when it can't be done
- Tool has steps to follow along with a form to fill out – when some preference is considered “risky” – not for all preferences
- Also developed scenario examples

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Process for Mitigating Risk and Honoring Choice

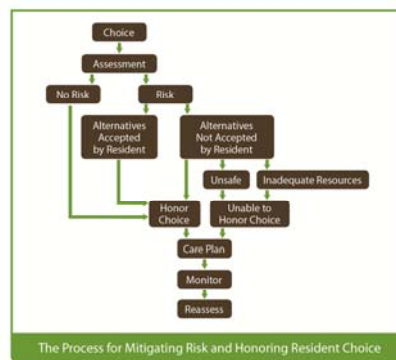
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- Weighing, with the person, the potential outcomes (positive and negative) of both respecting and aiding the person in the pursuit of choices
- Reviewing the potential outcomes (positive and negative) of preventing the person from acting on choices

Process for Mitigating Risk and Honoring Choice

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- Step 1: Identify and clarify the person's choice
- Step 2: Discuss the choice and options
- Step 3: Determine how to honor the choice (and which choices are not possible to honor)
- Step 4: Communicate the choice through the care plan
- Step 5: Monitor and make revisions to the plan
- Step 6: Quality Assurance & Performance Improvement



The Process for Mitigating Risk and Honoring Resident Choice

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Step 1: Identify and Clarify the Person's Choice

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- Interview and observe the person. Review the person's history to obtain detailed information about the choice .
- Is the choice a one-time request or a refusal?
- What is the reason the person desires this choice?
- Repeat back to the person your understanding of what she or he desires to choose or refuse.
- Determine if the person's choice presents a perceived risk or safety challenge to the person or others.
- Are there other alternatives that might be more readily implemented that are acceptable to the person?

| I. IDENTIFY AND CLARIFY THE RESIDENT'S CHOICE | | | | Date | Date | Date | Initials |
|---|--|--|--|------|------|------|----------|
| What is resident's preference that is of concern? | | | | | | | |
| Why is this important to the resident? | | | | | | | |
| What is the safety/risk concern? | | | | | | | |
| Who representing the resident was involved? | | | | | | | |
| Who on care team was involved in these discussions? | | | | | | | |

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| I. IDENTIFY AND CLARIFY THE RESIDENT'S CHOICE | | Date | Date | Date | Initials |
|---|--|------|------|------|----------|
| What is resident's preference that is of concern? | Mr. Eisenstadt desires to spend time daily outside in the fenced-in patio unsupervised, whenever he desires. He wants to be able to go for short walks as well as sit in the sun. | 9/18 | | | RB |
| Why is this important to the resident? | He says he likes to leisurely read the paper and enjoy the sights and sounds of being outdoors and the sunshine like he always did at his home, and doesn't want to be watched "like a small child." | 9/18 | | | RB |
| What is the safety/risk concern? | Mr. Eisenstadt walks with a walker subsequent to a mild stroke. He has had one fall in the dining room 6 months ago, with no serious injuries. | 9/18 | | | RB |
| Who representing the resident was involved? | Mr. Eisenstadt manages his own affairs. | 9/18 | | | RB |
| Who on care team was involved in these discussions? | Margie Statler, LSW, Renee Blankenhorn, RN | 9/18 | | | RB |

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Step 2: Discuss the Choice and Options

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- The intent of this step is for the team and person to reach a decision that is mutually acceptable.
- Educate about the potential outcomes of respecting and aiding in the pursuit of choice & potential outcomes of preventing the person from acting on choice.
- Person has the regulatory right to make choices and to refuse treatment.
- Offer ways in which you can accommodate the choice and also mitigate potential negative consequences as much as possible.

| II. DISCUSS THE CHOICE AND OPTIONS WITH THE RESIDENT | | Date | Date | Date | Initials |
|---|--|------|------|------|----------|
| What are the potential benefits to honoring the resident's choice? | | | | | |
| What are the potential risks to honoring the resident's choice? | | | | | |
| What alternative options were discussed? | | | | | |
| What education about the potential consequences of the choice alternative actions/ activities was provided? | | | | | |
| Who was involved in these discussions? | | | | | |

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| II. DISCUSS THE CHOICE AND OPTIONS WITH THE RESIDENT | | Date | Date | Date | Initials |
|---|---|------|------|------|----------|
| What are the potential benefits to honoring the resident's choice? | Honoring the choice enhances dignity and autonomy; provides circadian rhythm adjustment from sunshine; and provides opportunity for exercise. | 9/18 | | | RB |
| What are the potential risks to honoring the resident's choice? | Potential fall and sunburn risk. Also staff need to know where all residents are, in case of a fire or other emergency. Staff were also concerned in case he had a fall or medical event how he would be able to notify staff if he is outside alone. | 9/18 | | | RB |
| What alternative options were discussed? | It was proposed that Mr. Eisenstadt be outside only when activity programs were occurring on patio. Rejected by Mr. Eisenstadt because he said that he wants to be in charge of when he uses patio. | 9/18 | | | RB |
| What education about the potential consequences of the choice alternative actions/ activities was provided? | Nurse educated Mr. Eisenstadt about residual weakness from stroke to both the left leg and hand, and how the outdoor sidewalks might prove difficult for him to propel his walker safely. Also his medications make him more susceptible to sunburn. | 9/18 | | | RB |
| Who was involved in these discussions? | Mr. Eisenstadt, Margie Statler, LSW, Renee Blankenhorn, RN | 9/18 | | | RB |

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Step 3: Determine how to Honor the Choice

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- Some requests are potentially too harmful to other people to honor
- Other requests can and should be honored
- Document in the care plan the decisions reached and any plans for mitigation, alternatives, or reason for denial.
- List everyone who has been involved in these discussions.

| III. DETERMINE HOW TO HONOR THE CHOICE | | Date | Date | Date | Initials |
|---|--|------|------|------|----------|
| Of all options considered, is there one that is acceptable to the resident /representative and staff? Which one? | | | | | |
| If no option is acceptable to both the resident /representative and staff, what is the reason for the denial of resident choice? And what is /are the consequences or actions that will be taken? | | | | | |
| Who was involved in these discussions / decisions? | | | | | |

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| III. DETERMINE HOW TO HONOR THE CHOICE | | Date | Date | Date | Initials |
|---|---|------|------|------|----------|
| Of all options considered, is there one that is acceptable to the resident/representative and staff? Which one? | Mr. Eisenstadt rejects the option of going outside only when activities staff are holding programs. He retains his original desire to go outside whenever he wants. Care team agreed to honor this request and take steps to maximize safety. PT Peter Hall asked to assess walking safety and make recommendations. He recommended gait training outside, switching walker to a wheeled walker with a seat and brake, and purchase by resident of high topped sturdy shoes to mitigate ankle weakness. Mr. Eisenstadt agreed to these recommendations. He also agreed to wear a hat and use sunscreen on sunny days. | 9/18 | | | RB |
| If no option is acceptable to both the resident/representative and staff, what is the reason for the denial of resident choice? And what is/are the consequences or actions that will be taken? | | | | | |
| Who was involved in these discussions/decisions? | Mr. Eisenstadt, Peter Hall, PT, Margie Statler, LSW, Renee Blankenhorn, RN | 9/18 | | | RB |

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Step 4: Care Planning the Choice

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- Decide with the person the specific steps the staff will take to support that choice.
- Person participates in the care planning process and is made aware of the steps of the plan.
- Record the steps the staff will take to assist the person and mitigate potential negative outcomes to the extent possible.

| IV. CARE PLANNING THE CHOICE | | Date | Date | Date | Initials |
|---|--|------|------|------|----------|
| What specific steps will be taken to assure both the resident and the 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? | | | | | |

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| IV. CARE PLANNING THE CHOICE | | Date | Date | Date | Initials |
|---|--|------|------|------|----------|
| What specific steps will be taken to assure both the resident and the 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. | Mr. Eisenstadt will purchase sturdy high top shoes to assist in walking and a wide-brimmed hat. PT is providing wheeled walker with a brake and will hold training sessions on how to walk safely outside with the new walker. He agreed to use sunscreen as needed. He agreed not to go outside alone until after the shoes, hat, new walker and PT training occurred. Staff purchased a portable call button on a lanyard for him to take along when he signs out to go outside alone. | 9/18 | | | RB |

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Step 5: Monitoring and Making Revisions

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- Monitor the progress of the plan and its effects on the person's well-being.
- Assess ongoing desire of the person to continue with the initial choice.
- Care plans should be flexible; as people are allowed to change their mind.

| V. MONITORING AND MAKING REVISIONS TO THE PLAN | | Date | Date | Date | Initials |
|---|--|------|------|------|----------|
| How often will this decision be formally reviewed (recognizing that informal monitoring may take place on a daily basis)? | | | | | |
| Who has primary responsibility for monitoring the implementation? | | | | | |
| Was there another option considered to be the "next best step" that would be implemented next? | | | | | |

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| V. MONITORING AND MAKING REVISIONS TO THE PLAN | | | | | |
|---|---|------|------|------|----------|
| | | Date | 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 two weeks after Mr. Eisenstadt begins going outside alone. | 9/18 | | | RB |
| Who has primary responsibility for monitoring the implementation? | Peter Hall, PT, Margie Statler, LSW, Renee Blankenhorn, RN | 9/18 | | | RB |
| Was there another option considered to be the "next best step" that would be implemented next? | No | 9/18 | | | RB |

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Step 6: Quality Assurance and Performance Improvement

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- Areas for the QAPI team to consider for specific trending:
 - Denial of requests on a routine basis for more than one person
 - Failure to document assessment of decision-making capacity as related to consideration of requests
 - Areas of community inability to accommodate preferences and action planning for future growth
 - Resident and/or family council feedback
 - Trending of concerns, complaints, and compliments
 - Perceived high level risk activities, community responses, and risk management review

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Case Study Example

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- Mark Arnold
- 82. Diagnoses of COPD, fall with history of injury (multiple falls, one injury). Mild cognitive impairment, which has been stable for several years and not progressed and usually expresses itself when s/he is frustrated, with short temper.
- Was a business leader, well thought of in the community, very active and engaged in lots of civic and philanthropic activities.

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Case Study Example

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- RN: Nurse Betty
- Daytime supervisor over 6 living areas.
- Cares about the residents, but the administration is considering whether she can do with fewer staff on daytime shift because of the presence of the activity personnel, so she is worried about ability for her staff to supervise the residents

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Case Study Example

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- Son: Jon
- Lives 2 states away. Comes to visit 2-3 times a year (as he did for years before Dad moved into Sunshine Manor).
- Somewhat in denial about his various conditions and aging process. Still thinks of him as the go-getter who was going to make the world a better place for everyone.
- He has formal power-of-attorney (but not durable POA for Healthcare- no one has that).

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Case Study Example

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- Daughter in law: Inez
- Loves her father in law, but knows he can be stubborn and likes to do things his own way. Feels he often doesn't listen to others (including her, who just has his best interests at heart). Her husband has never been very close to his father.

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Case Study Example

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- CNA: Sandy
- Caring person who wants to do everything right for the resident s/he cares for—wants them to have the best care possible. Is overworked (but who isn't these days). Tries to stop and spend a few minutes with each resident, but some days it just doesn't happen cause s/he's got so much to do.

Case Study Example

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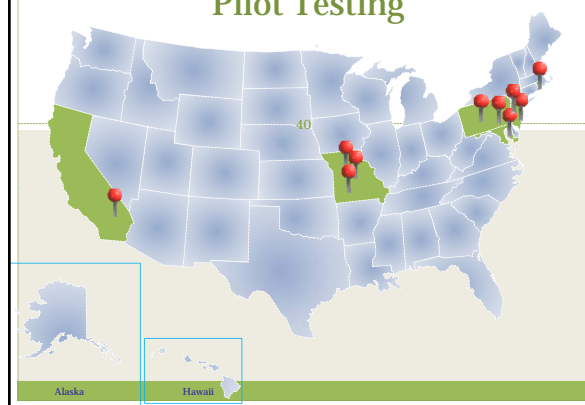
- PT: Jan
- Contract staff, is paid by the amount of therapy time provided (which doesn't include time for writing up notes).

Case Study Example

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- Step 1: Identify and Clarify the Person's Choice
- Step 2: Discuss the Choice and Options
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Pilot Testing



Pilot Testing

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- Process was developed with input from Task Force (over 50 health care and legal experts)
- Process reviewed by 5 health care professionals and 10 state surveyors who were not part of the Task Force process
 - Content/Language of process was modified based on their comments
- 11 communities in 6 states are using the process in collaboration with at least two residents who would like to make a choice the staff feel involves risk
 - Communities will complete an online survey and participate in a focus group to discuss their opinions and the outcomes of the care planning process

Pilot Testing

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- 11 communities participated, 8 responded
- Used with over 20 elders (ranging from 2-more than 5 per community)
- Used for 27 different preferences
- Tool was used most often to address food-related issues: diet consistency, fluid restriction, or diabetic diet.
- Unattended access to the outside was the next more frequent use.
- Other common preferences included refusal of treatment or medications, smoking, bed alarm use

Pilot Testing

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- All of the care communities indicated they were likely or definitely going to continue to use the PCCP Tool.
- One community has decided to incorporate into their electronic health record.
- Another wished there more information on assessing resident decision-making capacity was incorporated into the Toolkit.