

PERSON CENTERED CARE PLANNING | HONORING CHOICE WHILE MITIGATING RISK

The purpose of the Rothschild Person-Centered Care Planning process is to support long term care communities in their efforts to honor residents' choices and preferences that influence quality of care and quality of life, while mitigating potential risks associated with those choices and preferences. This process is specifically aimed at care planning when the choice carries sufficient risk that the community is considering not honoring the person's wishes.

STEP 1: IDENTIFY AND CLARIFY THE PERSON'S CHOICE AND PREFERENCES

Interview the person using the PELI and observe the person. Review the person's history to obtain detailed information about the nature and extent of the choice that the person wishes to make.

- ✓ Is the choice a one-time request or a long-term refusal?
- ✓ Is it consistently expressed or perhaps a brief reaction to some other concern?
- ✓ Repeat back to the person your understanding of what she or he desires to choose or refuse, to confirm both parties understand each other.
- ✓ Discuss the choice with the person's representative
- ✓ Record the nature and extent of the choice(s) the person wishes to make on the Documentation Form and place in the health record.

STEP 2: DISCUSS THE CHOICE AND OPTIONS WITH THE PERSON

Discuss with and educate the person about the potential outcomes, both positive and negative of respecting and aiding the pursuit of her or his choices and preferences, as well as the potential negative or positive outcomes of preventing the person from acting on his or her choices. The intent of this step is for the team and person to explore options that might be mutually acceptable. This is an opportunity for the person and multidisciplinary care team to engage in dialogue so that the person can explain what is important to him or her.

- ✓ Offer ways to accommodate the choice and also mitigate potential negative consequences as much as possible.
- ✓ Explain why a requested choice cannot be honored if it poses significant danger to others.
- ✓ After learning of and considering the potential consequences, the person may decide not to take his or her initial requested action, to curtail its frequency, or to select an alternative with fewer potential adverse consequences, or may continue to desire the original choice.
- ✓ Record the conversations with the person and representative on the Documentation Form and place it in the health record. Describe the discussion of the risks and benefits and whether the person exhibited adequate decision-making capacity related to the choice in question. Provide a record in writing about what was presented to the person and what the person's response was.

STEP 3: DEVELOP THE PLAN TO HONOR THE CHOICE AND PREFERENCE

Once a decision is reached as to how the team will accommodate a choice to maximize the person's well-being, the team will work out with the person the specific steps the team will take to support that individual's choice or preference. Have a copy of the person's most important preferences on hand for the meeting. The person

participates in the care planning process (as well as every step of this process for honoring choice) and is made aware of the steps of the plan.

- ✓ Ensure the participation and input of the direct care staff as they have the most contact with the person.
- ✓ Record the decisions reached and the steps the staff will implement to assist the person and mitigate potential negative outcomes to the extent possible.

STEP 4: MONITOR AND MAKE REVISIONS TO THE PLAN

The interdisciplinary team will monitor the progress of the plan and its effects on the person's well-being, as well as the ongoing desire of the person to continue with the plan as written. The team will work with the resident to revise the plan as needed and desired by the individual.

- ✓ As a person changes over time, one's needs and preferences and the way he or she expresses needs and choices will change.
- ✓ Care plans and staff should be flexible, as people have the right to change their minds.
- ✓ Monitoring should never be limited exclusively to auditing forms or records. Monitoring plans generally needs to include observing, assessing, and discussing with the person his or her response to the planned interventions at a frequency that is appropriate for the particular person and choice.
- ✓ Record the ongoing discussion in the care plan; the plan of care will be updated as needed to reflect these changes.

OTHER CONSIDERATIONS

The Quality Assurance and Performance Improvement team should review trends related to resident choice, preferences, and safety, particularly when individuals are routinely denied requests, or when the team identifies patterns of community care practices that might be improved by performance improvement action plans.

Areas that the CQI/QAPI team might consider for specific trending might include:

- ✓ Denial of requests on a routine basis for more than one person. Whenever the community denies honoring a choice or preference, it should be documented and reviewed for trends, the need to staff education, and/or policy changes
- ✓ Areas of community inability to accommodate individual's preferences and action planning for future growth. This may include planning for future changes to the physical environment or changes in resource allocation to better accommodate preference.
- ✓ Resident and/or family council feedback. If individuals feel their preference and choices are not being honored, a community-wide plan should be put into place that includes assessment using the PELI and staff training that focuses on learning how to offer safer alternatives that mitigate risk.
- ✓ Trending of concerns, complaints, and compliments.
- ✓ Perceived high level risk activities, community responses, and risk management review.

If several persons are routinely making similar requests or have similar preferences, the care team may want to refer these to the Quality Assurance and Performance Improvement team for determination of a general policy to cover the issue, rather than needing to repeatedly make individual decisions



Person-Centered Care Planning Honoring Choice While Mitigating Risk

By:
Margaret Calkins
Karen Schoeneman
Jennifer Brush
Robert Mayer

Second Edition

Person-Centered Care Planning

Honoring Choice While Mitigating Risk

The purpose of the Mayer-Rothschild Person-Centered Care Planning Process is to support long-term care communities in their efforts to honor residents' choices and preferences that influence quality of care and quality of life, while mitigating potential risks associated with those choices. This process is specifically aimed at care planning when the choice carries sufficient risk, perhaps related to impaired cognition and inadequate decision-making capacity, and the community is considering not honoring the resident's wishes. Following the Mayer-Rothschild Person-Centered Care Planning process will help the care community work with the individual to understand and respect choices to the greatest extent possible, in line with regulatory requirements.

The purpose of this process is to guide staff and clearly demonstrate to regulators or surveyors (if applicable), family members, and others that a care community has done due diligence in:

- Assessing the individual's functional abilities and relevant decision-making capacity,
- Weighing, with the individual and his or her representative¹, the potential outcomes (positive and negative) of both respecting and aiding the person in the pursuit of her or his preferences, and
- Reviewing the potential outcomes (positive and negative) of preventing the person from acting on his or her choices.

The assessment of risk in long-term care is often an unbalanced exercise. It generally only takes into consideration potential negative outcomes, primarily with respect to quality of care issues. Insufficient consideration is given to possible positive consequences or to how honoring, or not honoring, choices and preferences might impact quality of life. In the healthcare arena, safety – particularly physical safety and protection from illness – has generally been more highly valued than the positive psychological and emotional outcomes that may result from behaviors or activities which may have some level of risk attached. Traditionally, care communities consider risk management to mean keeping residents safe, but this view does not take into account that the potential loss of quality of life from not being able to do what is preferred is equally important. Regulatory bodies, as well as Person-Centered Care approaches, recognize that the responsibility to respect person's rights for self-determination is equal to the responsibility for individual safety concerns.

¹ In this document when we refer to representative, we mean any person who may, under State law, act on the resident's behalf when the individual is unable to act for himself or herself. Even if the individual has named a representative in a Durable Power of Attorney for Health Care or there is an applicable default representative statute in the particular jurisdiction, the individual's expressed preferences should prevail unless there has been a formal adjudication of incompetence or the person's attending physician has documented in the person's record the physician's professional judgment that the resident lacks decision making capacity. In all situations, the individual's (verbal or behavioral) expressed preferences should be duly considered and respected to the maximum extent possible.

Traditionally, the focus in long-term care has been on doing what is “in the best interest of the person” *as defined by* the healthcare professional staff, rather than as defined by the person. The whole process has been based on a historical medical model that assumes the “patient” is the passive and “compliant” recipient of care directed and provided by professionals. But person-centered care is based upon a fundamentally different perspective, which places particular value on an individual’s right to make decisions concerning every aspect of her or his life. In our society, people are not required to follow their health care provider’s advice, and many in fact choose not to do so. This right does not change just because care is being delivered in a care community instead of at home.

In order to optimize opportunities for individual choice and to mitigate risk, the interdisciplinary team along with the resident can use this care planning process to plan for each individual’s preference when that choice carries potential risk.

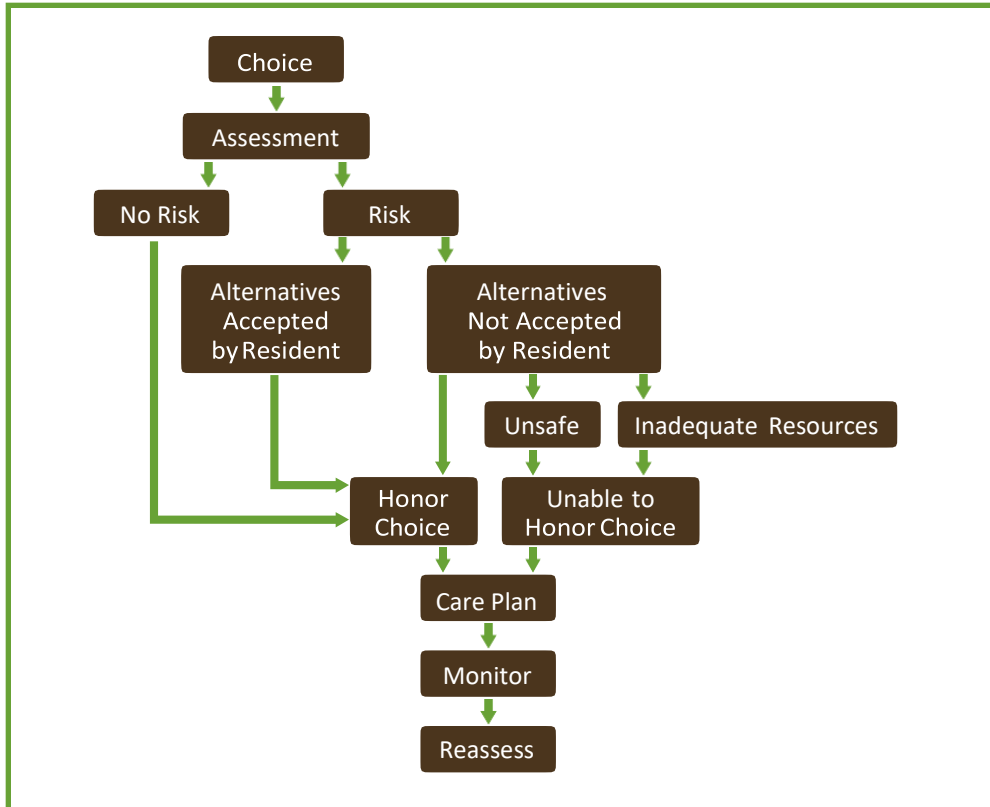
The Rothschild Person-Centered Care Planning process involves:

- I Identifying and clarifying the person’s choice and preferences
- II Discussing the choice and identifying options with the person
- III Determining how to honor the choice and preferences
- IV Monitoring and making revisions to the plan

The process is outlined in the following flow-chart, which can be used as a quick check by a community as it implements the Mayer-Rothschild Person-Centered Care Planning Process with an individual. The next sections of this document describe each step of the process in greater detail. There is also a documentation form that can be used to document all of the steps of the process, which should be included in the person’s health record. Finally, there are several sample scenarios that show how the process is implemented.

The following are resources for implementing this process:

- 1. Detailed description of the process for mitigating risk and honoring individual choice and preferences
- 2. References for assessing decision-making capacity
- 3. Flow chart of the process for mitigating risk and honoring individual choice and preferences
- 4. Blank form a care community can use to document the process
- 5. Sample completed forms documenting the process



The Process for Honoring Choice and Preferences and Mitigating Risk

The following process steps guide the interdisciplinary team to honor choices and preferences and mitigate risks

i. Identify and Clarify the Person's Choice and Preferences

Process

The process usually starts when a resident asks to, or refuses to, do something that is thought to be in their best interest. Interview and observe the individual. Review the person's history to obtain detailed information about the nature and extent of the choice that the person wishes to make. Is the choice a one-time request or a refusal ("I don't want to take this pill today"; "I want to shower without assistance today"), or is it ongoing ("I don't want to take this medication ever again"; "I don't want a feeding tube.")? Is it consistently expressed, or perhaps a brief reaction to some other concern? Ask what is the reason the person desires this choice if it is different from the care team recommendation? For example, Mrs. A may state that she prefers to use a cane rather than the recommended walker, because the walker makes her feel old and disabled. She would rather risk a fall than have such a negative self-image of herself.

Repeat back to the person your understanding of what she or he desires to choose or refuse, to confirm both parties understand each other.

Determine if the individual's choice presents a perceived risk or safety challenge to the resident, other residents, or the community. Clearly, people have less rights when it puts others at risk, than if the risks fall only to that individual. If a choice represents a change in care community policy or the resulting options stretch the community's comfort level, both the multidisciplinary care team and leadership (administrator, director of nursing, medical director, and physician) should be involved in the decision-making process.

Residents with Cognitive or Communication Impairment

The resident has primacy for decision-making, even if living with dementia or another form of cognitive or communication impairment, as individuals living with cognitive impairment are able to make many personal choices and express preferences. It is essential that care communities employ means to assess the individual's abilities to maximize autonomy and to identify the degree of impairment, if any. Capacity assessment should not be an all-or-nothing proposition, as has often been the case historically. The mere presence of a diagnosis of mild or moderate dementia or even major neurocognitive impairment is

insufficient by itself to justify restriction of a person's rights, 1) absent of a finding of significant functional impairment of the reasoning process and 2) the level of potential risk of the preference. When the communication skills of an individual living with dementia are limited, their actions and emotional state are often their only form of communication. An individual's emotional responses and actions should be considered a form of communication and an expression of preference(s). For example, a person who consistently resists entering the shower may prefer another method of keeping clean. Speaking in simple, direct language to individuals, potentially accompanied by gestures, pictures, written words or physical cues, may help staff to determine the unmet need or expression of choice that is driving a specific action.

The available representative, if one is appointed and actively involved in the person's life, can play a critical role in informing the care team of the individual's preferences and past habits as well as conveying insights about those decisions.

Documentation

The nature and extent of the choice(s) the resident wishes to make should be recorded on the Documentation Form and placed in the health record. Ensure that the individual's decision-making capacity and preferences for keeping representatives informed has been identified. If the individual has named a decision-maker, that person should also be included in identifying and clarifying the individual's choice.

ii. Discuss the options with the person

Process

This is an opportunity for the person and staff to engage in dialogue so that the person can explain what is important, and why.

Discuss with and educate the person about the potential outcomes of respecting and aiding the resident in the pursuit of her or his choices, as well as the potential outcomes associated with preventing the person from acting on his or her choices. It is critical to consider and discuss potential *positive outcomes* as well as potential negative consequences. Staff should explain that the individual still has the legal and ethical right to make choices and to refuse treatment. After learning of and considering the potential consequences, the person may decide not to take his or her initial requested action, to curtail its frequency, or to select an alternative with fewer potential adverse consequences, or may continue to desire the original choice. While some requests are potentially too harmful to other people to honor ("I want to drive to my childhood home"), many other requests can and should be honored by virtue of the team creating a plan to mitigate known potential negative consequences or offering a similar activity which has fewer potential adverse consequences (for example, riding in a car to the home but allowing someone else to drive) and may be more consistent with the resident's present cognitive and functional abilities. The

team should compare the person's choice to their condition to determine the nature of potential risks. If the resident's requested action poses significant danger to others, the team should clearly explain to the resident why they cannot honor that particular choice. Some resident choices/preferences cannot be accommodated as they would entail a significant allocation of the care community's resources.

The intent of this step is for the team and individual to explore options that might be mutually acceptable. Therefore, understanding the motivation and context for the person's request are critical developing appropriate options. This process of discussing the pros and cons of several alternatives may provide the best opportunity to assess the person's decision-making capacity as it relates to the specific decision to be made. This is important, since decision-making is situation specific. Although an individual may not be able to make certain decisions, what is ultimately relevant to an assessment is whether that person is able to make the particular decision in question. Ultimately, the team should offer ways in which they can accommodate the choice and also mitigate potential negative consequences as much as possible.

Returning to our example from above, the care team might ask whether Mrs. A would be willing to use the cane for shorter distances, but use the walker when a longer distance is involved. Alternatively, if she does not want to be seen "in public" with the walker, would she use it to get partway to her destinations, then change to a cane to enter the dining room or front foyer of the building? Determine if Mrs. A would benefit from either physical therapy, or balance exercises, and ask if she would be willing to do these to potentially reduce her risk of falling.

Going back to our example, let's look at two potential scenarios.

Scenario 1: The staff asked Mrs. A her preferences of the options they discussed, and she agreed to some physical therapy and using the walker for long distances — primarily to the front lobby and the chapel. The physical therapist was able to get a clamp and attach it to the walker that would hold a cane, so it was always easily accessible wherever she went. This would make it easier for her to use a walker for the longer distances, then switch to a cane when she was about to enter the room.

Scenario 2: Mrs. A states that she still does not want to use a walker at all. She will

try some balance training but does not promise to stick with it if she does not like it. The family is still divided on whether she should use the walker or the cane. The staff explains to them that this is their mother's decision to make. If she does not like the balance training, they will revisit the issue and try something else. Staff will ensure she has proper footwear to minimize slipping and will monitor her success and issues in using a cane.

Individuals with Cognitive or Communication Impairment

Attempt to communicate in a way that the resident can understand. This may mean providing educational material about the risks and benefits of the choice in many different forms (verbal, written, pictures) and simplified so that a person living with dementia can understand the information. After providing information in a simple, multimodal manner, the individual should be asked simple questions, one at a time, which will assess his or her understanding of the material.

For example, ask Mrs. A to explain what some of the potential consequences are if she continues to use only the cane. Does she agree that these risks might be mitigated by either therapy/balance training or by using the walker? Based on the response, determine how much and how well the resident comprehends and recalls what was explained. If the resident has trouble explaining or recalling the material, repeat, clarify, or modify it — and then reassess the person's understanding and recall. Staff may need to repeat this cycle several times with pictures and written material; not just verbal presentation of the information. A person living with dementia who cannot verbally communicate that he or she understood the information still may express an opinion or preference through his or her behavior.

In these cases, the representative should be consulted as part of the decision-making process in order to better understand some of the context for this individual preference, particularly if the individual is unable to offer a satisfactory explanation. In cases where the individual lacks sufficient capacity and the representative is not able to accurately convey what the individual's wishes might be, with the person's permission, the care team should consider gathering information about the person's preferences and habits from those most involved in his or her life, such as family, close friends or neighbors that frequently visit. If obtaining information from a resident, friend, or representative is difficult, staff can still learn about the individual through other sources, such as any knowledgeable staff members,

medical records, and by observing his or her reaction to particular approaches to care. Using the example from above, the representative may report that Mrs. A was always self-conscious about her appearance, and it was important to her to be seen as healthy and vigorous. However, it is important to note that sometimes what a resident may choose is different from what the family would prefer. Some members of Mrs. A's family may support her preference to use a cane, while others think she should use the walker because it is safer.

Documentation

The team documents the conversations with the individual and representative(s) on the Documentation Form and places it in the health record. Staff should detail what their understanding is about the individual's choice, how they discussed the risks and benefits with the individual and representative, and whether the individual exhibited adequate decision-making capacity related to the choice in question. Provide a record in writing about what was presented to the individual and what the individual's response was, in order to paint a complete and accurate picture of the situation. This can include the documentation of a reaction such as a nod, laugh, gesture, comment, grimace or other behavioral indicator such as pulling away. If the individual's choice posed a potential significant danger to either the resident or to others and was denied and no alternative was selected by the resident, explain this in the record. This documentation is critical, as it is relied upon should an unforeseen event occur. Having the documentation that shows all the steps taken, who was involved in the conversations, what options were discussed, and which were or were not acceptable, and why is what regulators and others will want to see.

iii. Develop the Plan to Honor the Choice

Process

If a mutual decision is reached as to how the team will accommodate a preference to maximize the individual's well-being, the team will work out with the person the specific steps the staff will take to support that choice. The individual participates in the entire care planning process and is made aware of the steps of the plan.

While it is important that all members of the interdisciplinary team

be involved in care planning, it is recognized that not every representative can always participate in a face-to-face meeting. It is very important to have the participation and input of the direct care staff as they have the most contact with the individual. Therefore, alternative means of communication should be made available, if needed, for providing input and review of the plan. On occasion, it may be a person's or representative's choice to meet with a smaller group of people rather than the entire team, and that preference should be accommodated.

Documentation

Record on the documentation sheet the decisions reached and the steps the staff will take to assist the person and mitigate potential negative outcomes to the extent possible. This information is then included in the person's plan of care.

iv. Monitoring and Revising the Plan

Process

The interdisciplinary team will monitor the progress of the plan and its effects on the person's well-being, as well as the ongoing desire of the person to continue with the choice. The team will work with the person to revise the plan as needed and desired by the individual. As a person changes over time, or as different ideas and options are considered and tried, one's needs and preferences and the way he or she expresses needs and choices will change. Care plans and staff should be flexible, as people have the right to change their minds. Monitoring should never be limited exclusively to auditing forms or records. Monitoring plans generally needs to include observing, assessing, and communicating with the person about his/her response to the planned interventions at a frequency that is appropriate for the particular person and choice.

Periodic formal reassessment is needed as individuals may change their mind over time and decision-making capacity may fluctuate or decline due to a urinary tract infection (UTI), medication effect, or other temporary physical health issue. Also, some individuals will require more frequent re-education than others; perhaps even every single time they engage in a common activity such as eating. Therefore, reassessment frequency should be individualized, on a case by case basis.

Documentation

The ongoing discussion will be documented in the care plan. The individual's plan of care will be updated as needed to reflect these changes.

Additional Considerations

The care community's Quality Assurance and Performance Improvement team should review trends related to resident choice and safety, particularly when residents are routinely denied requests, or when the team identifies patterns of community care practices that might be improved by performance improvement action plans. Topics that ought to be considered might be identified at resident or family council meetings.

Areas that the Quality Assurance and Performance team might consider for specific trending might include:

- 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 resident preferences
- Resident and/or family council feedback
- Trending of concerns, complaints, and compliments
- Perceived high-level risk activities, community responses, and risk management review

If several individuals are routinely making similar requests, the care team may want to refer these to the Quality Assurance and Performance Improvement team for determination of a general policy to cover the issue, rather than needing to repeatedly make individual decisions.

Documentation Form for Honoring Choice and Mitigating Risk

Resident Name: _____

i. Identify and Clarify the Person's Choice		Date	Initials
What is resident's preference that is of concern?			
Why is this important to the person?			
What is the safety/ risk concern?			
Who representing the person was involved?			
Who on care team was involved in these discussions?			
ii. Discuss the Choice and Options with the Person		Date	Initials
What are the potential benefits to honoring the person's			
What are the potential risks to honoring the person'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?			

iii. Develop the Plan to Honor the Choice		Date	Initials
Of all options considered, is there one that is acceptable to the person and staff? Which one?			
If no option is acceptable to everyone what is the reason for the denial of resident choice? And what are the actions that will be taken?			
Who was involved in these discussions/ decisions?			
What specific steps will be taken to assure both the person 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?			
iv. Monitoring and Making Revisions to the Plan		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?			

Other comments
