A Process for

Care Planning for Resident Choice

ROTHSCHILD PERSON-CENTERED CARE PLANNING TASK FORCE

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February 2015

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BACKGROUND

For many years, care communities have been saying that they cannot implement at least some elements of person-centered care because of fear that they will get cited by the surveyors if there is a negative outcome that might be attributed to those policies or practices, or possibly get sued by the resident's family. This is primarily because a number of person-centered practices, such as offering residents meaningful choices and honoring their decisions, represent significant deviations from prior accepted more paternalistic institution-centered practice. Examples abound, but include such issues as supporting the resident's wish to eat food that might be considered a choking hazard; wanting to not be tied to an alarm despite being at risk for falling; or wanting to go outside without a caregiver.

To respond to these concerns, the Erickson School, with support from the Rothschild Foundation, convened an invitational symposium in the fall of 2012 on "Surplus Safety." Almost 50 stakeholders from a diverse group of constituencies discussed the unbalanced notions of risk in long-term care, in which caregivers generally only take into consideration the potential negative consequences of a resident's choice, and do not sufficiently consider possible positive consequences or upside risk. In the healthcare arena, safety – particularly physical safety and health – has generally been more highly valued than the positive psychological and emotional state that results from being able to choose to engage in preferred behaviors or activities which may have some level of risk attached.

Following the Surplus Safety Symposium, the Rothschild Foundation convened another meeting, in April 2013, of primarily elder law experts. A Legal Liabilities Task Force was formed to address more specific strategies that would help care communities, who are actively working to respect resident rights in the promotion of self-determination and personal decision-making, avoid potential litigation if the resident chooses to make a decision that results in unintentional harm. The Task Force consisted of various care community and professional stakeholders, including several representatives from the legal community. Based in part on the discussions held at the Surplus Safety Symposium, it was the belief of the Foundation that the proper way to navigate this barrier to resident choice was to formulate some type of legal remedy, potentially through changes in existing statutes, a negotiated risk agreement, waivers, etc. The Task Force members disagreed. Rather than a legal remedy, it was the consensus of this group that the answer was in care communities themselves. In particular, care communities need to follow the requirements embedded in CMS regulations for resident education, the offering of alternatives that are less risky through the care planning process, and documentation of the processes that were followed. These regulations form the foundation for evaluating the standard of care that is provided, and if the care meets these standards, then the care community should not be held liable for negative outcomes. The challenge is that the regulations are not clear on what, exactly, constitutes an acceptable standard of care when resident preferences are not aligned with

professional recommendations. The Task Force recommended a uniform set of care planning policies and procedures to help surveyors, lawyers, families and care communities create care plans which would serve to recognize that the responsibility to respect resident rights for self-determination are at least equal to the responsibility for resident safety. Following the Legal Liabilities Task Force recommendations, we renamed this advisory group the Person-Centered Care Planning Task Force.

It is our expectation that by better understanding the real and perceived barriers to person-centered care, we can do a better job of building new approaches to begin to eliminate such barriers.

REGULATORY OVERVIEW

The federal emphasis on the importance of quality of life and resident autonomy and choice began with the release in 1986 of "Improving the Quality of Care in Nursing Homes," a blue ribbon panel Institute of Medicine report to Congress[1]. This key report, which led directly to the language of the Nursing Home Reform section of the Omnibus Budget Reconciliation Act of 1987 (commonly called OBRA '87), recommended significant changes to current regulations, including new sections on Resident Rights, Quality of Life, Resident Assessment, and Quality of Care. The report specifically supported the resident's right of refusal of treatment and choices over matters of importance, as well as participation in developing one's own plan of care. One key conclusion stated, "Because most nursing home residents live in nursing homes for many months or years, quality of life is as important as quality of care in these institutions." (p. 21)

1 From Improving the Quality of Nursing Homes: "In May 1982, the Health Care Financing Administration (HCFA) announced a proposal to change some of the regulations governing the process of certifying the eligibility of nursing homes to receive payment under the Medicare and Medicaid programs. The changes were responsive to providers' complaints about the unreasonable rigidity of some of the requirements. The proposed changes would have eased the annual inspection and certification requirements for facilities with a good record of compliance, and would have authorized states, if they so wished, to accept accreditation of nursing homes by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) in lieu of state inspection as a basis for certifying that Skilled Nursing Facilities (SNFs) and Intermediate Care Facilities (ICFs) are in compliance with the federal conditions of participation and operating standards.

The HCFA proposal was strongly opposed by consumer groups and most state regulatory agencies because the proposed changes were seen as a movement in the wrong direction — that is, towards easing the stringency of nursing home regulation — and because they did not deal with the fundamental weaknesses of the regulatory system. The controversy generated by the proposal caused Congress in the fall of 1982 to order the HCFA to defer implementing the proposed changes until August 1983 and ultimately resulted in a HCFA request to the Institute of Medicine (IOM) of the National Academy of Sciences to undertake this study. The contract between the HCFA and the IOM became effective on October 1, 1983. The charge to the IOM Committee on Nursing Home Regulation was to undertake a study that would "serve as a basis for adjusting federal (and state) policies and regulations governing the certification of nursing homes so as to make those policies and regulations as appropriate and effective as possible." The full report can be downloaded from **http://www.nap.edu/catalog.php?record_id=646**

Congress tasked the Health Care Financing Administration (now the Centers for Medicare & Medicaid Services – CMS) with developing person-centered and outcome oriented regulations, regulatory guidance, and a new survey process to focus on resident outcomes in terms of both Quality of Life/Resident Rights and Quality of Care. CMS released the regulations in 1989 (42 CFR, Part 483) and the regulatory guidance and survey process in 1990.

The status quo of the nursing home field at that time was largely that of a traditional, medical model of institutional care. So, the regulators (surveyors) interpreted the important choice and rights regulatory language embedded in OBRA in terms of a traditional medical model where the resident is expected to follow the advice of the healthcare professional, regardless of personal preference. Although the regulations mandated rights and choices, there were also regulatory Quality of Care mandates for good care, assessing each resident, and care planning for services needed by each resident to attain and maintain their highest practicable well-being. Although both the law and regulations placed equal emphasis on both Quality of Life and Quality of Care, in practice, both providers and surveyors often assumed that any resident choices to refuse aspects of care or to engage in perceived "risky" behaviors were not only less important to address but simply wrong. It was the responsibility of the staff to know what was best for each resident. So, for example, if a resident wanted to refuse a pill, staff often felt a responsibility to cajole the resident into acceptance or even hide the pill in apple sauce, and surveyors often agreed with this approach. Resident choices were viewed as acceptable as long as they were "good" choices that did not conflict with practice and policy for good care, as determined by staff. This approach is reinforced by the Resident Assessment instrument process (described in greater detail below), which assesses resident function (or more accurately dysfunction) and prescribes a process to identify steps to help the resident achieve his or her highest practicable level of well-being.

The specific regulations have remained largely the same since their 1990 introduction, but CMS has gradually added specific guidance (Guidance to Surveyors, popularly known as the Interpretive Guidelines) to explain the regulatory mandates, to describe good practices, and to provide procedures to evaluate compliance. In the late 1990s, CMS became aware of the burgeoning Culture Change or Person-Centered Care movement which focused on putting resident choice before institutional efficiency. CMS regulatory leaders heartily approved of the principles of the movement and began to support these innovations as a further fulfillment of the mandates of the law and regulations. Since 2000, CMS has revised the guidance for over 20 key regulatory segments, called Tags, to better reflect this shift in priorities.

A 2006 video was released by CMS to educate the Quality Improvement Organizations (QIOs) which presents their positive perspective and support for person-centered care practices. The video features Thomas Hamilton, Director of the CMS Survey and Certification Group, which oversees the Division of Nursing Homes, and Karen Schoeneman, the then CMS Quality of Life and Culture Change lead in the Division of Nursing Homes. In this video (available on You Tube and

the Pioneer Network website **http://pioneernetwork.net/Policy/Federal/**), Mr. Hamilton notes that culture change efforts are considered a fulfillment of the OBRA law and states that "…research shows us that residents of facilities changing their culture to one that is more resident directed are positively affected. The benefits seem to encompass not only improved resident health, but as a bonus, lowered facility staff turnover." He applauds efforts state survey agencies are making to help providers figure out issues of compliance with culture change practices. Karen Schoeneman describes what she has found in her visits to several culture changing homes, "In all the [culture changing] homes I've seen, there is a very positive change in the engagement of residents, an improvement in quality of life, which is a key part of the law and regulations. And when quality of life is improved, it seems that resident functioning has improved as well; things such as less incontinence, less weight loss, less use of antipsychotic drugs, even better ADL functioning and more." Thus, support for the values of culture change and person-centered care from CMS is clear and unequivocal.

JUST WHAT DO THE REGULATIONS SAY?

As with many government processes, the actual regulations are only one part of a larger and more complex system that must be adhered to. We will start by describing the actual language in the regulations relating to resident rights and choice, followed by language from the Interpretive Guidelines that helps to explain the intent of the regulations. The next section of the paper then describes the Resident Assessment Process (RAI), most of which is also mandated, which leads to the actual care plans that surveyors review and evaluate in order to determine whether a care community is in compliance with the regulations.

The following is selected language from 42 CFR, Part 483 that supports resident rights to make decisions and choices about their care:

> "The resident has the right to a dignified existence, self-determination. . . . A facility must protect and promote the rights of each resident . . . . " (483.10, Tag F150).
>
> The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United States. The resident has the right to be free of interference, coercion, discrimination, and reprisal from the facility in exercising his or her rights." (483.10(a)(1 and 2), Tag F151).
>
> "The resident has the right to refuse treatment, to refuse to participate in experimental research, and to formulate an advance directive. . . ." (483.10(b)(4), Tag F155).
>
> The comprehensive care plan must include . . . "services that are to be furnished to attain or maintain the resident's highest practicable physical,

> mental, and psychosocial well-being as required under 483.25; and any services that would otherwise be required under 483.25 but are not provided due to the resident's exercise of rights under 483.10, including the right to refuse treatment under 483.10(b)(4)" (483.20(k), Tag F279).
>
> "The facility must create an environment that is respectful of the right of each resident to exercise his or her autonomy regarding what the resident considers to be important facets of his or her life. This includes actively seeking information from the resident regarding significant interests and preferences in order to provide necessary assistance to help residents fulfill their choices over aspects of their lives in the facility." (483.15(b), Tag F242).

One key regulatory section in the Interpretive Guidelines concerning Quality of Care (483.25, F309) seems to be the area that is causing confusion between choice and good care. Its language states, "Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care." This Quality of Care section contains several Tags (e.g., pressure ulcers, accident prevention, incontinence, nutrition) that each define and specify good care and regulatory compliance. For example, part of the language at the Nutrition regulation, (483.25(i)(2), Tag 325), states: "[a resident] receives a therapeutic diet when there is a nutritional problem." However, the guidance on Diet Liberalization states that "a liberalized diet can enhance quality of life and nutritional status of older adults in long-term care facilities." Another, even broader section of this Tag, Resident Choice, was added to emphasize the importance of this right. "If the resident declines specific interventions, the facility must address the resident's concerns and offer relevant alternatives."

While this language might seem to be perfectly clear — residents have the right to "decline specific interventions" (and presumably ask for an alternative) and "the right to be free of interference, coercion, discrimination, and reprisal from the facility in exercising his or her rights"— its adoption and implementation are not. How communities address resident concerns, and how relevant alternatives are offered is not always clear, nor necessarily consistently evaluated from one surveyor to another. Further, other organizations have their own interpretation of what the guidance actually means. The CMS Interpretive Guidelines for Tag F28, 42 CR, 483.20 (k)(2) state:

> While Federal regulations affirm the resident's right to participate in care planning and to refuse treatment, the regulations do not create the right for a resident, legal surrogate or representative to demand that the facility use specific medical intervention or treatment that the facility deems inappropriate. Statutory requirements hold the facility ultimately accountable for the resident's care and safety, including clinical decisions.
>
> Thus care communities must accommodate resident preferences and right to refuse treatment but are also responsible for the resident's care and safety.

While this may seem inherently contradictory in some cases, the language of F309, "...in accordance with the comprehensive assessment and plan of care" raises the additional dimension of a care community's need to assess the resident's decision-making capacity, which in turn may modulate the degree of accommodation that is appropriate or the resident's right to refuse treatment. A resident who retains sufficient decision-making capacity may make what the care community staff considers to be a "bad" decision, but it remains his or her decision to make. On the other hand, a resident who lacks adequate capacity to act as the final decision maker still should be included in the discussion, and their preferences accommodated to the maximum extent possible, even if that resident's expressed wishes may not ultimately override the duty of the community to maintain the safety of that resident.

UNDERSTANDING THE SURVEY PROCESS

Organizational Structure

CMS contracts with each state to conduct the survey process. CMS and the state have joint responsibility for training the surveyors (who are state employees). The regulations listed above are enforced by over 5000 state surveyors who visit each care community yearly. In addition to the Federal regulations, most states also have state-level regulations that these surveyors may also need to address during their survey visits. These individuals must apply the complex federal and state regulatory mandates to actual situations they encounter during their survey visits. Moreover, each state has its own unique "culture," and each has its own values which are emphasized when training surveyors about what is best in actual practice as a result of history, past practice, public interest, and individual preference of the trainers and managers. Because of this, there can be significant differences from state to state in what surveyors will deem compliant in terms of accommodating resident preferences. As the care communities begin to make changes that liberalize and acknowledge preferences to a greater degree than ever envisioned before, a disconnect has sometimes arisen between these communities and the surveyors, who have developed their own interpretation of regulation and practice. Many providers worry about what surveyors will say when they arrive, if the care community has agreed to support resident choices that pose some degree of risk. As previously mentioned, while CMS has provided some training to help introduce the new concept of person-centered choice to the surveyors, results have been mixed.

CMS also has 10 regional offices. Each office is responsible for a set of states. They conduct their own visits to monitor state surveyor performance, as well as independent visits to a small set of care communities. They can either support or deny deficiencies that the state team has cited. Each region also has its own culture and values regarding the interpretation of how and in what ways a community should honor resident choice. Some regions are more involved with person-centered care and have adopted a more liberal viewpoint, which they have conveyed to the states in their region. Therefore, the only way a state surveyor will

likely find liberalizing innovations compliant is that the surveyor must: a) believe in the importance of supporting choice; b) believe that their state supports this value; c) believe that CMS regional office surveyors will support such innovations; and d) convince the rest of their own team to support the honoring of resident choice. The surveyor must take into account: 1) the needs of the specific resident; 2) the resident's specific choice; 3) the care community's education of the resident; 4) attempts to mitigate negative outcomes through the care plan; 5) documentation of the process; and 6) monitoring of the outcomes.

Care Planning Process

> "…must provide services and activities to attain or maintain the highest practicable physical, mental, and social well-being of each resident in accordance with a written plan of care." (OBRA '87)

The care planning process is based on the Resident Assessment Instrument (RAI), which includes the Minimum Data Set (MDS), which contains more than 450 items designed to assess the functional status, mood, and medical conditions of each resident on admission and periodically thereafter. The resident assessment identifies the areas where the resident has one or more condition(s) that needs to be addressed – which is usually a trigger for a more detailed evaluation and development of specific goals and interventions for each issue in the care plan. Until 2010, the MDS focused almost exclusively on clinical elements of care, which supported the notion that quality of care was more important than quality of life. The most recent MDS 3.0 revision increases the voice of residents in the assessment process through a set of questions that ask about certain preferences and how much importance a resident attaches to each. That change should support person-centered care if the care team takes account of these preferences in developing the plan of care.

CMS does not dictate in any way the structure of the care plan, nor the policies and procedures that inform the care plans, nor the documentation required for the care plan. Although CMS does not specify how a care community should develop or write its care plans, it does mandate that the individualized plan of care for each resident be based upon a specific and comprehensive resident assessment, using the MDS.

Depending on the resident's needs, the care plan may include:

- What kind of personal or health care services are needed
- What type of staff should provide these services
- How often the services are provided
- What kind of equipment or supplies are needed
- What kind of diet is needed, if a specific diet is required
- Health goals

This is where the existing established processes rub up against person-centered care values. It is easy to see that the deficit-based nature of the RAI process focuses on

"problem conditions" primarily related to clinical care and outcomes. It is easy to see how resident preferences, especially for activities that are not directly related to an MDS-assessed care issue, have not been given the same weight as clinical issues in the mandated components of the care planning process. Even preferences that are related to MDS triggered issues (Care Area Assessments – CAAs) have traditionally been overridden when they are perceived to have potentially negative consequences. Thus it is not surprising that resident preferences are not routinely assessed or included in the care plan, in part because specifically assessing resident preference has only become a structured and required activity as part of the new MDS 3.0 issued in 2010, and only for the relatively small set of preference questions (such as waking time) that are included in the 3.0.

Since it is the care plan that synthesizes all of this collected information and sets out the way it will be utilized to support quality of life and quality of care for each resident, it is the care plans (in large part) that surveyors review to determine if the care community is appropriately meeting each resident's needs.

CHALLENGES TO CHANGE

In taking a close look at the challenges that the current regulations, survey process, and provider concerns pose, the Task Force discerned the following key questions:

First, the focus 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 RAI process has been based on a historical medical model that assumes the "resident" is the passive and "compliant" recipient of care provided by professionals. But person-centered care comes from a fundamentally different perspective, which puts particular value on an individual's right to make decisions concerning every aspect of her or his life. A person is not required to follow a health care provider's advice, and this right does not change just because care is being delivered in a care community instead of at home. For example, a primary care physician continues to see a person despite the fact he or she does not follow the doctor's advice to exercise more to lower his or her blood pressure. At the same time, while a person's basic right to make personal choices is the default position, when an individual moves a to a care community, changes in functional ability, cognition, and decision-making capacity are typically present. As noted in F309, the accommodation of decision making rights may need to take account of the condition of the individual as determined via the comprehensive assessment and plan of care. The result is that, as decision-making ability declines and risks to safety grow, the right to make certain specific decisions may need to be limited. For example, a resident would retain the right to leave the community freely unless cognitive impairment had progressed to the point that the volitional exercise of this right caused ignorance of basic safety awareness and an inability to compensate for avoidable risks. In such a situation, the resident's "best interests" would guide decisions because the exercise of autonomy would compromise one's safety. It is therefore essential that communities

have mechanisms to effectively assess decision-making capacity, with the goal of maximizing the autonomy of each individual, while at the same time taking necessary steps to maintain safety when the resident is incapable of making his or her own autonomous choices.

So the first question is how to identify a resident's preferences. Outside of the questions that are included in the MDS, there is no mandated format for assessing resident preference. Residents express preferences every day in myriad ways. They say they do not want a shower. They happily go outside. They get up and leave an activity. Residents communicate verbally, behaviorally, and emotionally. Direct care staff in care communities interpret this communication on a daily, if not hourly basis. And of course, the issue is much more complicated when the person is living with dementia and has both decisional and communication challenges. The Advancing Excellence website has some excellent resources on how to assess resident preferences (**https://www.nhqualitycampaign.org/goalDetail.aspx?g=PCC#tab4**). We clearly need a uniform process and format in order to identify and document those preferences.

Second, when is it appropriate NOT to honor a resident's preferences? Our laws have determined that there are times when the obligations of the community supersede those of the individual. Occasionally, what a resident might prefer to do is so clearly and patently unsafe to others (e.g. wanting to continue to drive an electric wheel chair despite the fact that the person has run into others with it, or wanting to harm another resident) that staff must override the resident's wishes. How do we deal with these preferences? Additionally, as noted above, it may be appropriate not to honor a resident's preferences when that person's cognitive decline has progressed to the point that autonomous decision-making poses a clear safety risk to themselves or the community.

Third, we recognize that the vast majority of the time, residents preferences are not clearly so hazardous. However, they might not be in, what some staff members would consider, the best interest of the resident. For example, the resident not only wants to go outside, but he or she wants to walk into town. He or she does not want to take that pill that their physician has prescribed because of the bad taste or because of the perceived side-effects.

So how does the care community accommodate resident preferences when the action/activity/behavior is seen as having some potential risk for a negative outcome but the resident retains capacity to exercise rights? In what ways should the community modify or adjust the care planning process to determine when the benefits to the individual outweigh the potential risk? The regulatory guidance refers to both education and offering the resident (presumably safer) alternatives. It also refers to not assuming a decision once made holds true forever, so that ongoing efforts at education and the offering of (safer) alternatives are expected. But while this language is clear in the guidance, again there is no commonly accepted process for honoring these resident preferences through care planning.

Fourth, because each care community develops its own care plan format, along with its own policies, procedures and forms, it is even more difficult for surveyors to evaluate whether, in accommodating resident preferences for risk-related activities, the care community has fully met the requirements (which are largely unspecified) for education and lower risk alternatives. Surveyors must determine whether proper assessment has been conducted to assure that the resident retains adequate decision-making capacity to decide about lower risk alternatives and education. Providers need to have a process that will demonstrate at once to surveyors, family members, and residents that they have followed best practice in working to accommodate resident preferences and to mitigate known potential risk in order to minimize the chance of an unsatisfactory survey or potential litigation.

WORK TO DATE

The Rothschild Person-Centered Care Planning Task Force worked for a year to create such a process. Stemming from the Surplus Safety Symposium and the Legal Liabilities Task Force, this Task Force comprises members from relevant professional, clinical, advocacy, and regulatory organizations, who have worked together to create a care planning process that will help communities identify and care plan around risk-related activities that will honor residents' preferences. Members and organizations that have participated are listed in the Addendum at the end of this document.

The Task Force was convened in October 2013. Presentations and discussions identified the significant challenges in implementing person-centered care planning in nursing homes, both in general and particularly when it is associated with some level of risk. There was general agreement that the current processes do not encourage care communities to actively determine residents' preferences in a meaningful way and do little to support a care community accommodating a resident's preference for a risk-related behavior. Therefore, the Task Force concluded that the best way to address these challenges would be to create a defined process that outlines the necessary steps (from the regulatory perspective) of education, inclusion, offering alternatives and re-evaluation to support care communities that are dedicated to accommodating resident preferences as much as possible.

The Task Force divided into three working groups who developed the process, articulated the special accommodations that are necessary when a resident is living with dementia, and developed a series of scenarios to show how the process works. The Person-Centered Care Planning Task Force has developed a series of documents (attached) that identify what type of care planning processes are necessary (e.g. education about risks and offering of safer alternatives) and acceptable (e.g., format of education, number of times it is offered, number and types of safer alternatives offered, etc.) for surveyors to be comfortable that the care community is carefully weighing, with the resident and his/her chosen representatives, risk versus

choice in determining what leads to an individual resident's "highest practicable physical, mental, and social well-being". We invite the many voices who represent residents, providers, surveyors and others to assist the Task Force in transforming this initial process into a meaningful piece of work that will inform the care plan process for care communities across the country and begin to remove an important barrier to honoring resident choice and real person-centered care.

OVERVIEW OF PROCESS FOR CARE PLANNING FOR RESIDENT CHOICE

The purpose of the Rothschild Person-Centered Care Planning process is to support long term care communities in their efforts to honor residents' choices 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 Rothschild Person-Centered Care Planning process will help the community work with the resident to understand and respect choices to the greatest extent possible, in line with CMS regulations.

The purpose of this process is to guide staff and clearly demonstrate to residents, state surveyors, family members, and others that a care community has done due diligence in:

- Assessing the resident's functional abilities and relevant decision-making capacity,
- Weighing, with the resident and his or her representative[2], the potential outcomes (positive and negative) of both respecting and aiding the resident in the pursuit of her or his choices, and
- Reviewing the potential outcomes (positive and negative) of preventing the resident 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 choices 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 is equally important. CMS regulations, as well as Person-Centered Care approaches, recognize that the responsibility to respect resident rights for self-determination is equal to the responsibility for resident safety concerns.

2 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 resident is unable to act for himself or herself. Similarly, even if the resident 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 resident's expressed preferences should prevail unless there has been a formal adjudication of incompetence or the resident's attending physician has documented in the resident's record the physician's professional judgment that the resident lacks decision making capacity. In all situations, the resident's expressed preferences should be duly considered and respected to the maximum extent possible.

According to CMS regulations, the resident has the right to:

- Choose activities and schedules (Tag F242).
- Interact with members of the interdisciplinary team, friends and family both inside and outside the care community (Tag F172 and Tag F242).
- Make choices about aspects of his or her life in the care community that are important to him or her (Tag F242).
- Participate in care planning (Tag F280).
- Refuse treatment (Tag F155).
- Both quality of care (Tag F309) and quality of life (Tag F240) that recognizes each individual and enhances dignity.
- Achieve the highest practicable level of well-being (Tag F309).
- The same rights as any resident of the Unites States (Tag F151).

The challenge in meeting all of these regulatory mandates is that, for so long, the focus 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 a cognitively capable 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 fact, CMS regulations require these rights be respected.

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

The Rothschild Person-Centered Care Planning process involves:

I Identifying and clarifying the resident's choice

II Discussing the choice and options with the resident

III Determining how to honor the choice (and which choices are not possible to honor)

IV Communicating the choice through the care plan

V Monitoring and making revisions to the plan

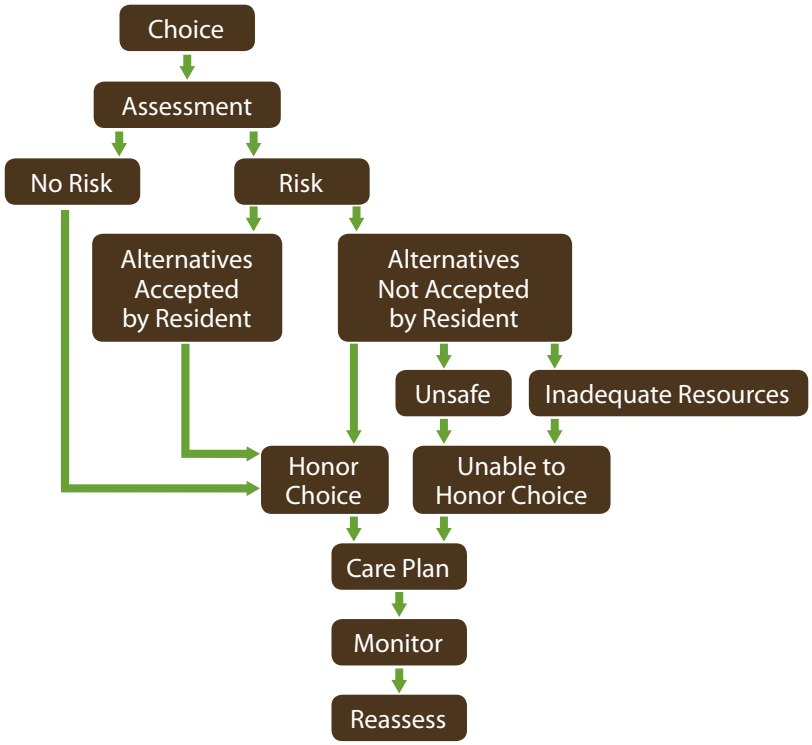
VI Quality Assurance and Performance Improvement

The process is outlined in the following flow-chart, which can be used as a quick check by a community as it implements the Rothschild Person-Centered Care Planning process with a resident. 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

resident's chart or care plan. 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 resident choice
2. Flow chart of the process for mitigating risk and honoring resident choice
3. Blank form a care community can use to document the process
4. Sample completed forms documenting the process



The Process for Mitigating Risk and Honoring Resident Choice

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

I. IDENTIFY AND CLARIFY THE RESIDENT'S CHOICE

Process

Interview and observe the resident. Review the resident's history to obtain detailed information about the nature and extent of the choice that the resident wishes to make. Is the choice a one-time request or a refusal ("I don't want to take my pill"; "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? What is the reason the resident 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 resident your understanding of what she or he desires to choose or refuse, to confirm both parties understand each other and that the resident understands the relevant concerns, appreciates the likely outcomes of various alternatives, and exhibits a process of reasoning that coupled with the understanding and appreciation of consequences supports an informed decision. While the decision belongs to the individual with decision-making capacity, it can be helpful to discuss it with the representative (if one is appointed and with permission of the resident) in order to better understand some of the context for this individual preference, particularly if the resident is unable to offer a satisfactory explanation. In cases where the resident lacks sufficient capacity and the representative is not able to accurately convey what the resident's wishes might be, with the resident's permission the care team should consider gathering information about the resident'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 resident 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.

Determine if the resident's choice presents a perceived risk or safety challenge to the resident, other residents, or the community. Are there other alternatives (safer or easier to accommodate) that might be more readily implemented that are acceptable to the resident? 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 absent a finding of significant functional impairment of the reasoning process. When the communication skills of a resident living with dementia are limited, their actions and emotional state are often their only form of communication. A resident's emotional responses and actions should be considered a form of communication and an expression of preference(s). For example, a resident who consistently resists entering the shower may prefer another method of keeping clean. Speaking in simple, direct language to residents, 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 resident's life, can play a critical role in informing the care team of the resident'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 chart. Ensure that the resident's decision-making capacity and the resident's preferences for keeping representatives informed has been identified. If the resident has named a decision-maker, that person should also be included in identifying and clarifying the resident's choice.

II. DISCUSS THE CHOICE AND OPTIONS WITH THE RESIDENT

Process

This is an opportunity for the resident and staff to engage in dialogue so that the resident can explain to the staff what is important to him or her and what he or she needs to live a meaningful life.

Discuss with/educate the resident about the potential outcomes of respecting and aiding the resident in the pursuit of her or his choices, as well as the potential outcomes of 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 resident still may have the legal and ethical right to make choices and to refuse treatment. After learning of and considering the potential consequences, the resident 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. This process of discussing the domains noted may provide the best opportunity to assess the resident's decision-making capacity as it relates to the specific decision to be made. This is particularly helpful, 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. The team should offer ways in which they can accommodate the choice and also mitigate potential negative consequences as much as possible. Understanding the motivation and context for the resident's request will significantly aid in developing appropriate options. The intent of this step is for the team and resident to explore options that might be mutually acceptable.

Returning to our example from above, the care team might ask whether the resident 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.

Residents 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 resident 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 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 resident'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 resident living with dementia who cannot verbally communicate that he or she understood the information still may express an opinion or preferences through his or her behavior. In these cases, the representative should be consulted as part of the decision-making process.

Note that we do need periodic reassessment, as residents 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 residents will require more frequent 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 team documents the conversations with the resident and representative on the Documentation Form and places it in the chart. Staff should detail what their understanding is about the resident's choice, how they discussed the risks and benefits with the resident and representative, and whether the resident exhibited adequate decision-making capacity related to the choice in question. Provide a record in writing about what was presented to the resident and what the resident'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.

III. DETERMINE HOW TO HONOR THE CHOICE

Process

While some resident requests are potentially too harmful to other people to honor ("I want to drive a car again"), 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 a desired location, 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 resident's choice to the resident's 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. (For example, a resident wants to leave campus for a few hours daily to go shopping, accompanied by staff.) In those instances, alternatives should be sought to the extent possible, e.g. a family member takes the person shopping a few times a week. 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 staff asked the family to provide several canes, which could be left in different areas of the community that Mrs. A liked to visit. 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.

Documentation

The team should document briefly on the Documentation Form the decisions reached and any plans for mitigation, alternatives, or reason for denial. If the resident'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. List everyone who has been involved in these discussions.

IV. CARE PLANNING THE CHOICE

Process

If a mutual decision is reached as to how the team will accommodate a choice to maximize the resident's well-being, the team will work out with the resident the specific steps the staff will take to support that choice. The resident participates in the 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 resident. 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 resident'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 briefly on the documentation the decisions reached and the steps the staff will take to assist the resident and mitigate potential negative outcomes to the extent possible. This information is then included in the resident's plan of care.

V. MONITORING AND MAKING REVISIONS TO THE PLAN

Process

The interdisciplinary team will monitor the progress of the plan and its effects on the resident's well-being, as well as the ongoing desire of the resident to continue with the choice. The team will work with the resident to revise the plan as needed and desired by the resident. 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 and assessing the resident and his/her response to the planned interventions at a frequency that is appropriate for the particular person and choice.

Documentation

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

VI. QUALITY ASSURANCE AND PERFORMANCE IMPROVEMENT (QAPI)

Process

The care community's QAPI team should review trends related to resident choice and safety, particularly when residents are routinely denied requests, or when the QAPI team identifies patterns of community care practices that might be improved by performance improvement action plans.

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

- Denial of requests on a routine basis for more than one resident
- Failure to document assessment of decision-making capacity as related to consideration of requests
- Areas of community inability to accommodate resident 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

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

DOCUMENTATION FORM FOR HONORING RESIDENT CHOICE AND MITIGATING RISK

Resident Name: Harry Eisenstadt

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
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

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
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
Was care plan updated?					
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

Other comments

DOCUMENTATION FORM FOR HONORING RESIDENT CHOICE AND MITIGATING RISK

Resident Name: Elaine Murtha

I. IDENTIFY AND CLARIFY THE RESIDENT'S CHOICE		Date	Date	Date	Initials
What is resident's preference that is of concern?	Mrs. Murtha states that she 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			RM
Why is this important to the resident?	The texture and taste of the pureed food is unappealing. Especially since she retired, having healthy, nicely prepared and presented meals has been a high priority for her. Pureed foods do not fit into that preference.	9/5			RM
What is the safety/risk concern?	Mrs. Murtha has choked once (needing a Heimlich maneuver), takes a very long time to chew her food, and often coughs after swallowing.	9/5			RM
Who representing the resident was involved?	Mrs. Murtha, son and daughter-in-law. Son has a durable Power of Attorney for health care, and feels his mother should follow the advice of the professionals.	9/5			RM
Who on care team was involved in these discussions?	R. Moody-DON, T. Caffot, daytime RN, P. Porter, primary CNA, J. White, SLP, G. Ford, dietician	9/5			RM
II. DISCUSS THE CHOICE AND OPTIONS WITH THE RESIDENT		**Date**	**Date**	**Date**	**Initials**
What are the potential benefits to honoring the resident's choice?	Increased caloric consumption, greater satisfaction, higher quality of life, and liberalization conforms to current standards of practice.	9/5			RM
What are the potential risks to honoring the resident's choice?	Risk of choking during meals.	9/5			RM
What alternative options were discussed?	1) Working to improve the flavor and presentation of pureed foods 2) Trying a modified texture vs pureed process level 3) Working with Speech Language Pathologist and Dietician to identify: preferred foods that are safer without being pureed; which foods are deemed very unsafe if the texture is not modified; and foods that Mrs. Murtha prefers from these options. 4) Teach Mrs. Murtha the universal signal for choking, so she could get help quickly if needed 5) Mrs. Murtha will participate in dysphagia therapy to improve chewing and swallowing as indicated 6) Always having at least one soft "preferred" food, such as a creamed soup, available.	9/5			RM
What education about the potential consequences of the choice alternative actions/activities was provided?	Asked Mrs. Murtha to discuss with the staff the risks of eating regular textured foods, so they can be sure she understands. Social Worker explained to son that PoA for HC doesn't allow him to make choices for his mother while she is still capable of making decisions. The care community has the responsibility to determine and meet the resident's own preferences. Social worker explained to the son that Mrs. Murtha still retains decision-making authority and she is working with the staff to come up with a diet that honors most of her choices while eliminating the most dangerous foods. The son agreed it is important to honor choices as long as the staff think their mutually-agreed plan will be ok.	9/5			RM
Who was involved in these discussions?	Son, R. Moody-DON, T. Caffot, daytime RN, P. Porter, primary CNA, J. White, SLP, G. Ford, dietician	9/5			RM

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?	Options #3 and #5 were most preferred by Mrs. Murtha. First, staff will identify the foods that are considered to be most high risk, and make sure that on the days when that food is being served, the alternate menu option was something Mrs. Murtha liked and could eat with a regular or soft texture with less risk. Second, the dietician agreed to try to make her plate more appealing in its presentation — recognizing that this was something they should do for everyone. Finally, the family was asked to bring in some of her favorite foods that are naturally soft.	9/5			RM
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?	Mrs. Murtha, Son, Sally, Dietician, SLP, CNA	9/5			RM
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?	Yes	9/5			RM
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)?	Plan is to spend 1 week going through the menus to identify high risk foods and acceptable alternates for Mrs. Murtha. This coincided with the beginning of the next 5 week menu rotation. Primary CNA will document Mrs. Murtha's comments regarding food, in additional to their routine caloric assessment. SLP and dietician will meet with Mrs. Murtha and CNA each week for the 5 weeks to see how the new menu is working. A Speech-language pathology treatment plan for dysphagia will be initiated.	9/5			RM
Who has primary responsibility for monitoring the implementation?	CNA will track Mrs. Murtha's comments. Dietician to track consumption.	9/5			RM
Was there another option considered to be the "next best step" that would be implemented next?					

Other comments

DOCUMENTATION FORM FOR HONORING RESIDENT CHOICE AND MITIGATING RISK

Resident Name: Jerome Wilder

I. IDENTIFY AND CLARIFY THE RESIDENT'S CHOICE		Date	Date	Date	Initials
What is resident's preference that is of concern?	Mr. Wilder would like to have a glass of scotch prior to dinner each night. He wants to keep the alcohol in his room and to pour himself a drink whenever he desires.	9/18			RB
Why is this important to the resident?	Enjoying an occasional drink at the end of the day is a routine which has been an integral part of most of Mr. Wilder's adult life and he doesn't want to give up something he truly enjoys just because he is living in a nursing home. His wife agrees that he has not been himself since the nursing home told him that he couldn't drink when he wanted.	9/18			RB
What is the safety/risk concern?	Mr. Wilder is taking medication for depression that should not be taken with alcohol. Alcohol interactions with this medication may cause nausea, headaches, drowsiness, dizziness, fainting, changes in blood pressure, or loss of coordination. In addition, alcohol may interfere with his concentration and ability to use his walker, and therefore could lead to a serious accident. The nursing home does not have the budget to purchase alcohol for residents.	9/18			RB
Who representing the resident was involved?	Mr. Wilder, his spouse	9/18			RB
Who on care team was involved in these discussions?	Margie Statler, LSW, Renee Blankenhorn, RN	9/18			RB
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; also participation in life routine.	9/18			RB
What are the potential risks to honoring the resident's choice?	Potential fall and serious health complication from medication interaction. Staff are also concerned that because of Mr. Wilder's history of depression, he may have several drinks while sitting alone in his room or drink at other times during the day. Staff do not want Mr. Wilder to fall when he walks to the dining room after drinking.	9/18			RB
What alternative options were discussed?	It was proposed that staff store the scotch and pour just one drink when Mr. Wilder requests it before meals. It was also suggested that Mr. Wilder have a small snack with his drink so he would not be drinking on an empty stomach. The RN suggested speaking with the pharmacist and doctor to see if the medication should be given at a different time of day. Mrs. Wilder suggested that she purchase the scotch. Mrs. Wilder often visits after dinner and offered to discuss with her husband that he have a drink after dinner on the days she visits. This way, she will be company for her husband and there will not be as much of a concern about Mr. Wilder walking to the dining room after he has had a drink.	9/18			RB
What education about the potential consequences of the choice alternative actions/activities was provided?	Nurse educated resident about 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 interact with medications.	9/18			RB
Who was involved in these discussions?	Mr. Wilder, his spouse, Margie Statler, LSW, Renee Blankenhorn, RN	9/18			RB

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. Wilder rejects the option of having to ask the nurse for a drink and not storing the alcohol in his room. He retains his original desire to pour himself a drink before dinner when he wants it. Care team agreed to honor this request and take steps to provide a lockable drawer for the alcohol in his room. Mr. Wilder will be given the key to the drawer. PT Peter Hall asked to assess walking safety to dining room after Mr. Wilder has had a drink to ensure he is not at risk for a fall. Mr. Wilder agreed to these recommendations. He also agreed to have a snack with the drink and inform the nurse if he desired to have more than one drink.	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. Wilder, Peter Hall, PT, Margie Statler, LSW, Renee Blankenhorn, RN	9/18			RB
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.	The pharmacist and doctor will be consulted about the medication schedule. Care team will provide a lockable drawer for alcohol purchased by Mrs. Wilder. PT will assess walking safety to dining room after Mr. Wilder has had a drink to ensure he is not at risk for a fall. Mr. Wilder will have a snack with his scotch and to inform the nurse if he desires to have more than one drink.	9/18			RB
Was care plan updated?					
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. Wilder begins having an alcoholic drink prior to dinner.	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

Other comments

DOCUMENTATION FORM FOR HONORING RESIDENT CHOICE AND MITIGATING RISK

Resident Name: Mrs. Sing

I. IDENTIFY AND CLARIFY THE RESIDENT'S CHOICE		Date	Date	Date	Initials
What is resident's preference that is of concern?	Mrs. Sing wants to ambulate independently to the bathroom without staff supervision/assistance.	7/26			AC
Why is this important to the resident?	Mrs. Sing believes she can only maintain continence if she goes to the bathroom the moment she feels the urge to go.	7/26			AC
What is the safety/risk concern?	She has had 1 fall in the bathroom. Staff are concerned she might have another fall.	7/26			AC
Who representing the resident was involved?	Mrs. Sing	7/26			AC
Who on care team was involved in these discussions?	PCP – S. King GNP, B. Reeves Registered Dietician, M. Jones RN DON, S. Pushard LCSW, D. Williams RN, P. Wood Dietary Manager	7/26			AC
II. DISCUSS THE CHOICE AND OPTIONS WITH THE RESIDENT		**Date**	**Date**	**Date**	**Initials**
What are the potential benefits to honoring the resident's choice?	Maintenance of continence, greater self-esteem	7/26			AC
What are the potential risks to honoring the resident's choice?	Undetected fall	7/26			AC
What alternative options were discussed?	Discussed previous fall, and determined that fall occurred in part because Mrs. Sing has a hard time managing the door swing with her walker. Discussed taking door off and replacing with a privacy curtain. Also discussed a PT eval/training on how to manage door and walker better. Discussed trying to use the toilet regularly, so she can empty her bladder before she feels the urge to go. Discussed adding an additional grab bar in the bathroom for her stability.	7/26			AC
What education about the potential consequences of the choice alternative actions/activities was provided?	Mrs. Sing is aware of fall risk, but thinks her previous fall was "just an accident" since she has gone to the bathroom without incident many times before and since.	7/30			AC
Who was involved in these discussions?	Mrs. Sing, Mrs. Sing's daughter Julie Harris, PCP – S. King GNP, B. Reeves Registered Dietician, M. Jones RN DON, S. Pushard LCSW, D. Williams RN, P. Wood Dietary Manager	7/30			AC

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?	Mrs. Sing agreed to use the toilet on a regular basis, but stated that if she felt the urge to go, she would still go to the bathroom on her own. She also liked the idea of removing the door and replacing it with a curtain, because she knows she struggles to manage the door and the walker.	7/30			AC
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?	N/A	7/30			AC
Who was involved in these discussions / decisions?	Mrs. Sing, Mrs. Sing's daughter Julie, Mrs. Sing's son-in-law Joe, Primary Care Provider S. King GNP, B. Reeves Registered Dietician, S. Pushard LCSW, D. Williams RN	7/30			AC
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.	First, RN to coordinate PT meeting with Mrs. Sing to review discussions and conduct eval. for bathroom access, training and adaptive equipment needs (grab bars, better lighting, etc). PT recommendation to remove door / replace with curtain, add automatic night light, add one additional grab bar. SW to coordinate these changes with maintenance. Mrs. Sing has a watch with an alarm—CNA will help her set it to gently remind her to use the bathroom more frequently.	7/30			AC
Was care plan updated?	Yes	7/31			AC
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)?	2 weeks – meet to evaluate the changes. Determine if regular toileting is working.	7/31			AC
Who has primary responsibility for monitoring the implementation?	LPN to oversee PT and Maintenance determining what needs to be done, and getting changes made.	7/31			AC
Was there another option considered to be the "next best step" that would be implemented next?	If curtain facilitates safer entry to bathroom, may consider eliminating the toileting schedule	7/31			AC

Other comments

Sample Form

DOCUMENTATION FORM FOR HONORING RESIDENT CHOICE AND MITIGATING RISK

Resident Name: _____

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?					
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?					

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?					
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?					
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?					

Other comments

ROTHSCHILD PERSON-CENTERED CARE PLANNING TASK FORCE

1. **Robin Arnicar,** National Association Directors of Nursing Administration in Long Term Care
2. **Heidi Barcus,** London & Amburn
3. **Carol Benner,** Consultant in the fields of performance improvement and long term care
4. **Marjorie J. Bott,** University of Kansas School of Nursing
5. **Carmen Bowman,** Edu-Catering
6. **Jennifer Brush,** Brush Development; Rothschild Person-Centered Care Planning Task Force Steering Committee
7. **Kenneth Burgess,** Poyner Sprill, LLP.
8. **Margaret Calkins,** IDEAS Institute; Rothschild Person-Centered Care Planning Task Force Steering Committee
9. **Eric Carlson,** Justice in Aging
10. **Diane Carter,** American Association of Nurse Assessment Coordination
11. **Mary Casper,** HCR ManorCare
12. **Kim Clayton,** Nursing Home Administrator, Consultant
13. **Gail Clarkson,** American Health Care Association; The MediLodge Group
14. **Amy Cotton,** National Gerontological Nursing Association, Eastern Maine Healthcare Systems
15. **Lynda Crandall,** Pioneer Network
16. **Mary Ellen Dellefield,** VA San Diego Healthcare System
17. **Patty Ducayet,** National Association of State Long Term Care Ombudsman
18. **Charlotte Eliopoulos,** American Association for Long Term Care Nursing
19. **Carol Ende,** The Eden Alternative
20. **Myron Gelsinger,** LifeBridge Health
21. **Robert Gibson,** Edgemoor DP SNF
22. **David Godfrey,** ABA Commission on Law and Aging
23. **Marianna Grachek,** American College of Health Care Administrators
24. **Robyn Grant,** National Consumer Voice for Quality Long-Term Care
25. **Margie Heald,** Office of Health Care Quality, State Survey Agency
26. **Jennifer L. Hilliard,** LeadingAge
27. **Cory Kallheim,** LeadingAge
28. **Ruta Kadonoff,** American Health Care Association
29. **Marshall Kapp,** Florida State University Center for Innovative Collaboration in Medicine and Law
30. **Michele Laughman,** Division of Nursing Homes, Survey & Certification Group, Centers for Medicare & Medicaid Services
31. **Cathy Lieblich,** Pioneer Network
32. **Robert Mayer,** Hulda B. and Maurice L. Rothschild Foundation; Rothschild Person-Centered Care Planning Task Force Steering Committee
33. **David McGuffey,** Elder Law Attorney, Practice of David L. McGuffey
34. **Barb Miltenberger,** American Health Lawyers Association
35. **Sue Misiorski,** PHInternational
36. **Evvie Munley,** LeadingAge
37. **Doug Pace,** Advancing Excellence in Long Term Care Collaborative
38. **Sam Plaster,** Missouri Department of Health and Senior Services
39. **Linda Roberts,** Linda Roberts Consulting
40. **Joseph Rodrigues,** State Long-Term Care Ombudsman, California Department of Aging
41. **Judah Ronch,** The Erickson School at University of Maryland Baltimore County
42. R**aymond Rusin,** Rhode Island Department of Health, Office of Facilities Regulation
43. **Karen Schoeneman,** Retired CMS Deputy Director; Developer of Creating Home CMS/PN Symposiums; Rothschild Person Centered Care Planning Task Force Steering Committee
44. **Carol Shockly,** Office of Long Term Care, Arkansas Department of Human Services
45. **Jo Siebert,** Former state surveyor, elder care advocate
46. **Lori Smetanka,** National Long-Term Care Ombudsman Resource Center; National Consumer Voice for Quality Long-Term Care
47. **Nate Sweeney,** St. Elizabeth's
48. **Kimberly S. Van Haitsma,** College of Nursing, Program for Person-Centered Living Systems of Care, Pennsylvania State University
49. **Jacqueline Vance,** American Medical Directors Association
50. **Laura M. Wagner,** University of California, San Francisco School of Nursing, Department of Community Health Systems
51. **Peggy E. Williams,** QIS Trainer/Surveyor, Healthcare Management Solutions LLC