Family Matters: Creating Care Partners

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Session Objectives

- Be able to identify strategies for building relationships and trust with resident family members.
- Take home tools to increase family involvement in the care planning process.
- Be able to discuss the role of the relationship with family members in risk and clinical care decisions.

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Question 1

In an ideal world what would the relationship between you and the nursing home your loved one is in look like?

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Question 2

What are the barriers that could prevent this ideal from being your reality?

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Question 3

How can these barriers be overcome?

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A Few Barriers

- Traditional Nursing Home Structure
- Unrealistic Expectations
- Lack of Trust
- Power dynamic (control)
  - Professional titles
  - Caregiving roles
- Communication
- Grief process for family member

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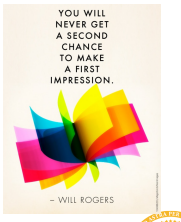
Starting the Relationship

- Trust
- Expectation
- Shared Understanding
- Language
  - Nursing Home Speak
  - Control vs. Partnership



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Move-In

- Personalize the experienc
  - Everyone has a role
- Clinical preparedness
- Family guidebook
- Tour & Introductions
- Task vs Person Centered

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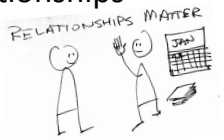
On-going Relationships

- Communication
  - Assumptions
  - Non-verbal
  - Honesty/Trust
  - Balanced- not only on the bad or required
  - Social Media/e-mails
- Hospitality
- Integrating family into community life



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Careplans

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Careplans

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What/Why

- Understanding
- Temporary plan
- Invitation
- Resident goals
- Feedback opportunity

Who/When

- Resident choice
- Direct care staff
- Convenience
- On the spot talks

Where/How

- Location matters
- Alternatives
- Arrangement matters
- Language matters

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Choice: Risky Business

- Risk is normal part of life
- Shared Understanding
  - Team members are prepared and expected to support resident decisions.
  - Decision making when the choice of the resident may not be in agreement with policy, may pose risk to the resident, or does not agree with the caregivers' personal value set.

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RISK – Person Centered Care

- Considerations
  - Risk discussion with staff
    - Clarify facility position on risk
    - Expectations of how staff are to respond
    - Consider the severity of risk
  - Education
  - Documentation
  - Avoid "blanket policies"

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Case Study

- Resident Tom is 76, very intelligent and is very proud of being a great contributor to his community over his life time.
- Nearing the end of his life, he was diagnosed with dysphagia following a swallow study. The physician orders nothing to be taken by mouth, to moisten his mouth and administer feeding by peg tube.
- Tom was insistent on two things: his diet coke and his tapioca pudding.

The challenge: how do we deal with request, knowing it is against physician's orders, and knowing that the swallow study showed very high aspiration.

How would we approach this challenge?

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Approach

- **Person Centered Care Model**:
  - Direct care staff listens to the request.
  - Passes information to charge nurse
  - Nurses/Social worker engages resident and family in conversation about the request and discuss the risk if resident chooses to eat.
  - The nurse documents the conversation, notifies the physician of resident's choice and documents in residents medical records including the **care plan**.
  - Family and staff help resident to use swallowing precautions to minimize as much risk as possible.
  - Nursing staff is empowered to provide care to the resident as per his choices.
- **Medical model:**
  - "NO" and that would be the end of the story.
  - End of life request would be ignored
  - Resident's family has to sneak resident the food and feel the guilt of their actions.
  - Staff feel they have failed

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Case Study

- Norma is 84 years old with progressing dementia. Her increased weakness affects her ability to be safe up in room by herself. She wants to be independent with ADLs and prefers to have the door to her room shut at all times.
- She had several falls and family wants her to have a personal alarm so that she is never falls.
- Personal alarms cause her anxiety and limits her mobility which would continue to increase weakness.

Challenge: How do we handle the unrealistic expectations of family? How can family and facility staff work toward a plan of care that will mitigate risk of falls and give the resident rights.

- **How would you approach this challenge?**

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Approach

- Person Centered Care Model:
  - Resident, Family invited to a team meeting with direct care staff that are consistently assigned to Norma.
    - Discuss situations around falls.
    - Provide education and best practice research
    - Develop plan that mitigates risk of injury when falls occurs and Norma can be free of restraints, maintaining the independence she still has.
- Medical Model
  - Resident would continue to use personal alarm as per families wishes.
  - Norma's anxiety increased to aggressive behavior.
  - Drugs requested to control the anxiety.
  - Weakness and falls continue.

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Why the effort?

- Create Care Partners
- Reduce staff time on family concerns
- Mole hills are mole hills
- Create "we" instead of "us vs. them"
- Improved care for resident
- Opportunity for organization
  - Volunteers, donations etc.
  - Word of Mouth advertising

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Considerations: RISK

Things to consider when developing your training on how to respond when residents make a risky decision

We do not have a formal training developed for you. Each home must look at their own practices and expectations re: Risk and build a training around that. The training should be specific to your home.

There are some things we encourage you to consider when developing your training:

Before developing the training it will be helpful for the team to get together and try to **clarify your position on risk**. What do you expect of your staff? How do you want the team to respond when a resident makes a risky decision? What kinds of situations do you want the nurse to be directly involved with? What kind of situations do you just want the team to tell the nurse about later?

For example: I might be comfortable with a direct caregiver giving an elder with Diabetes a piece of pie and then informing the nurse that she has done so, so blood sugar can be monitored.

I might be comfortable with a direct caregiver supporting a resident in the request to skip breakfast because they are not hungry. I would want that communicated to the team so everyone would know to offer the resident something to eat again in a little while.

However, I might not be comfortable with a direct caregiver giving a requested steak to a person with a diet order for Pureed foods due to a high risk of choking. In that case I may want the nurse involved before the steak is served.

As a team, talk through possible situations and think about how you want your team members to respond.

Teach your team how to respond to an elder making a risky decision. Be sure your team understands that all residents have the right to make their own decisions and the right to make what may seem like risky decisions. Your goal is to accommodate resident decisions while mitigating risk. We can no longer simply tell a resident that they cannot do something.

Encourage your team not to respond with "I need to ask the nurse" as this indicates to the resident that the nurse has the final say instead of the resident. If nurse support is needed it may be better to respond, "OK, let me see what I can do about this".

As a team you will **consider the severity of risk** to self and others as you decide what your expectations are. Will the choice place the elder or others in immediate jeopardy or a life-threatening situation? How will you train your team to think through this?

All team members should be expected to **determine exactly why a person is choosing not to follow a physician order while they are directing their own life**. Train caregivers to ask questions of elders and try to work through the elders concerns. Caregivers should understand that they are expected to talk with elders about these things.

Talk about available alternatives and staff approaches to mitigate risk. Talk about alternatives your direct care staff can offer and different staff approaches that a nurse might use. Can you train your direct caregivers to offer these alternatives rather than immediately saying "I'll go ask your nurse"?
We are required to educate elders about the consequences of their decisions. All team members should understand that while they are expected to support resident decisions, they are also responsible to educate residents of any potential consequences or health risks that might result from their decision.
Keep in mind that if a person makes *the same* risky decision over and over, we are not required to provide them "a lecture" each time they make the same decision. For example: If a person with Diabetes has decided that they are going to have a serving of regular dessert each day at lunch, this can be addressed in the Care plan. Educate the elder about the potential health risks of their decision and offer healthy alternatives. If they continue to state that they plan to eat a dessert each day at lunch the team should document this and address it on the care plan. They do not need to re-educate the elder every day at lunch. However, is recommended that on-going assessment should be done to determine the resident's wishes have not changed. The subject should be revisited again at each Care plan meeting and if the elders condition changes.

Consider where/how you want these things documented. Team members should understand that all efforts made by the team to mitigate risk need to be documented. Take credit for what you have done to try to keep the elder safe. Discussions you have had about why the resident is making the decision, alternative you have offered and education you have provided to the elder about the risks of their decision should all be documented. Team members need to understand the documentation process in your home and what is expected of them.

Person centered care plans should address risk. If a resident consistently makes decisions that are not in line with physician orders this should be addressed on the care plan. Involving direct caregivers in the care plan process can go a long way in empowering them to support resident decisions and to know how to respond when a resident makes a risky decision.

Encourage team members to make decisions on an individual basis. Avoid "blanket policies". For example: It may not be safe for a person with Dementia to sit outside alone and watch the cars go by, so a "blanket policy" would say that no one will be allowed to do so.