How Life Storytelling Can Improve Care and Create Connections

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Objectives

• Discuss and understand the research that supports the value of life story telling.

• Compare and contrast current DIY questionnaires versus person-to-person interviews.

• Evaluate the power of narratives and how they can impact care
What the research is telling us

“Life story work has the potential to: enable care staff to see the person behind the patient; allow family carers to uphold their relatives’ personhood; enable the voice of the person with dementia to be heard, verbally and non-verbally; be enjoyable for all concerned and enable the person with dementia to feel proud about themselves and their lives.”


“The creation of a life story book … has benefits for people with dementia, relatives and staff in care homes.”

What can prevent a person from being well-known?

Dementia

- Inability to tell their own story in words
- Viewing the person through the “lens” of dementia
  - No longer tied to their past
  - No longer connected to family, friends, or community
  - Loss of self/Loss of identity—not good historians

But is this really true?

How can we overcome this stigma and view the person with dementia through another lens---KNOWLEDGE OF WHO THEY ARE/WERE PRIOR TO THE DISEASE?
What can prevent a person from being well-known?

- A culture that is not based in person centered approach
- A lack of information
- Non-curious care partners
- Ageism and assumptions
- Associates not being given the time
- A focus on the “Golden Girls”
What are the ills of not being well-known

• Not feeling a sense of belonging
• Lack of ability to form a bond with care partner—bad for both partners
• Lack of purpose or connection to the community
• If a person’s routines, habits, preferences, and personal styles are not followed—may lead to a lack of cooperation or desire to participate in their own care
• Lack of engagement/participation may lead to a decrease in self-esteem
  • Doing what we do well is what makes us feel good about ourselves
The life story is the most powerful tool we have for providing person-centered care.
Why life story KNOWING is important

It is not enough to simply gather information—telling/showing that information to those who require it is critical.

How are you connecting your associates to the information?
And then...the most important step: Integration

Integrating what information we learn about the person is critical to provision of person centered care

- Knowing the person gives us the tools we need to truly *partner* with them in their care
- Enables the provision of meaningful, purposeful engagement
- Understand their family systems
- Know how best to help structure their daily experience
- Problem-solve behavioral expressions
Vandy professor wins Nobel Prize

Nashville Sound of the '80s has gone its diverse ways
What is important to know and when?

What is critical to know PRIOR to move-in?

(especially in dementia care)

• Preferred name?
• Right or left handed?
• Deeply held religious/spiritual practices?
• If military service in past—do they like to reminisce about it or are there sensitivities?
• Close family names?
• Did they leave a pet behind?
• Bathing preferences and beauty routines?
• What soothes them?
• Sleep/wake times?
• Favorite foods?
What is our current standard?

Currently families and staff fill out questionnaires

Questionnaires can be:
• time consuming and frustrating for both associates and family
• can take months to get back from families or may never get done
• often illegible or incomplete
• uneven knowledge: some are detailed, others empty
• families find them often painful to answer
Group Activity

Step One: Each person should take out a sheet of paper and describe in 5-10 lines their parent’s marriage.

Step Two: Some will volunteer to read the results and describe their experience.
The Power of Storytelling

Group Activity--Whiteboard

What are the elements of a good life story?
Group Activity

**Step One:** Break into pairs and interview one another about your parent’s marriage. Try to elicit narrative.

**Step Two:** Write a brief report of your partner’s story.

**Step Three:** Some will share their stories and talk about the difference in the 1st exercise and the experience of writing your own and the 2nd exercise and having someone else to write it for you.
Summary

• Life storytelling is central to person-centered care.
• DIY questionnaires are burdensome on families and often ineffective.
• Whether with caregiving staff or professional writers, interviewing the family and capturing their answers is more effective.
• Remember the tips for your staff on how to best capture a narrative: make a checklist of important points and show don’t tell.
• Stories put the person in person-centered care.
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