

## DOES HE TAKE SUGAR?

# GIVING PEOPLE WITH DEMENTIA A VOICE: HOW STORYTELLING CAN SHAPE FUTURE CARE

**P**lanning for future care is something most of us avoid. It's uncomfortable, emotional, and often feels like something to deal with "later."

But for people living with dementia, "later" can arrive sooner than expected. These conversations are often delayed until a crisis hits. This means decisions are usually made for them, not with them. And in that moment, something important is lost. Because the real question shouldn't be about sugar at all. It should be: What is important to this person right now? A new study set out to change that by exploring a simple but powerful tool: storytelling.

**The research asked a big question: Can storytelling help people with dementia express what matters to them before they move into a care home?**



Stories are how we share who we are, our memories, values, routines, and the little details that make us feel like ourselves. For people with dementia, storytelling can help maintain identity and dignity. As one participant said, staff often talk over the person and ask family members instead "Does he take sugar?"

It's the kind of question that helps someone make a cup of tea. But it also reveals something deeper. When that question is asked, it's rarely directed at the person themselves.

The study found that storytelling:

- Helps people feel heard
- Builds trust between staff, families, and the person with dementia
- Makes care more personal and meaningful
- Helps staff understand behaviours that might otherwise seem confusing

**Stories give context. They help care staff see the person, not just the diagnosis**

**“Staff have significant time pressures... how can we find that time in care to really use storytelling?”**

Storytelling is one of the most natural things we do. It's how we explain ourselves, connect with others, and make sense of our lives. Long before care plans and assessments existed, there were stories.

And for people living with dementia, those stories still matter, perhaps more than ever.

A story can hold identity when memory begins to shift. It can reveal what brings comfort, what causes distress, what feels familiar, and what truly matters. It can turn a list of needs into a living, breathing picture of a person.

Yet, despite this, storytelling is rarely used intentionally in care planning. It's seen as an informal, optional extra rather than essential.

There's no single “right moment” to start talking about future care. Instead, it depends on something far more human: emotional readiness. Acceptance of a diagnosis. Trust in the person asking the questions. When storytelling is framed as a way to leave something behind, a legacy, a record of what matters it feels different. Less like planning for loss, and more like preserving memories.

**“I always find it sad that I learn more about someone at their funeral and think there were missed opportunities for conversations or meaningful activities.”**

For storytelling to work, the environment matters. People need to feel safe, not just physically, but emotionally. They need space to speak without being corrected, rushed, or spoken over. Interestingly, those closest to us can sometimes make this harder. Family members, often with the best intentions, may step in to fill gaps, answer questions, or reshape the narrative. In doing so, they can unintentionally quiet the very voice we're trying to hear.

Creating space where the individual can speak freely, even if the story is fragmented or nonlinear, is essential. Because the value lies not in accuracy, but in expression.

We often think storytelling begins with a question: “Do you remember when...?” But memory doesn't always respond to direct prompts. Instead, stories are often unlocked by evoking the sense. Through the smell of something familiar cooking. The rhythm of a song. The feel of a well-worn object or material. The sight of a photograph or a place once loved.

**“Putting something meaningful in people's hands is a great way to start a conversation or story.”**

The research proposes storytelling based on four themes can help people with dementia provide vital information for care staff.

People – relationships, friendships, family

Places – homes, holidays, meaningful locations

Items – keepsakes, clothing, treasured objects

Traditions – routines, rituals, cultural practices

**Wearing a loved one's cardigan can bring comfort and connection.**

Care professionals agreed that choosing the right people to facilitate storytelling workshops is essential, particularly given the time commitment involved. Participants highlighted that some care staff naturally “get it,” bringing a certain “magic,” empathy, and flexibility to their support, qualities that make them ideal facilitators. Effective facilitators need not only dementia knowledge and communication skills, but also a genuine interest in people, trustworthiness, and the ability to help individuals feel comfortable enough to share through a balance of interest, humour, vulnerability, and engagement.



The research found value of storytelling spanned across the all stages of dementia, both in shaping care plans before formal support is needed and in giving people a voice in reviewing their care, aligning with Care Quality Commission expectations.

Capturing and presenting personal stories for use in care plans emerged as a crucial yet often overlooked aspect of dementia care. Conversations about “what the person wants and how to deliver it” rarely take place during transitions into care homes, particularly when moves are rushed, such as during hospital discharge. When people with dementia and their families better understand what a care plan involves, they are more likely to record meaningful information, though this relies on care professionals valuing and correctly using what is shared.



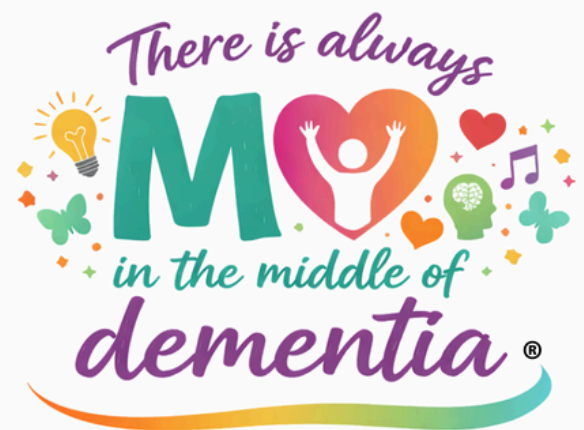
**A man stopped eating because he believed he couldn't pay. Giving him a wallet and coins solved the problem.**

When care professionals understand someone's life, where they've been, what they've loved, what they've lost, care begins to change. Behaviour is no longer just behaviour. It becomes communication.

What might look like agitation could be a response to something deeply rooted a memory, a fear, a need that hasn't been met. And with that understanding comes the ability to respond differently.

**A woman became distressed in a purple bedroom because, in her culture, purple is associated with death.**

At its heart, this work is about protecting personhood. Dementia can affect memory, language, and behaviour, but it does not erase identity. The essence of who someone is remains. It ensures people are not reduced to a diagnosis or a set of needs. It keeps their identity present in the decisions made about their care. It gives them a voice even when words become harder to find.



**By asking, “What is the feeling?” care professionals can interpret behaviour as communication,**

For storytelling to move from idea to everyday practice, there are real challenges to address time pressures in care settings that make meaningful conversations difficult. Time to listen, to understand and to connect

The potential benefits are significant not just for individuals, but for families and care professionals too.

This research shows that storytelling isn't just a pleasant activity, it's a powerful way to preserve identity, strengthen relationships, and ensure people with dementia have a voice in decisions about their future. Because ultimately, good care starts with a simple question, not “Does he take sugar?” but: “Who is this person, and what matters most to them?”

Email [martha@icareexcellence.co.uk](mailto:martha@icareexcellence.co.uk) to learn more about My Story, My Future Storytelling Resource and evidence-based training iSTORY & iDEM