

## Why the ‘distorted memories’ of people with dementia are so important

**W**hat is the best way to help people who have dementia? Many interventions are aimed at enabling them to retain self-defining memories and beliefs. In [reminiscence](#) therapy, they are invited to talk about past events or experiences with the help of prompts such as photographs or significant objects. In *validation* therapy, there is an explicit recognition that they may no longer be in touch with reality due to memory impairments, and could benefit from exploring their own sense of reality, building trust with caregivers and reducing anxiety. In *life story work*, people with dementia are helped to come up with a story that reminds them of key events and aspects of their lives, promoting connections with friends and family. In the controversial *contented dementia* approach described by Oliver James’s book of the same name, the caregiver is encouraged to enter the often-delusional world of the person with dementia and ‘play along’, following a script and without contradicting.

What these different approaches all have in common is an acknowledgement that, in people with dementia, core beliefs about who they are (what is often called *identity* or *sense of self*) are threatened by memory loss, and need to be preserved to enable socialisation and improve function. Scientists have observed that when we get older we seem to have more memories and more detailed recollections of the events experienced in adolescence or early adulthood (from 10 to 30 years old), during the so-called *reminiscence bump*. This is because we take those events to be self-defining, central to who we are.

We tend to underestimate the extent to which we change through time due to a consistency bias – we simply fail to update our self-image in the light of new developments. But this is particularly evident for someone with dementia, who often sees herself as she was before the onset of illness, when she was active, busy and independent. By being encouraged to remember the achievements and passions of our younger selves, we can hang on to the sense of who we are.

In her book *Keeping Mum* (2011), the British philosopher Marianne Talbot describes how her mother was a great storyteller before she had dementia. One of her best stories was how one day, when she was 14, Marianne’s mother was late for school because her own mother had just given birth to twins. The headmistress did not believe that that was the reason for being late and punished her, which she felt was a great injustice. When dementia advanced, the story about the twins’ birth ended up being merged with other stories (for instance, other stories about being late for school) and was repeated many times.

[dementia 7 2018](#)

In their [research](#) on narrative and identity in Alzheimer’s disease, Lars Christer Hyden and Linda Örvulv both of Linköping University in Sweden, studied stories told by two women with Alzheimer’s disease, one of them called Martha.

Martha often told the story of how she had learned to drive and bought a car, defying the doubts of her husband and her own family. This was something she was proud of because not many women at the time would have done the same. Aspects of her story were repeated frequently, even during the same conversation, and presented a number of inconsistencies.

The distorted and repetitive memories that Marianne's mother and Martha reported are problematic because the inconsistencies meant that some of their beliefs were likely to be false. The repetitions suggested that they had no awareness of having told the story before, to the same audience. It is, nonetheless, important to repeat stories that we find central to our lives, even if they contain inaccuracies and audiences stop being engaged. Why so?

When we no longer have access to autobiographical information, we can progressively lose our identity – that is, we retain fewer beliefs about ourselves and our past, and the content of those beliefs becomes ever more [vague](#). This has a negative effect on our wellbeing: we lose the confidence to answer questions and participate in conversation with others, and find it particularly challenging to integrate information from the lives we lived before the illness began.

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In the face of a threatened identity, the ability to tell a story that played a key role in our lives and underlies our self-conceptions (the *unfairly punished teenager*, the *defiant woman*) is vital on two counts. First, we reap *psychological* benefit from a greater sense of wellbeing. The telling of the story is likely to enable social exchanges and enhance self-confidence at a time when the risk of isolation is high.

Such psychological benefits can easily translate into epistemic benefits – a positive effect on the capacity to acquire, retain and use relevant knowledge. All those social exchanges, after all, allow us to continue sharing information with others and receiving feedback from them. Repeating the same story increases the chances that the story will be remembered for longer, reinforcing our conception of ourselves.

In the case of Marianne's mother, it was the sense that she was an honest girl who had been unfairly punished; in Martha's case, it was the sense that she would follow her own mind and not be conditioned by the views of others. Self-defining beliefs are retained as a result of repeatedly reporting memories that are distorted.

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Obviously, an accurate memory report would play these positive roles and

avoid all the trouble with inaccuracies and inconsistencies: reality would not be misrepresented. However, in the clinical context of dementia, accurate memories are hard to come by because there are fewer constraints on memory reports and fewer opportunities for self-correction. Challenging a report as inaccurate might not have the desired outcome of prompting more accuracy, but could result in a refusal to engage further. The story would be lost.

This has some interesting implications for how the reporting of distorted memories in dementia is managed. Trading serenity for authenticity by encouraging people with dementia to live happily in a

delusional world rather than miserably in the actual world might sound patronising and disrespectful. However, a careful examination of the positive epistemic role of distorted memories in the preservation of self-defining beliefs – and an acknowledgement of the fragility of both personal stories and storytellers in dementia – should promote a reassessment here.

Martha might have forgotten all about being a strong-willed woman if not for the broken record of her inconsistent story about getting a driving licence and buying a car. And that is why we should be open to the possibility that, in some circumstances, false beliefs are incredibly useful and, as counterintuitive as it might seem, essential to the retention of the knowledge that matters.

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