

Terminal lucidity: Why do loved ones with dementia sometimes 'come back' before death?

May 7 2024, by Yen Ying Lim and Diny Thomson



Credit: Andrea Piacquadio from Pexels

Dementia is often described as "the long goodbye." Although the person is still alive, dementia slowly and irreversibly chips away at their

memories and the qualities that make someone "them."

Dementia eventually takes away the person's ability to communicate, eat and drink on their own, understand where they are, and recognize [family members](#).

Since as early as the [19th century](#), stories from loved ones, caregivers and [health care workers](#) have described some people with dementia suddenly becoming lucid. They have described the person engaging in meaningful conversation, sharing memories that were assumed to have been lost, making jokes, and even requesting meals.

It is estimated [43% of people](#) who experience this brief lucidity die within 24 hours, and 84% within a week.

Why does this happen?

Terminal lucidity or paradoxical lucidity?

In 2009, researchers Michael Nahm and Bruce Greyson coined the term "[terminal lucidity](#)," since these lucid episodes often occurred shortly before death.

But not all lucid episodes indicate death is imminent. [One study](#) found many people with advanced dementia will show brief glimmers of their old selves more than six months before death.

Lucidity has also been [reported](#) in other conditions that affect the brain or thinking skills, such as meningitis, schizophrenia, and in people with brain tumors or who have sustained a [brain injury](#).

Moments of lucidity that do not necessarily indicate death are sometimes called [paradoxical lucidity](#). It is considered paradoxical as it defies the

expected course of neurodegenerative diseases such as dementia.

But it's important to note these episodes of lucidity are temporary and sadly do not represent a reversal of neurodegenerative disease.

Why does terminal lucidity happen?

Scientists have struggled to explain why terminal lucidity happens. Some episodes of lucidity have been reported to occur in the presence of loved ones. Others have reported that [music can sometimes improve lucidity](#). But many episodes of lucidity do not have a distinct trigger.

[A research team from New York University](#) speculated that changes in [brain activity](#) before death may cause terminal lucidity. But this doesn't fully explain why people suddenly recover abilities that were assumed to be lost.

Paradoxical and terminal lucidity are also very difficult to study. Not everyone with advanced dementia will experience episodes of lucidity before death. Lucid episodes are also unpredictable and typically occur without a particular trigger.

And as terminal lucidity can be a joyous time for those who witness the episode, it would be unethical for scientists to use that time to conduct their research. At the time of death, it's also difficult for scientists to interview caregivers about any lucid moments that may have occurred.

Explanations for terminal lucidity extend beyond science. These moments of mental clarity may be a way for the dying person to say final goodbyes, gain closure before death, and reconnect with family and friends. Some believe episodes of terminal lucidity are representative of the person connecting with an afterlife.

Why is it important to know about terminal lucidity?

People can have a variety of reactions to seeing terminal lucidity in a person with [advanced dementia](#). While some will experience it as being peaceful and bittersweet, others may find it deeply confusing and upsetting. There may also be an urge to modify care plans and request lifesaving measures for the dying person.

Being aware of terminal lucidity can help loved ones understand it is part of the dying process, acknowledge the person with dementia will not recover, and allow them to make the most of the time they have with the lucid person.

For those who witness it, terminal lucidity can be a final, precious opportunity to reconnect with the person that existed before dementia took hold and the "long goodbye" began.

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