

# Dementia caregivers' dilemma: 'No tube feeding? Am I killing him?'

Tube feeding worsens a patient's quality of life. But many caregivers feel they have no choice.



In advanced stages of dementia, older adults slowly lose the ability to eat and drink, become bedridden and more prone to infections. Failure to understand this trajectory in dementia leaves caregivers confused and ill-prepared to make crucial decisions regarding care for their loved ones, such as how to manage eating difficulties. ST PHOTO: NG SOR LUAN

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He couldn't say anything. But Elizabeth would look into his eyes and he would hold her gaze. She would then greet him and he would smile at her.

He was already in the late stage of dementia but was still responsive. Elizabeth (not her real name) felt he was still there.

Tirelessly, she cared for her father, who was bedridden and incontinent. He also had difficulty swallowing.

Elizabeth tried everything to get him to eat just a little more food: she used thickener, prepared soft foods, even blended foods. But mealtimes extended beyond an hour with lots of coughing. The doctor cautioned that her father might choke if this continued. But what about tube feeding?

Both her father's doctor and speech therapist suggested that a thin plastic tube inserted through her father's nose into the stomach could offer a solution.

Elizabeth promptly agreed,

seeing no other option available to her.

But were the consequences evident?

Advanced dementia is an incurable condition, which shortens the lifespan of patients. Globally, dementia is the seventh leading cause of death. Yet, while many caregivers recognise there is no cure for dementia, few comprehend its life-limiting nature.

At Duke-NUS' Lien Centre for Palliative Care, we conducted a study, titled Panel study Investigating Status of Cognitively Impaired Elderly in Singapore (PISCES), in which we surveyed 215 family caregivers of individuals with advanced dementia every four months, between May 2018 and June 2022.

We found that only 26 per cent of participants recognised their loved one's advanced dementia as a life-limiting condition. Moreover, their "understanding" would shift by the day – sometimes they thought their loved one was already at the end of the road, but at times, they felt there was still a long journey ahead.

Many caregivers perceive symptoms of dementia like forgetfulness and cognitive decline as part of the normal

ageing process. However, in advanced stages of dementia, older adults slowly lose the ability to eat and drink, become bedridden and more prone to infections.

Failure to understand this trajectory in dementia leaves caregivers confused and ill-prepared to make crucial decisions regarding care for their loved ones, such as how to manage eating difficulties.

## MANAGING EATING DIFFICULTIES

Eating difficulties are nearly universal in older adults with advanced dementia. When eating difficulties arise, caregivers struggle with an emotionally difficult decision.

Should they continue with hand feeding despite the perceived risks of weight loss, dehydration, starving and choking; or turn to tube feeding?

Their considerations are multi-faceted. Another dementia caregiver from our PISCES study, who looked after her mother, shared: "I realised that it's just a process where the body has come to a stage when it is shutting down. So why force her to eat when she doesn't want to eat?"

But yet another caregiver held a different view: "You can't just

starve a person because he or she doesn't eat, right? I mean, it's a basic, you know, thing to do, right?"

Leading geriatrics societies, such as the American Geriatrics Society, do not recommend tube feeding for older adults with advanced dementia.

Instead, experts recommend careful hand feeding because it has been shown to be as good as tube feeding. This is based on a lack of evidence that feeding tubes extend survival. There is also growing evidence of complications related to feeding tubes including blockage, dislodgement and agitation, as well as increased use of restraints and pressure ulcers.

While some individuals with dementia may benefit from tube feeding during an acute illness if they were previously eating well, long-term tube feeding to manage eating difficulties is unlikely to result in weight gain or improve survival.

Nevertheless, the PISCES study found that many caregivers believe tube feeding is the only option to manage eating difficulties and are unaware of the complications that may arise from its long-term use. Some agreed to tube feeding when other family members insisted.

Elizabeth said she could not make the decision to not tube feed her father. "I think it's not my call to make," she shared. "It's different if he (my father) made the decision, then it's easier for me to order but now, if I were to do it, then it feels like I am killing him."

Yet, as caregivers observe their loved one's quality of life diminish with tube feeding, many regret their decision and feel they were not adequately informed to make it.

In our study, half of caregivers who initiated tube feeding acknowledged, in hindsight, that it reduced their loved one's quality of life.

Moreover, we found that caregivers who initiated tube feeding experienced significantly more anxiety and depression than caregivers who did not.

For Elizabeth, the decision to resort to tube feeding is one she now questions. While the feeding tube provided him with nutrition, her father would often pull it out of his nose.

As his condition worsened, he developed multiple infections over time requiring hospitalisations and surgery.

All the while, he developed sores and more blisters and bed sores all over his body.

Having seen her father's

struggles over the years, Elizabeth insists she would not have agreed to tube feeding so quickly – perhaps not at all – and certainly would not want it for herself.

## THERE ARE OPTIONS

How can we help caregivers like Elizabeth avoid feelings of regret? First, we must recognise that advanced dementia is a life-limiting illness affecting body functions beyond the brain.

This represents a shift in how we think about advanced dementia in older adults, not approaching it as a disease we can conquer, but supporting older adults and their caregivers to live with dignity.

Societal recognition of this reality, in turn, supports caregivers like Elizabeth by providing a foundational understanding of advanced dementia to inform care decisions.

Second, before making decisions, caregivers need clear and balanced information to understand the pros and cons of the relevant feeding options to manage their loved one's eating difficulties.

Elizabeth believed she did not have a choice, but it is important to recognise that alternatives do exist.

While tube feeding can reduce feeding time and ensure medication and nutrition are provided, nasogastric feeding tubes, the type most frequently used in Singapore, may cause discomfort as they are inserted through the nose.

This can cause individuals with dementia to become agitated and try to remove the tube, which can result in caregivers resorting to the use of physical restraints, such as belts or sheet ties. In the same PISCES study, we found that physical restraints are commonly associated with feeding tube use in Singapore.

There is also a risk of lung infections, and the need for the tube to be re-inserted frequently due to blockages. Moreover, nasogastric tubes are not designed for long-term use and need to be replaced at regular intervals.

Alternatively, caregivers can adapt hand feeding methods to suit their loved ones, offering smaller portions, adapting feeding techniques, changing food textures, and enhancing flavours to their preferences.

This allows their loved ones to continue to enjoy the taste of their favourite foods, although meals may take longer, and some caregivers may have concerns about insufficient intake. If the individual consistently refuses food, it is important for caregivers to consult healthcare professionals for guidance on how they can continue to hand feed.

Deciding whether or not to tube feed is a deeply personal choice that caregivers must make based on consideration of their loved one's wishes, values and goals of care.

There is no right or wrong decision – everyone's journey is different. We must support caregivers in making informed decisions that suit their unique circumstances.

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