

■ OPINION

Dealing with current stigmas of dementia

THE THOUGHT of having our memories erased and being unable to recognise the people we cherish would elicit fear in most individuals. For adults with a dementia diagnosis, this fear is magnified – even more so for those closest to them.

Dementia is one of the major causes of disability in older adults and is recognised as a public health priority by the World Health Organization.

September is dedicated to raising dementia awareness, and September 21 was set aside to commemorate World Alzheimer's Day. This year, its theme is "let's talk about it".

Nothing can prepare an individual or family for the impact of dementia.

Although each person with dementia is unique, most families share the common sentiment that the condition is a heartbreaking experience, as one essentially grieves the loss of a loved one even while they are alive.

About 50 million people are living with dementia worldwide. A global dementia prevalence is forecast to reach 75 million by 2030 and 131.5 million by 2050.

About 66% of those living with dementia reside in low- and middle-income countries.

As a syndrome, dementia is the general label given to a cluster of irreversible changes in memory, communication, reasoning, executive functioning and attention.

A key risk factor for developing the condition is advancement in age; for this reason, there is a widely misinformed view that dementia is an inevitable outcome of old age. This, however, is not the case.

Dementia is the result of distinctive pathologies that affect different parts of the brain.

This presents a wide range of symptoms that profile dementia into several subtypes (for example, vascular dementia arising from stroke or heart

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disease), the most common being Alzheimer's dementia, which results from Alzheimer's disease.

When talking about dementia, it's important to consider the misconceptions and stigma associated with such a diagnosis.

Because it is a degenerative condition, one misconception is that very little can be done to improve the quality of life of those who suffer from it. This narrative paints a bleak future for people with dementia, and is one that must be challenged.

Communication is an integral part of the human experience as it creates possibilities to develop social connections with others. Communication difficulties persist across all dementia subtypes.

Depending on the subtype, dementia sufferers typically experience difficulty in understanding language or finding the right word when describing events, retelling stories or sharing jokes. They might also repeat questions that have been answered or confuse people's names, which could affect meaning.

Over time, with a loss of language, those with the condition are likely to withdraw from interpersonal interaction altogether.

These communication difficulties can be distressing to spouses, children

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or grandchildren as they might be unaware of how to provide appropriate support when interacting with their loved one.

Ultimately, these challenges could create a social and emotional divide between those with dementia and their family; this puts a strain on family relationships.

There are various strategies that family members can employ during a conversation to support someone with dementia:

Gain the attention of the person by using their name to address them. This not only shows respect for them but also upholds their self-identity and personhood.

Use multiple forms of communication (spoken language with facial expressions) to enhance the meaning of what is being expressed.

Avoid completing their sentences – rather stop and wait. This will allow them time to process information and to respond at their own pace.

Incorporate familiar music and songs into conversations – music is one area that is often well preserved in people with dementia. This can provide everyone involved with an enjoyable activity through which to connect. Offer the person choices to promote their independence in daily decision-making.

From a human rights perspective, people with dementia have a right to participate in decisions and have their voices heard.

Many often feel that their opinions aren't taken seriously or their views are ignored, even within their own homes. There are various advocacy organisations, such as Dementia Alliance International (www.dementiaallianceinternational.org), that are leading the charge in advocating for the autonomy and independence of people with dementia to express their opinions in matters that affect their lives.

Caring for a family member with dementia can pose significant emotional and caregiving challenges. There are, however, services available that offer support and assistance to families and caregivers.

Dementia South Africa (www.dementiasa.org) and Alzheimer's South Africa (<https://alzheimers.org.za>) are two examples of non-profit organisations that offer workshops, training and advice. These services are available in several South African languages and are accessible across all provinces.

By increasing the conversation around dementia, we are creating opportunities to confront prevailing stigmas. In doing so, we are hopeful that the negative narrative associated with dementia can change.

Positive outcomes are achievable through supportive interventions that promote the participation, inclusion and independence of those with dementia. This hopefulness inspires us all to remain present and enjoy each moment we have with the ones we cherish most.

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