

Ambiguous loss in dementia care

This can happen when someone is physically present but psychologically absent

Community

Elderly

Mental health

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One needs to build resilience through the journey of caring for a loved one with dementia. Photo: Shutterstock.com

The lived experience of ageing brings with it a multitude of achievements and gratifications but also losses. Losses can vary: they can be physical, emotional, social and spiritual losses. Losses can be explicit and easy to recognise, or implicit, vague and ambiguous, such as the losses associated with dementia.

Ambiguous loss was pioneered by psychotherapist Pauline Boss (2001), who outlined two types of ambiguous losses. The first type of ambiguous loss occurs when someone is psychologically present but physically absent. Examples include the loss of physical contact due to immigration, kidnapping or missing bodies during war, or someone who is lost and never found.

Ambiguous loss also occurs when someone is physically present but psychologically absent, that is, emotionally or cognitively impaired or missing. This type of ambiguous loss occurs in addictions, traumatic brain injuries, depression and/or anxiety, and any condition or illness that impacts a significant other's mind or memory, like with Alzheimer's disease or other dementias.

Dementia is an umbrella term of a collection of symptoms that are caused by disorders, of which Alzheimer's disease is the most common. These disorders have a detrimental effect on the brain and subsequently impact memory, thinking, behaviour and emotions.

It may, however, be difficult for the person who is experiencing ambiguous loss to recognise that they are grieving or to comprehend the grieving process when the skills of the person with dementia (PWD) change with time. Furthermore, the grief and emotions experienced are often not recognised, understood, or even acknowledged by the person's network.

The act of grieving is like a rollercoaster. Most often, theories of grief suggest that a person goes through several non-linear phases, sometimes experiencing different phases at the same time as well.

While caring for someone in the early stages of PWD, one might have feelings ranging from despair to hope that a cure will soon be found, especially when we start actively scouring the internet for a miracle cure that, unfortunately, still does not exist. Denial that there is anything wrong and repressing thoughts and emotions are also quite common. One might experience anger towards the PWD or themselves for something that they might have done. Furthermore, if there is a time where the situation is accepted, one may find that they can cope and make the best of things.

Other times, one may feel overwhelmed again, by sadness or simply feeling numb to the whole situation. These feelings are normal in the process of grief, not just in ambiguous loss, but also other types of losses. It is important to understand that professional emotional support is key to learn to acknowledge and work on personal well-being.

In her book entitled *Loving Someone Who Has Dementia* (2011), Boss outlines seven guidelines to build resilience through the journey of caring for a loved one with dementia:

Finding meaning

Boss notes that finding meaning in what we're doing and the emotions experienced is essential to prevent feelings of hopelessness and helplessness. A key factor in this process is to learn to accept the concept that the "relationship is lost, yet still exists". Striving to comfortably accept a dual thinking process is difficult for everyone. It takes time to understand and accept the stressful paradox of dementia care like, for example, that of the child now parenting the parent. Some find meaning through art expression, or music or through journal writing or through religious stories.

Balancing control with acceptance

We all sometimes ruminate on things that are out of our control, how the streets are flooding now that the first rains have started, other people's beliefs and actions, natural disasters, the past. To stay in control while caring for a PWD, we must learn to differentiate between what we can control and what is out of our control. The more we try to seek control on the ambiguousness of dementia, the more distressed we can become.

"Finding meaning in what we're doing and the emotions experienced is essential"

We need to accept that life is not always fair, and that notwithstanding everything, we are still doing the best we can. It is beneficial to focus on the things we can control, go to a dementia activity centre, learn potential activities, organise a break, and ask for help from family members to take regular breaks each week.

Broadening one's identity

It is normal during caregiving to have to broaden one's identity, the child becoming the caring parent, or the spouse taking on new roles such as the cook or money manager. Research shows that most often the care falls in the lap of the spouse or the daughter. However, there is also ongoing research highlighting the significance of the roles male spouses take as caregivers, rejecting the stereotype that caregiving should be done by the women in the family.

Manage one's mixed emotions

While caring for a significant other with dementia, it is normal to experience negative emotions like anger and guilt and wish for everything to end. However, it is important to recognise such moments and talk with peers and professionals to avoid harm to oneself or to others.

Holding on and letting go

Dementia, unfortunately, has a detrimental effect on relationship attachment; however, we still have choices. We can either close the PWD out of our lives, or a better choice, but one which requires more compassion, is settling for a partial relationship. This compromised relationship is due to the disease and is no fault of the carer(s) or their loved one with dementia, and is painful. Hence, more secure attachments need to be developed with friends and relatives.

Imagining new hopes and dreams

Hope in dementia care is very vague. However, coming to terms with the ambiguity of dementia care will provide a sense of hope. In forming new relationships outside and within our support network, we are more likely to identify new hopes.

Taking the time to mind oneself

As if the day of a dementia caregiver is not already overloaded, imagine how it feels when someone tells you: “Most of all, take time for yourself”. As hypocritical as that phrase may sound, one of the most important things when devoting oneself to caring for someone else, is being mindful of how the feeling and emotions are experienced. It is not selfish to think for a moment about oneself.

If grief is not acknowledged by us and the people around us, it exacerbates and increases the risk of loneliness and social isolation. In fact, actively seeking support is key to positively manage feelings of ambiguous loss in dementia care.

It is important to note that the network of people who can provide support can go beyond that of the biological family. These may include friends, neighbours, faith leaders, staff at dementia activity centres or joining a peer support group like the Malta Dementia Society.

By giving a voice to these feelings with mental health professionals or the Dementia Helpline on freephone 1771, or reaching out to the Malta Dementia Society, one can understand that the losses and grief being experienced are a reasonable reaction to dementia, which changes the person over time.

Talking to people who are going through similar experiences provides the opportunity to learn strategies for managing and living with the ambiguous losses and grieving.

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