

The hidden weight of caring

While much is spoken about the practical challenges of dementia care, the psychological toll often remains unnoticed, even sometimes to carers themselves

Words Emma Green

Caring for a loved one with dementia is often described as a selfless act. Still, it can be one of the most emotionally complex, draining and isolating roles a person can take on. Dementia care isn't just about preparing meals or ferrying someone to numerous appointments - it involves constant vigilance, endless patience and plenty of emotional labour.

Carers can be caught off guard by the intensity, variety and contradiction of emotions they might experience while looking after a loved one with dementia. Powerful emotions like grief and anger can be confusing and deeply distressing, especially when they clash with other feelings of love, loyalty and duty. Understanding these difficult emotions and learning how to respond to them with compassion rather than self-judgment can help you to get a better handle on them, for both your sake and the person you care for.

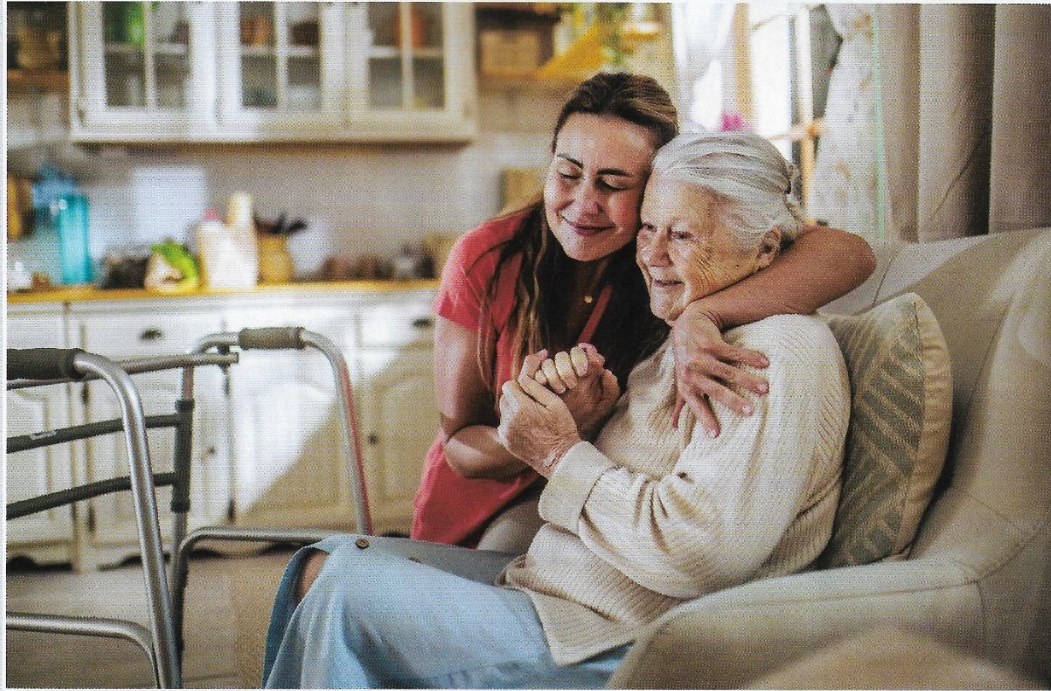
Frustration, resentment and anger

Dementia can make life slow, repetitive, but also unpredictable. Tasks that once took minutes now take hours. Conversations repeat. Plans unravel. You may find yourself trying to reason with

someone who can no longer follow logic, who struggles to be reassured or who completely resists any help. Even when you understand how dementia works intellectually, on an emotional level, it can still be hard to accept that things are no longer possible in the way they once were - and frustration and impatience can often follow. You may snap, rush, or feel on edge, then

immediately feel ashamed for it. Impatience arises not from a lack of love, but is more likely to be an indicator that you are tired, overstimulated and under sustained stress. Over time, even the most patient person can find themselves reaching their limit. 'When you feel the frustration building, step away into a different room, outside into fresh air or call a friend and vent if that's





helpful,' advises clinical psychologist, Dr Anna Colton.

Many carers experience resentment - towards the situation, the disease, other people and sometimes even towards the person they care for. Resentment can arise when a carer's needs are consistently placed last; they feel as if their life has been put on hold, they've been forced into a role that they didn't choose, or they are having to shoulder most of the burden. They may also resent the disease for what it has taken from them - not only the person they love but the carer's time, energy, freedom and identity too.

Anger can also surface in response to other complex emotions such as helplessness, grief, exhaustion and injustice. This can be frightening, especially when it is directed towards someone vulnerable. Having these feelings doesn't mean that you wish any harm to your loved one, though; it just reflects how high and unevenly carried the cost of caring can be. Trying to suppress anger, however, doesn't make

it go away - instead, it can turn inwards, transforming into guilt or depression.

'It's really important to keep doing things that keep you connected with who you are,' says Dr Colton, who was a dementia carer to her own mother and is soon launching her new podcast, *Do I Know You? Dementia Understood*. 'It can be through friends, activities, going for walks or listening to music, but ideally with some social connection. Exercise is brilliant for low mood and mental health, and boxing or kickboxing is particularly good for processing anger.'

Grief

Dementia involves ongoing loss. You may be grieving for the person who once was, the relationship you shared and the future you imagined. 'Dementia only goes in one direction,' says Dr Colton. 'It is often termed the longest goodbye, and that's very true - it is the longest and cruellest. Bit by bit, the person you love declines, changes and disappears over time.'

One of the most painful aspects of dementia caregiving is mourning someone who is still alive. Many carers feel stuck between loving someone who is physically present but psychologically changed. This is known as ambiguous loss, and because the loss is gradual and ongoing, there is no clear moment as to when someone is 'allowed' to grieve. This is why it is so important to regularly give yourself permission to grieve and to acknowledge the emotional impact of the disease.

'(Dementia) is a constant process of grieving the person they were, dealing with anticipatory grief of what's to come and continually adjusting to their new state, in every way: memory, personality, independence/dependence and physical capability,' explains Dr Colton.

Guilt

Perhaps one of the heaviest burdens that carers carry is guilt, particularly about their own emotions. They may feel guilty for being irritable, for difficult

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decisions made, for wanting time away from their loved one, for feeling relief when someone else takes over, and for even imagining a life after caregiving. They may also feel guilt for neglecting other areas of their life, such as spending time with their children, due to their caregiving responsibilities.

Carers often blame themselves for every setback or mistake. This guilt is often fuelled by unrealistic expectations of what a good carer should be - endlessly patient, self-sacrificing, always stoic - and to be anything but a figure of sainthood at all times equates to being a failure. They may also experience guilt because they feel they're not doing enough. This can also stem from holding themselves to impossible standards - of being unable to prevent decline, of not being able to provide round-the-clock care or from considering professional care options.

Dementia, however, is an incurable condition, and no amount of care can stop its progression. Needs increase over time, while energy, patience and emotional reserves are often stretched

thinner and thinner. The idea that you should be able to 'do it all' is unrealistic and damaging. Dementia care is not a test of devotion - it is a long-term responsibility that requires support, boundaries and realistic expectations.

When guilt rears its ugly head, try to acknowledge all the things that you are doing, rather than those you feel that you aren't. Ask yourself: 'Would I judge another carer as harshly as I judge myself?' Caring well doesn't mean never feeling frustrated or overwhelmed - it means continuing to show up, even when it is hard.

Exhaustion

Over time, the cumulative emotional strain of caring can lead to burnout. It is a natural consequence of prolonged stress along with the depletion of resources without adequate rest, support or emotional release. Mental exhaustion can show up as difficulties with concentrating, memory and decision-making, brain fog and forgetfulness, while emotional

exhaustion can manifest as low mood, irritability, feeling emotionally flat or overwhelmed, anxiety and depression, and a chronic sense of emptiness.

If you are noticing signs of burnout, then take them seriously. This might mean asking for practical help, arranging respite care or speaking to a healthcare professional about how you are coping. Small changes such as establishing regular breaks, clearer boundaries or moments of quiet can also make a difference over time.

Loneliness

Many carers can feel deeply lonely. Invitations are often declined because



leaving the house feels too risky or exhausting. Friends may drift away, assuming you're too busy. Over time, your world can shrink to medical appointments, medications and constant vigilance. You may feel isolated, but you are certainly not alone in this experience. Talking with others who 'get it' and who understand the multitude of emotions that come with this role, such as caregiver support groups, can offer comfort and validation without judgment or the need to explain.

For busy, overstretched caregivers, connection doesn't need to look like long social outings or catch-ups. Sometimes it means small, intentional touchpoints, such as brief, regular phone calls or chatting in an online caregiver forum. 'It doesn't matter where you find it - online, through hobbies, clubs or through your own circle of friends and family,' says Dr Colton. 'Intentionally build in the time to see people a few times a week, even if it means getting in a carer for an hour, asking other family members to come in and give you a break, or inviting people round for a cuppa.'

"Your world can shrink to appointments, medications and constant vigilance"



Anxiety

Each new decline can feel like the ground shifting and anxiety can arise from this unpredictability. Carers might worry about what will happen next: 'Will they wander? Will today be a good day? Am I doing the right thing?' They may also have concerns regarding the future: what the next stage of the disease might bring, long-term care options, financial implications, as well as their own ability to cope. Living in this state of constant vigilance can keep the nervous system on high alert. Anxiety thrives in isolation, whereas talking openly about fears with a trusted friend or counsellor can make them feel more manageable.

Dementia care is an emotionally layered process. You can love someone very much, yet still struggle with the realities of caring for them. Feelings of love and loyalty won't cancel out exhaustion, grief, or stress; they co-exist alongside them. Having negative emotions isn't a sign that you are a bad carer - it means you are a human dealing with an inhumane situation.



Dealing with difficult emotions

Acknowledge your feelings

Remember, emotions are not moral judgments but are signals that something is either amiss or needs paying attention to. Saying to yourself, 'this is frustration', or 'this is grief', also creates distance between you and the emotion, reducing the urge to suppress or explode.

Let go of the myth of the 'perfect carer'

There is no ideal way to care for someone with dementia. There is only good enough care, given by a tired human doing their best. If you are ensuring their safety, their dignity and meeting their basic needs, then you are doing enough, even on the days it doesn't feel like it.

Find outlets for release

You may not have time for long breaks, but emotional purging matters. Cry in the shower, step outside for fresh air, scream into a pillow or write uncensored thoughts in a notebook. The goal is not to remove the emotion, but to let it move through your body instead of staying trapped.

Use grounding techniques

When emotions feel overwhelming, grounding yourself can help to regulate your nervous system. Slow breathing, body scans, and mindfulness techniques like naming what you can see and hear around you can interrupt spiralling thoughts and prevent emotional escalation.