

LOSING MY PARTNER TO ALZHEIMER'S

Dr Cordelia Galgut reflects on the emotional impact of caring for her beloved wife, who has Alzheimer's. She also offers suggestions to counsellors who are working with clients in similar situations

My beloved wife started showing pronounced signs of dementia some eight years ago. Tragically, the disease has progressed considerably and now appears to have the hallmarks of advanced Alzheimer's. At the beginning of 2022, after she had two strokes, I had to make the appalling decision to agree to put her into residential care. I was no longer able to manage, much as I desperately wanted to.

The past year has been the worst of my life, agonisingly difficult to live through, even though I have endured other, extreme traumas. For example, I have twice been diagnosed with breast cancer. I am thinking also of my mother's illnesses and death, as well as other, challenging periods in my life. Still, this past year has been the most difficult so far.

In this article, I speak about my own experience. However, from the conversations I have had with others in similar circumstances, I know that my reactions, thoughts and feelings are far from unique. I have tried to offer a raw account of where I am psychologically right now, in the hope that it will help people to understand how to support someone in my situation.

I am 68 and, throughout my life, I have often encountered an unwillingness or inability to take on any suffering of mine in a real and accepting way,

especially when it endures. I was often, for example, expected to show no sign of an emotional response to my cancer diagnoses, even in healthcare settings with clinicians. I experience similar expectations now. People seldom want to hear that I have effectively lost my partner of more than 40 years.

Of course, cancer is hard for people, as is loss. So, I have a lot of sympathy for anyone who needs to close their ears and eyes to the emotional trauma of such events, particularly when the emotional upset doesn't go away after a set period of time.

A counsellor would hopefully be more aware and open to my emotional state. It takes so little to support someone when they are suffering – and I think the principles of good support are fundamentally the same, whatever the cause of the suffering. Counsellors and psychotherapists must be willing to suspend judgment, listen and really hear, look and really see. In my view, those principles are way more important than just trying to find solutions.

I, for one, appreciate anyone who is supporting me emotionally, either professionally or personally, to be willing to recognise and accept that they cannot know what it really feels like to be in my situation. Such an acknowledgement can be therapeutic, because it can help a person feel met. I know that some clients don't want us to admit we don't know

things. But, in my own professional practice, I have sometimes taken the risk – and it has been appreciated by my clients. Obviously, it's a fine balance to strike. But if someone is living with a partner with Alzheimer's or coping with a partner in residential care, I think it can be a useful disclosure.

I am clearly in heavy process over the impact of the past eight years, particularly the past 12 months. The 'loss' of my partner after so many decades is particularly devastating, because I am having to cope alone. I am also watching her deteriorate more each day and witnessing the levels of cognitive impairment she suffers. Words can barely express how intolerable I find this. I now understand better why people don't, or rarely, visit their loved ones in residential care. Obviously, there can be other reasons, but the fact that visiting is so hard must surely be a big factor.

'People seldom want to hear that I have effectively lost my partner'

The situation is also not helped by my age and the fact that I am in poor health. I probably don't have enough years ahead of me to make a new life for myself, even if I wanted to. And I don't, currently. All of those big existential questions are staring me starkly in the face, so close up now that they can make me feel suffocated and paralysed.

The curse of the myth

Myths abound, as they do in relation to all traumas and their fallout, quite possibly because they serve to make the person voicing the myth feel more comfortable. I'm not surprised by the myths, but they are varying degrees of irritating and often downright infuriating. The following are a few myths that I find particularly irksome, but the list is by no means exhaustive.

I can't see a problem

I would often hear this 'observation' when my wife first started showing signs of dementia. It's not easy to describe how hard it was to cope, both with my own conflicts and with others' unwillingness and

inability to see a problem. The myth predominates that if someone can maintain a public face, of sorts, in the earlier stages of dementia, as is often the case, then there can be nothing wrong. I acknowledge that I would have been more aware of changes in my wife's behaviour, not least because I knew her so well. However, in my opinion, it wouldn't have taken much for people in general to have looked further than the end of their nose.

The inability and unwillingness of others to see and accept what is happening as dementia progresses make it especially important for anyone who is emotionally supporting someone in my situation to be aware and validating, not only of the inevitable, horrible conflict we experience when someone we love is in the early stages of dementia, but also of the way we are subjected to entrenched, pervasive and inaccurate myths that massively complicate our processing.

I also think it's important to realise that, even after a person is diagnosed, there is often a strong belief present that it's only a bit of a problem, because their public face can remain for a long time, even when they are well into the later stages of dementia and, in the case of my partner, Alzheimer's.

Alzheimer's is an unspeakably cruel affliction. On the one hand, I struggle to forgive the incredulous people who made my life so much harder during those initial years. On the other hand, I understand why they were so incredulous. I guess it still angers me that they didn't believe me. I was the expert on my partner, after all. Of course, the psychologist in me knows why, but it doesn't help much.

The incredulity of others, coupled with my own shocked and conflicted response to the signs of dementia in my partner, made me think I was going crazy at points – and it was awful and upsetting. Nobody has ever apologised to me since my partner's Alzheimer's has become so pronounced as to be the absolute reverse of miss-able. Not that it really matters now, but I am aware that nobody has acknowledged they were wrong.

I know what you are going through

People say this to me a lot, usually if their mother or father has or has had Alzheimer's. My own mother had vascular dementia, so I know how it feels to be in this situation with a parent: it's awful and brings its own pain and suffering. And clearly there are parallels. However, most people don't live with their parents as older adults, whether or not they are their sole carers.

It's obviously not a competition. However, I think that any counsellor supporting the partner of someone with Alzheimer's, or any other dementia, needs to recognise the difference. If the person with dementia is your parent, or someone who isn't your

partner, you can usually physically walk away, back into your own life, as I did when my mother had dementia. And that makes a huge qualitative difference. Your life is not obliterated in the same way. The person with dementia is not your other half, a turn of phrase that I have always disliked, but that resonates for me these days. I know that physically walking away doesn't protect against emotional pain and suffering, but at least there is another life and very likely a partner. And, from where I sit, that is very different.

I realise that my thoughts might be contentious. For example, if your parent has dementia, you might have to deal with all the childhood triggers that perhaps don't come up when it's your partner. So, I apologise if anyone feels I am belittling their suffering; that is not my intention at all.

You can get on with your life now she's in a home

After several years of looking after my partner, and then two years of the pandemic, I was ground down and desperate. I knew that I wasn't doing well enough and that she needed more. But it was only after she had two strokes in quick succession that I finally admitted defeat.

The feeling of intense failure persists. I could not continue to be there for her 24/7 – and that remains a huge issue for me. The guilt I feel every day is crushing. People regularly tell me that I shouldn't feel guilty, but no amount of rationalising these feelings away helps for long. And if there is one thing my psychological brain knows well, it's that the feelings won't go away, just because I want them to. There is also precious little point in layering suffering on top of suffering, by putting pressure on myself to make them do so. All my clinical experience and my own lived experience bear this out, too. My suffering is part of the human condition, to be endured as it ebbs and flows, until it maybe lessens, as it probably will over time, and as I learn to live alongside it, depending on what happens next.

My intense struggle to accept that my wife is, in many ways, no more, is heavily in the mix, too. Yet she still is who she was, in some ways, and that is endlessly discombobulating for me. But watching her die cognitively is no less than agonising. Someone said recently: 'It's killing you.' And I had to agree. On many levels, it really is. I have to want to live on and, as yet, I kind of want to but haven't found an anywhere near comfortable and enticing enough set of reasons to do so. I don't want to kill myself, yet I have little enthusiasm for life. That's intense grief, I guess. I am inconsolable. And woe betide the person who tries to placate me, unless they are just reflecting back what I say, which can also be irritating.

It's maybe good for my fellow counsellors to know that there probably isn't much consoling to be done.

Just sitting and being with me, rather than trying to problem solve, is all I will tolerate. I clearly can't speak for everyone else in this situation, but I know I am not alone in feeling as I do, either. Platitudes abound and they are not helpful.

'Watching her die cognitively is no less than agonising'

And yet I am told with alarming regularity that I can get on with my life now, or variations on that theme. But it's not that simple. And it's a huge responsibility when someone you love is in residential care. There are also always practical things to do and horrible decisions to be made, of one sort or another.

Additionally, I choose to see my partner every day, and I know the staff rely on my daily visits. Also, on the rare occasions when I haven't been able to visit – for example, when she had COVID – she is aware that I have not been in. I want to see her, too. And it's important that I am vigilant. I am still caring for her, just from more of a physical distance.

The separation anxiety for both of us is huge, and it endures after almost a year apart. It's awful. I love her and miss her so much, even the manifestation of her that exists today, which is vastly different from the partner I had, before Alzheimer's took its hold. She also shows she is concerned for me, through the murky haze, and I find that both intensely moving and disconcerting, all at once. The loss of my partner, who still cares about me more than anyone else, is beyond tolerable for me, as is the sorrow that she has suffered and still suffers as much as she does.

I am thankful that she now appears less aware of her impairments, and I can only hope that lasts. I am so grateful to her for everything she was and everything she did for me. I was an emotional mess when she and I met, in my mid-20s, and the positive regard she showered on me saved me in many ways. In a way, this commitment to be there, till death us do part, in sickness and in health, is an unbearable burden on me now. But I wouldn't have it any other way, either.

In this article, I have purposefully let rip, so you can witness some of the complexity of what I am going through. And, of course, this is only the tip of the iceberg.

With my counsellor hat on, I can see that colleagues might consider that the only way I can now live a tolerable life is to try to step back and create some emotional distance between me and my beloved wife as she is now; see her as dead in many ways. The problem is that her connection to me and mine to her remains, despite advanced Alzheimer's. Maybe that separation is easier in actual death, because there is no choice, physically, at least. I don't know. However, what I do know is that I absolutely dread the finality of her physical death, even though she could then rest in peace.

I don't have the answers but, to reiterate, I wouldn't want anyone piling in with their version of what I should be doing right now. I would prefer people to

suspend their judgment and refrain from offering advice. There is no black and white, just many shades of grey; not 50, though!

I would like to add that I have noticed there can be an unspoken assumption that the loss I feel is not as great or painful because my partner and I are a same-sex couple. Obviously, that's complete nonsense – and coping with others' homophobia, on top of the hell of my current situation, makes it all the more intolerable. Anyone working with same-sex couples needs to be aware of this possibility and do what they can to nail their own colours to the mast, and make it crystal clear they know that this extra burden might be there.

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Supporting someone living through the pain of losing a partner who is slowly succumbing to Alzheimer's dementia can be difficult, writes **Liam Hallett**. In many ways, the loss can be more complex, protracted and palpably more painful than the sudden death of a partner or, indeed, the loss of a partner to a different terminal illness.

Alzheimer's dementia slowly eats away at the identity of the individual, their personality, memories and sense of self. Consequently, it can erode the sense of the client and their partner as a couple, with that meaningful weave of shared, day-to-day, human idiosyncrasies that makes up much of the fabric of a relationship, a relationship that they have grown to trust and rely on, as they move through an ever-changing and challenging world.

And yet the person with dementia continues to exist, both bodily and, at times, psychologically. There are fleeting glimpses of their former self, a welcome and familiar friend, emerging out of a fog of forgetfulness, only to disappear once again into confusion and disorientation. It can be a slow and repetitive process of compounded serial loss and anticipatory grief for the client, with little respite adequately to grieve or process the losses as the illness progresses, particularly in the midst of the physical, psychological and emotional toll of caring for someone with dementia.

To support a client through this difficult, complex process can be challenging. Many of our psychotherapeutic models and approaches that foreground change and outcome are often inadequate

for the task, so they can leave us feeling helpless. We might then reach for therapeutic platitudes and premature solutions that, at best, can leave the client feeling misunderstood or objectified; at worst, the client can feel blamed or indeed ashamed for not being able to manage better or progress.

And yet, clients who are facing insurmountable challenges that burn them to the core of who they are – and to which there are no easy answers or solutions – frequently require little more than the therapeutic relationship itself, as well as our willingness to be an active, authentic and human presence in the experience of the client.

As therapists, we can often do no more than be with the client, to explore their pain, empathise with their uncertainty and confusion, bracket our assumptions and acknowledge that we cannot know. We can stay with them as they ride the rollercoaster of hope and hopelessness that is the Alzheimer's journey. It's not an easy ask for us as counsellors – deep therapeutic relationships rarely are. But how we support the client need not be complicated.

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