

Living grief and bereavement

A booklet for anyone working with carers of people with dementia



tideTM

together in dementia everyday

Carers told us that they can experience complex feelings of grief when the person they care for is still alive, and that these feelings can last long after the person dies. We realised that there was not enough information and awareness available on this difficult and emotional topic. We therefore decided to conduct research amongst our network.

We spoke to around 100 carers across the UK, through an anonymous online survey and focus groups. All the information you find in this booklet comes directly from carers.

We tried to reflect different experiences in this booklet. However, we acknowledge that each carer's journey and experience of professional support is unique. You might not recognise any of the following experiences.

The large number of responses made us realise that this is an important topic that has been ignored for too long. This booklet is only the start of a much larger campaign to shine a light on living grief. We are committed to continuing this conversation. We welcome your ongoing feedback and involvement.

We know that you are trying your best to support carers of people with dementia. We hope that this booklet can help you better understand this complex issue and support you in your practice.

“Whatever you're feeling is okay and normal. There is no right or wrong way to grieve.”

Feelings of loss and grief

Many of the people that you come into contact with in your work will have experience of caring for someone with dementia. It is important to understand what they can be going through at any given moment in order to change the way you are interacting with them.

At any given moment carers can experience feelings of loss and grief. Carers can grieve the loss of the person with dementia as who they were. The person with dementia's personality can change and they can lose fundamental parts of their identity – what makes them who they are. They might not be able to have the same conversations as before, or do the things they used to love doing. Carers might feel like they are losing the person twice, once because of dementia, and again when they die.

"It's an agony. They're not here, but they are. I have her, but I haven't."

"I am no longer a daughter in the truest sense of the word."

"I didn't recognise it as grief at first but losing the person I loved and then finding myself living with someone I didn't know was stressful and emotionally really painful."

Carers can grieve the relationship they had with the person with dementia. They can lose their confidant, partner or support. The roles can be reversed and they can miss having that person to rely on. It can feel like they are losing shared memories. Or memories that haven't been made yet.

They can experience these feelings when witnessing a deterioration in the person's condition, when they lose specific abilities, such as their speech, or mobility. Or when the carer realises that the situation is not going to get better. They might feel helpless and that they are failing because there is nothing they can do to stop this.

The caring role can be so overwhelming and all consuming that they do not have the time or energy to face their own grief.

These feelings can be triggered randomly. Carers can experience them every now and again, or constantly. They can feel at the point of diagnosis, at transitions into care, or at the point of death – and they can last for a significant period of time.

Grief can be triggered when the person forgets a memorable date, like a birthday or anniversary. Not because of the date, but because they would never have forgotten it before.

Carers can be suddenly overwhelmed with grief when they see the normal life of their peers and are confronted with what they don't have anymore, or will never have with their person.

“She forgot who I was. She had known me for 45 years. At that moment I grieved more than I did even at her funeral. That was the moment she died for me.”

“The worst and best trigger to grief is the sparkle moment, when you get a glimpse of who they were. I live for these moments.”

“I’m grieving for the things I’m losing out on.”

“I have never experienced grief like what I felt when I transferred her into care.”



Identity

As well as grieving for the person with dementia, carers can grieve a loss of their own identity. It can feel like they have taken on a new, all consuming, identity of a carer.

"I don't feel like the old me anymore, as a person who contributes to society. I feel very isolated and that I'm just here to be a carer."

There can come a point when they will lose this new identity as well. When the person with dementia dies, or moves to a care home.

"What am I when my mum dies? My whole life revolves around caring. When she's gone, what will I do?"

"I didn't know how not to be a full-time carer. I couldn't recall who I had been before the caring started."

Their identity in relation to others can be affected too.

"I'm in transition, he's in care and I'm not a widow, nor am I a married woman."

"I'm a Gay man, and lost that identity. I rarely spoke to men at all. I lost my sexuality and contact with my gender."

"My children need their mum back."

These losses can be isolating and can make carers feel alone.

"I grieve for myself in my aloneness, as I cannot communicate or love him as I once could."

"I'm an only child of an only child, I have no children or partner. My mum is the only one who remembers large parts of my life. It all dies with me."

"I have felt many times that I don't really matter anymore."

Their professional identity can change as well, which can trigger feelings of grief.

“From being a healthcare professional whose experience and opinions were valued, I felt I was treated as an appendage who was wilfully misunderstanding the system.”

“I miss me as I was – a wife, mum, granny, working in a job I enjoyed.”

Carers can also feel like their identity has been enriched because of their caring role and the volunteer roles they have taken on.

“I learned a great deal about myself that I may not otherwise have discovered. I surprise myself at times.”

“It gave me a great sense of happiness when I could be there for him when no-one else could.”

“I took on many volunteer roles, and tried to help others through this.”



Experiences of support

Carers have different experiences of professional support in their grief when caring for someone with dementia. Many carers receive good support from a variety of different professionals. Many others have been disappointed.

Often the grief carers can experience when the person with dementia is alive is not recognised or acknowledged as grief.

“My feelings were misunderstood and labelled as depression, stress or anxiety. That is there too, but the grief needs to be addressed from diagnosis.”

“There was no recognition by anyone of the legitimacy of the grieving process whilst he was living and when he died, most referred to it as “blessing” I felt that as a family we couldn’t openly grieve.”

It is important for you to understand these feelings as grief. As a professional, you play an instrumental role in supporting a carer, as well as the person with dementia, in this time.

“We suggest that a diagnosis of dementia is not just given to the individual, but to the wider family. However, the stark reality is that there remains a clinical focus on the person with dementia, and the impact on the wider family carers is completely forgotten. We are left to get on with it.”

“I seem to be invisible to some people, sometimes my needs have not been seen or understood, or prioritised by health and social care professionals – they see him, not me.”

You don't have to be a health and social care professional to come into contact with carers. Your colleagues or the people you manage might have a demanding caring role. They can grieve but might feel unable to admit this out of fear for consequences.

"My work was very supportive and understanding. They allowed me time off to accompany my mum to appointments."

"I wanted to progress my career but felt unable to, both emotionally and physically, as caring was becoming all consuming."

"My manager stopped me from doing the job I love as they decided I would not want a promotion; they transferred me to an admin job away from my team."

Often carers have to fight for support for themselves and the person with dementia. They have to find their way through the maze of the health and social system. You have an opportunity to provide meaningful support by making an effort to understand what carers can be going through.

"I feel it's hard for people to understand unless they have lived with it."



Advice to professionals

While you might never be able to fully understand what a carer is going through. You can learn about their experience and adapt your practice accordingly.

It is important for you to understand experiences of grief during the dementia journey. There is no timeline of grief and every carer will experience it differently.

"I just feel so sad a lot of the time, with a herculean task I'm bound to fail at. I want them to know I am carrying the weight of the world on my shoulders and at times it's killing me."

"Just because I smile and laugh doesn't mean that I'm coping."

"I want them to know this doesn't just go away."

Carers can benefit from an understanding, kind and empathetic approach, but need real and practical support as well.

"I don't want others feeling sorry for us, we would rather have support."

"Being told how wonderful you are by someone who doesn't understand what you are experiencing can be patronising and depersonalising."

This support can take different shapes. For instance, specialised bereavement counselling to carers when the person with dementia is alive can be helpful.

“Treat me as a partner in care. Don’t ask for repeated histories, offer basic comforts such as a chair to sit on when I come along to appointments.”

“Be honest about the disease progression and what is going to happen at the point of death.”

“If you’re handing me a leaflet on grief services, do it before the person dies. Not right after.”

Acknowledge the carer as an individual in their own right, not as just a carer for the person with dementia. Be person centred in your approach to them.

“Asking “are you okay” isn’t enough, because I’m unlikely to say what is really going on. Ask more specific and focused questions.”

“Give me the space I need, but keep offering help.”

“Take time to listen.”

Offer flexible working and understand that at any given time carers are doing the best they can.

We would like to extend a heartfelt thank you to everyone who contributed to this booklet, either by participating in the research or by producing the booklets.

If you would like to get in touch with us about your experiences please do not hesitate to contact us.

You can email carers@tide.uk.net or phone one of our offices to speak to someone.

For Scotland and Northern Ireland call 0141 353 5607

For England and Wales call 0151 237 2669

You can also find us online or on social media, where we would love to continue the conversation.

-  www.tide.uk.net
-  [@tide_carers](https://twitter.com/@tide_carers)
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