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Living grief and bereavement

A booklet for carers of people with dementia

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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 other carers.

We tried to reflect different experiences in this booklet. However, we acknowledge that each carer's journey is unique and you might not recognise yourself in 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 we can't fix your grief, but we hope that the carers who have contributed to this booklet can provide you with some reassurance that you are not alone in your feelings.

> **"Whatever you're feeling is okay and normal. There is no right or wrong way to grieve."**

Feelings of loss and grief

Throughout and after your time caring for someone with dementia you can experience feelings of loss and grief.

You can grieve the loss of the person as they were. Their 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. It might feel like you 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."

You can grieve the relationship you had with them. They were your confidant, your partner, your support. Now the roles can be reversed and you miss having that person to rely on. It can feel like you are losing shared memories. Or you can grieve for memories that haven't been made yet.

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

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

These feelings can be triggered randomly. You can experience them every now and again, or constantly. You may feel them 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.

You can be suddenly overwhelmed with grief when you see the normal life of your peers and you are confronted with what you don't have anymore, or will never have with your 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."

"I'm grieving for the things I'm losing out on."

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

Identity

As well as grieving for the person you care for, you can grieve a loss of your own identity.

You can feel like you lost what made you who you are – you have taken on the 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 you will lose this new identity as well. When the person you care for 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.”

You can grieve your identity in relation to others. Your whole family can be affected.

“I’m in transition, he’s in care and I’m not a widow, nor am I a married woman.”

“My children need their mum back.”

“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.”

These losses can isolate you and make you feel alone.

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

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

"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."

Your professional identity can change, 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."

You might also feel like your identity has been enriched because of your caring role.

"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."

Unspoken thoughts and feelings

Throughout your time caring you might find yourself having thoughts and feelings you feel guilty about. You might feel like you will be judged if you say them out loud. You are not the only one who thinks or feels this way.

You could wish that the person you are caring for dies peacefully. Even though that means that you will miss them. Often you will feel guilty for even thinking this.

You might have thought about walking away or doing something to end the situation.

"I want my grieving to finish. I actually want him to die although I feel guilty about saying that."

"I thought about driving into a wall at high speed, as that would be kinder to both of us. Then I realised they might survive and I may not. Then, who would look after them?"

These thoughts can come up because you don't think you and the person you are caring for have a quality of life. This is not what they would have wanted.

"I hate being a carer."

"My life is shit right now."

"I have a lot of resentment for this life, for it not being normal. I wish this wasn't my life.

"I know we're asked not to use the word suffering but for the last two years of her life we were."

Your relationship with the person you are caring for can change. You might not love them in the same way, or might not enjoy spending time with them.

> **“My love for the person is changing. I often think I don’t have the ability to cope but I feel obliged to look after them.”**

> **“I feel like I should spend more time with my mother but there is minimal interaction and conversation is meaningless. I don’t want to spend time with her, for which I feel guilty.”**

> **“Lying in bed with someone who wanted to be intimate but was a complete stranger to me was very distressing. Intimate relations with a stranger is an awful experience.”**

You also might be worried about the lasting effects of this caring role on you, and your family.

> **“It’s hard to keep going sometimes as the caring is so relentless.”**

> **“Is it worth it?”**

You are not the only one who thinks or feels this.

> **“What you are feeling is entirely normal under the circumstances.”**

Advice from carer to carer

"Whatever you're feeling is okay and normal. There is no right way to grieve."

There is no solution or cure for the grief that you can experience. However, others who have been through what you are going through have given advice on how to live with these feelings.

"Take care of yourself. You're no good to care for your loved ones if you don't look after yourself."

"Make it a priority to look after yourself"

"Don't feel guilty about taking time off from being the carer."

Talk to others about what you are feeling. Remain connected with friends or family. Speak to professionals, or join a carers group – whether online or in person. You are not the only one.

"Peer support is the best. They really understand and you can scream with them without appearing weak. They get it."

"It's okay to talk about this as grief, you have lost someone even though they are physically still around."

"Find people who are in a similar situation. I was caring for someone with a very specific type of dementia and none of the carers I spoke to had experienced anything like this. This destroyed my hopes and dreams."

"Don't try to do it alone. The person you're caring for may never be able to acknowledge they need help so don't wait for them to be ready. Ask for it anyway, even if it means conflict with the person you're caring for. The longer you wait, the worse the crisis is likely going to be."

"Don't feel guilty about considering residential care. There may come a time when no one person can cope with advanced dementia alone. It's not a failure of love or devotion."

"You only have to get to the end of today. Tomorrow will certainly be different. It may be better, it may be worse. But it's best not knowing until it happens."

"Find humour, and laugh together if their dementia allows."

"Remind yourself that you are doing the best you can."

"Be honest about how you are feeling. I know the rest of the population would be horrified by our feelings and condemn us as uncaring. We are far from uncaring, we are just human beings doing an incredibly difficult task for which we had no prior warning or training."

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.

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If this booklet has raised something for you and you would like advice on where to go next, or you would like to share your experiences with someone, please don't hesitate to contact us.

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

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

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