

# Grief & bereavement

For family and carers bereaved of a loved one with dementia



**Alzheimer  
Scotland**  
Action on Dementia

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**For family and carers bereaved of a loved one with dementia**

This booklet is designed by bereaved carers for bereaved carers and will include different topics including:

- 1. What is grief**
- 2. Coping with grief**
- 3. Tips for readjusting**
- 4. Looking after yourself**
- 5. Where to find help and support**

## What is the difference between bereavement and grief?

**Bereavement** is the factual loss of someone, once someone has died you are bereaved of that person.

**Grief** is the human response to the death. Responses to grief will differ from person to person, but all are valid.

Although grief is extremely painful, it is a normal response to loss and is your way of helping yourself heal.



# 1. What is grief?

## Grief

Everyone experiences grief in different ways, there is no correct way to grieve. Some feelings you may experience include:

- Shock
- A need to isolate yourself
- Anger or frustration
- Guilt
- Denial
- Anxiety
- Sadness
- Acceptance

Some people may feel relief. You might feel different emotions from one day to the next.

You are likely to go back and forth between feelings such as denial and anger.

## Living grief

Some people experience living grief when a loved one is diagnosed with dementia. This is why dementia is sometimes referred to as the “Long Goodbye”. Carers have often spoken about starting the grieving process at the stage of diagnosis. This can also be known as ambiguous loss.

## Loss

You might find it difficult to manage your emotions and feelings after the death of a loved one with dementia, you may feel you have lost:

- Your relationship
- Companionship and support
- Communication
- Hobbies and activities
- Your freedom to do things you enjoy
- A way of life
- Future plans, like retirement or holidays

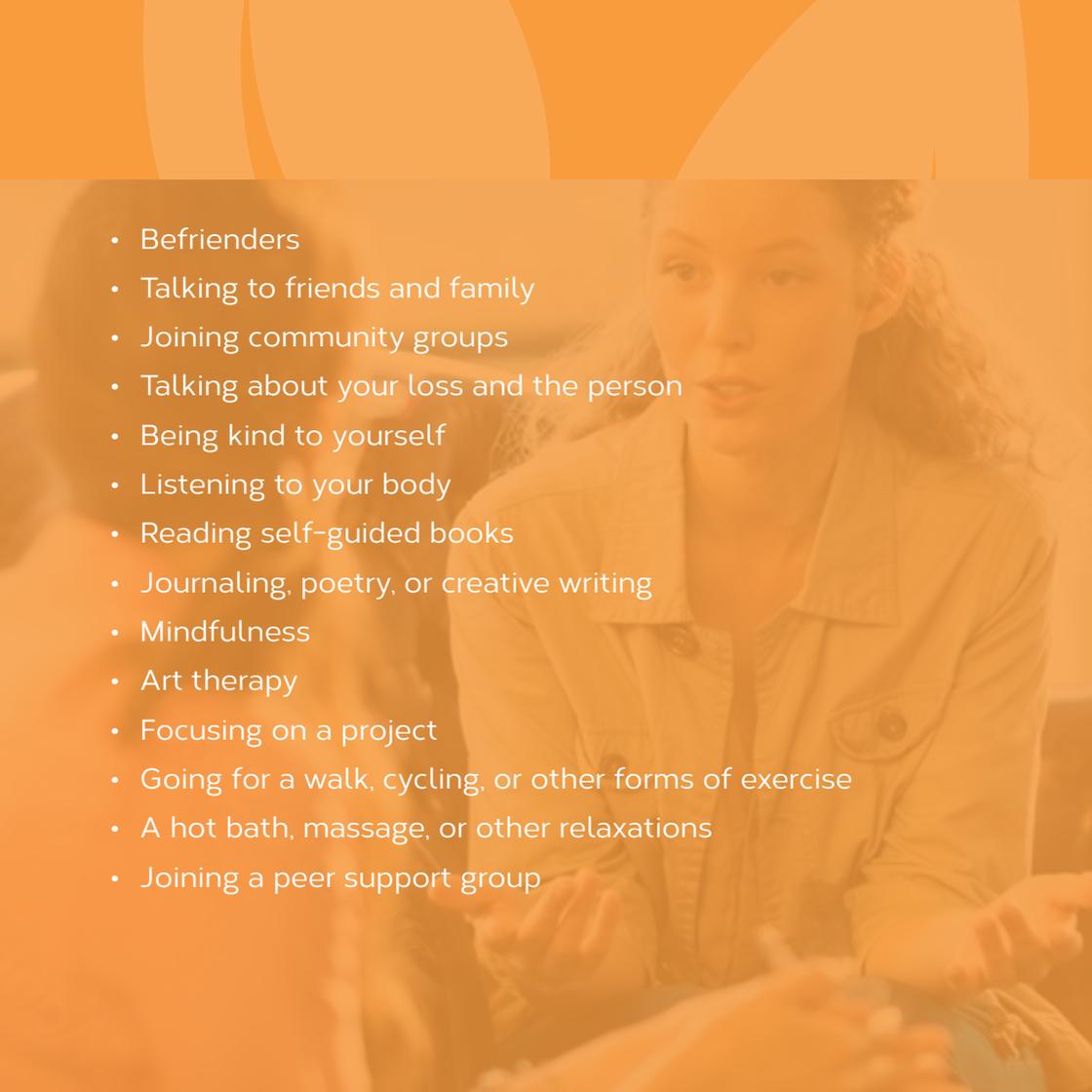
## 2. Coping with grief

Grieving the loss of a loved one is one of the most emotional experiences we will have in our lifetime. Grief often continues long after the death that causes it.

Coping techniques that have worked for one person's experience of grief and loss might not fit your current experience. How grief looks and feels changes for each individual loss.

We have put together a list (right) of what others have found helpful. Allow reflection time to ask yourself what is working for you and what is not.

*"If you can see your friends regularly, that does really, really help. Particularly people who have similar experiences to yourself. I find that particularly helpful because we can be very open with each other about what we're feeling. Some of my friendships have really developed in a way that would never have been possible before."*

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- Befrienders
  - Talking to friends and family
  - Joining community groups
  - Talking about your loss and the person
  - Being kind to yourself
  - Listening to your body
  - Reading self-guided books
  - Journaling, poetry, or creative writing
  - Mindfulness
  - Art therapy
  - Focusing on a project
  - Going for a walk, cycling, or other forms of exercise
  - A hot bath, massage, or other relaxations
  - Joining a peer support group

### 3. Tips for readjusting

- **Talk about your loved one**

Reminisce about them and the life you shared. It can be hard to talk about a loved one who has died because of fear that it might be awkward, but it might help you adjust.

- **Eat properly**

Carers have said that it can be hard to cook for one. Try batch cooking or ordering premade meals. It is important to make sure you are eating, even if it's something small.

- **Get enough rest**

If you are struggling to sleep then mindfulness can be helpful to help focus your mind or speak to your GP as they can offer medications that could help and/or refer you for counselling.

- **Give yourself space and time to grieve**

Many carers refer to dementia as the long goodbye. Your grief will be different to many but similar to some. Take things slowly, one step at a time.

- **Don't be afraid to ask for help and support if you need it**

It can be hard for others to support you through your grief. It is important that you tell people how you feel and what your needs are. Most people will want to feel useful, and some guidance can be helpful for both parties.

- **Try to do things with other people**

You could start doing past hobbies again, consider starting new ones or learn a new skill.

- **Keep active**

Returning to normal activities can help you to re-establish your routine. Take your time and slowly reintroduce yourself to activities you once enjoyed. Exercise can be helpful to focus the mind. Try light exercise like a short walk with a friend or perhaps joining a walking group or exercise class.

## 4. Looking after yourself

### **Making time for ‘me time’**

It is important that you make time for “me time”. This doesn’t necessarily mean you should spend time by yourself. It means doing something just for you. It could be spending time with loved ones, making space for a hobby you enjoy or watching your favourite film.

Self-care is an act you take to maintain your own physical, mental, and emotional health. There are many forms self-care can take. It could be as simple as ensuring you are getting enough sleep or going outside for a few minutes daily for fresh air and exercise.



“Having been a full-time carer for over 5 years for my dad who had Alzheimer’s, people tell me that life will return to normal following his death. Being a carer was an intense and all-absorbing experience. Following my dad’s diagnosis, he was looked on differently by his community. This was due to his perception of things, and his reactions to them changing. Smiling and nodding became our special code and a way of coping with incidents rather than becoming upset. In the last months of his life, our life became a microsphere of existence where he was the central character.

Transitioning to my pre-carer role has been difficult but I am moving forward. I no longer have to plan my day. I can do things as I please. I miss not doing what I did when my dad was alive. At the times when I feel really low, I smile and nod and I hope my dad will be smiling and nodding too.”

Bereaved carer

## 5. Where to find help and support

- Contact your GP or Health Centre
- Alzheimer Scotland 24 hour Freephone Dementia Helpline: 0808 808 3000
- Cruse Bereavement Care Scotland: 0808 802 6161 or email [support@crusescotland.org.uk](mailto:support@crusescotland.org.uk)
- Counselling Directory: [www.counselling-directory.org.uk](http://www.counselling-directory.org.uk)
- Samaritans Helpline: 116123
- For financial support contact your local Citizens Advice Bureau: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)



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