

Grief & bereavement

Resource pack



**Alzheimer
Scotland**
Action on Dementia

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*"No one ever told me that
Grief felt so like Fear."*

C S Lewis



"I often hear that a person hopes for a manual or guide to help move on from their grief, wanting the phrase time is a healer to be true but from my learning I took away that grief lives with us – that it can change and adapt over time."

*Shereen McFadden,
Alzheimer Scotland Counsellor*

Theories on grief

There are many theories psychologists use to try and explain what we experience when someone close to us passes. No grieving process is the same, but these 'models' can help us better understand emotions which may feel unfamiliar and overwhelming.

Kübler-Ross Change curve

The 'Kübler-Ross Change curve' is possibly the most recognized model and what people are most familiar with. This model suggests that there are 5 stages of grief: shock & denial, anger, bargaining, depression and acceptance. The model does not suggest that we all work through these in a set, linear order. Rather we flit back and forth between them, visiting and revisiting the stages in no set order as we adjust.

It is natural for people to make this journey in their own way and using their own coping strategies. It is only when someone feels 'stuck' in their grief that they may need some intervention.

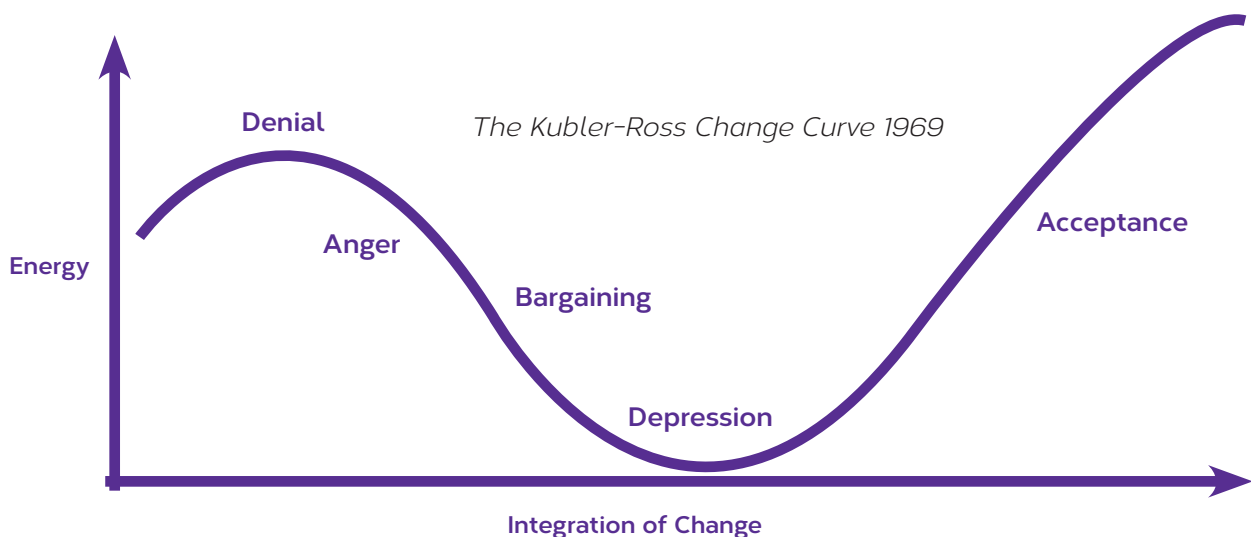
Denial – Initially a person may be in a state of denial or disbelief that this is happening to them. They may feel life makes no sense and has no meaning or feel numb or in a state of shock.

Anger – When a person starts to live in the 'actual' reality they may ask "Why is this happening to me?". They may feel like life isn't fair or place blame on others.

Bargaining – A person may try and work through possible alternative outcomes in their mind asking 'What if...' and try to avoid grief through a type of negotiation.

Depression – This is what most people think of as grief – feelings of emptiness, numb, foggy, world seems too much/overwhelming, hopelessness.

Acceptance – Not 'my loved one died and it's okay' but more that 'my loved one died, but I'm going to be okay.' At this stage the good days start to outnumber the bad.



Worden's Tasks of grief

Where the Kübler-Ross Change Curve looks at stages of grief, Worden focuses on tasks that we must do to 'work through' our grief in a healthy way. The goal is not to reach a point in life where we feel like we are 'over it' or finished with our grief. We never forget, but we can learn to manage our emotions to move forward in life.



the tasks of grief

T = To accept the reality of
the loss

E = Experience the pain of the loss

A = Adjust to the new environment
without the lost person

R = Reinvest in the new reality

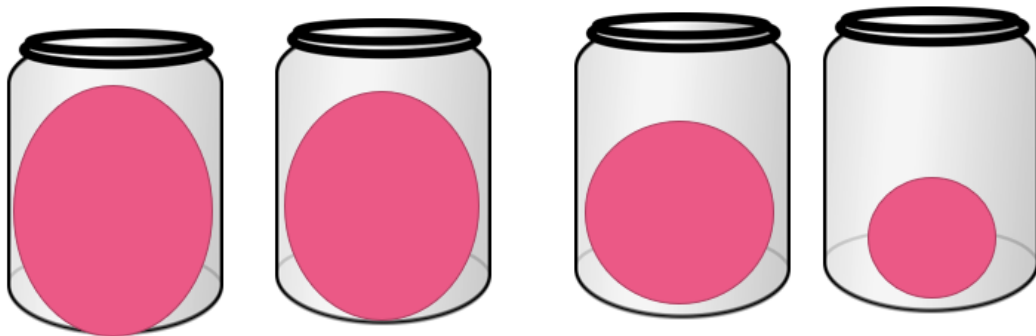
The completion of these tasks will not come about in an ordered and methodical manner. We complete these tasks by working on them, and through remembering, expressing and emoting.

We cannot complete the tasks, and therefore cannot work through our grief by denying, withholding, or distracting ourselves from grief.

Theories on grief

Lois Tonkin – Growing around grief 1996

Growing around grief is a model created by Grief Counsellor Lois Tonkin. Think of grief as a ball in a jar. At first grief is a large ball, taking up nearly all the space inside the jar and leaving no room for anything else. We might imagine that as time goes on the grief will shrink, but Tonkin asks us to think of it a different way. Rather than grief shrinking, it stays the same size but life – or the jar – grows around it. Some days grief might feel just as intense as the first day on others we might find that we are living in the space that now exists in our growing jar.



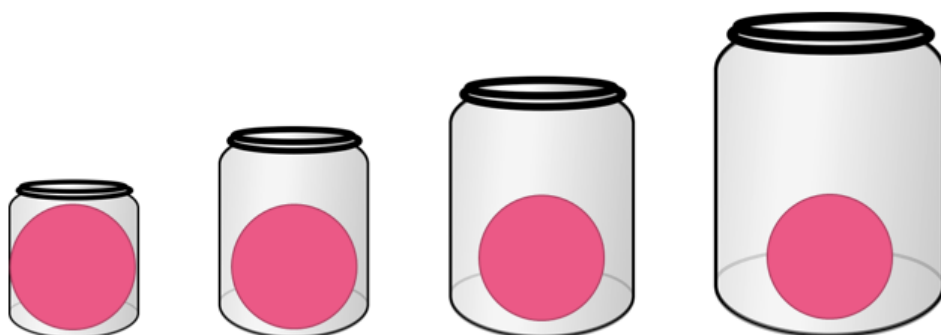
Thinking of this is a different way, imagine you have the flu.

This visual way of looking at grief was described by Dr Delaney at an Irish Conference – 'Good Grief, coping with loss.' Again, the jar represents your life but this time the ball represents the flu.

Imagine you have the flu, initially you are so unwell it consumes your life, no room for anything other than feeling miserable and unwell. As the days progress and you start to feel a bit better, you have room and energy to do more in your life until you are fully well and there is barely a hint of the flu.

How would you feel if grief was seen this way? Where you had to get better from it to the point you barely felt it?

Now imagine that the ball within the jar is grief, all-consuming and there is very little room in your life for anything other than how you are feeling. How would you feel if instead of the ball getting smaller the jar got bigger and though the grief was still felt and was still a big part of your life the jar got bigger to allow you to do more and experience more. Grief is given the respect and acknowledgment it deserves, not seen as something to get better from, only to live with.



Practical matters

The days immediately following a death can be a particularly difficult time with a number of practical matters to be dealt with alongside grief and mourning. Here are some things you should think about.

Benefits

• Citizens Advice

A bereavement can cause a change in circumstances, and the benefits that an individual is entitled to. Many people experience money worries after the death of a partner, or someone in their household and you should check you are receiving all the benefits you are entitled to. If you are unsure, then you should contact Citizens Advice.

Citizens Advice Scotland is an independent organisation that offers an impartial advice service. They can offer information on bereavement benefits and other financial support you may be entitled to.

www.citizensadvice.org.uk/scotland/resources-and-tools/search-navigation-tools/search/?q=Bereavement

• Carers Allowance

The death of the person you looked after may influence your own financial situation and you may need to find out which benefits you can claim now your circumstances have changed.

If you are receiving Universal Credit, the carer element can continue for the rest of your Universal Credit assessment period in which the death occurred, and for the next two assessment periods. At the end of this time, it will stop, and you may need to discuss a new claimant commitment with your work coach.

If you are 65 or over and were entitled to Invalid Care Allowance on the 27th October 2002 (as Carer's Allowance was then called), you will be entitled to Carer's Allowance indefinitely after the person you looked after has died.

If you are receiving a carer premium as part of your Income Support, income-related Employment and Support Allowance, income-based Jobseekers Allowance, Pension Credit, Housing Benefit or Council Tax Reduction, this can continue for eight weeks following the death.

• Bereavement Support Payment

If your partner died more than 21 months (about 2 years) ago

You may still be able to claim BSP if your husband, wife, or civil partner's cause of death was confirmed more than 21 months after the death. Call the Bereavement Service helpline. If you claim later, you will get fewer monthly payments.

Bereavement Service helpline
Telephone: 0800 731 0469

- Income Support
- Employment and Support Allowance
- Jobseekers Allowance
- Universal Credit
- Pension Credit
- Housing Benefit
- Council Tax Reduction
- Working Tax Credit

Practical matters

Registering the death

A close relative or partner should register the death in any registration office within 8 days.

'Tell Us Once' service

'Tell Us Once' is a free service that lets you report a death to most government organisations in one go. This service is free to use and covers:

- HM Revenue and Customs (HMRC)
- Department for Work and Pensions (DWP)
- Passport Office
- Driver and Vehicle Licensing Agency (DVLA)
- The local council
- Veterans UK
- Some public sector pension schemes

How to use 'Tell Us Once'

A registrar will explain the Tell Us Once service when you register a death. If you do not use 'Tell Us Once' you will need to tell each of the relevant organisations about the death separately.

Funerals

Funerals can be an opportunity to celebrate the individual's life, a chance to say goodbye and a way of offering support and love for the individuals closest to the person. After the funeral the 'wake' is an important part of healing

- You can contact the funeral director before you have registered the death if you feel ready to do so.
- You should look out the will of the person who has died - their solicitor may have a copy.
- You can take your time to plan the funeral and the funeral director will support you through this.

Funeral Support Payment

You may be entitled to 'Funeral Support Payment' to help pay for funeral costs if you live in Scotland and receive certain benefits. It usually will not cover the full cost of the funeral, but it should help pay for some costs. It can be paid either to you or the funeral director who is helping you plan the funeral.

For more information, visit:

www.gov.uk/funeral-payments



Coping after the funeral

Bereavement is different for everyone. We all cope in unique ways. Your way is right for you. Life after a death and the funeral is always difficult. You don't have to go through this alone. There are a number of organisations and services that can support you through this time.

- **NHS Inform Bereavement Zone**

The Bereavement Zone from NHS Scotland provides information that can support you through the actions that need to be taken in the early days of a bereavement and guidance on what you might expect to experience in the days ahead. This includes practical advice on coping with grief and information to support you through the death.

www.nhsinform.scot/care-support-and-rights/death-and-bereavement

- **Cruse Scotland**

Cruse Bereavement Care Scotland (CBCS) is Scotland's largest bereavement charity, promoting the well-being of bereaved people in Scotland. Their team of trained volunteers provide free care, and seek to help anyone experiencing bereavement to understand their grief and cope with their loss.

www.crusescotland.org.uk

Tel: 0808 802 6161

email: support@crusescotland.org.uk

- **Samaritans**

The Samaritans provide support to anyone in emotional distress, struggling to cope, or at risk of suicide through their free, 24 hour helpline. Every day, they respond to around 10,000 calls for help.

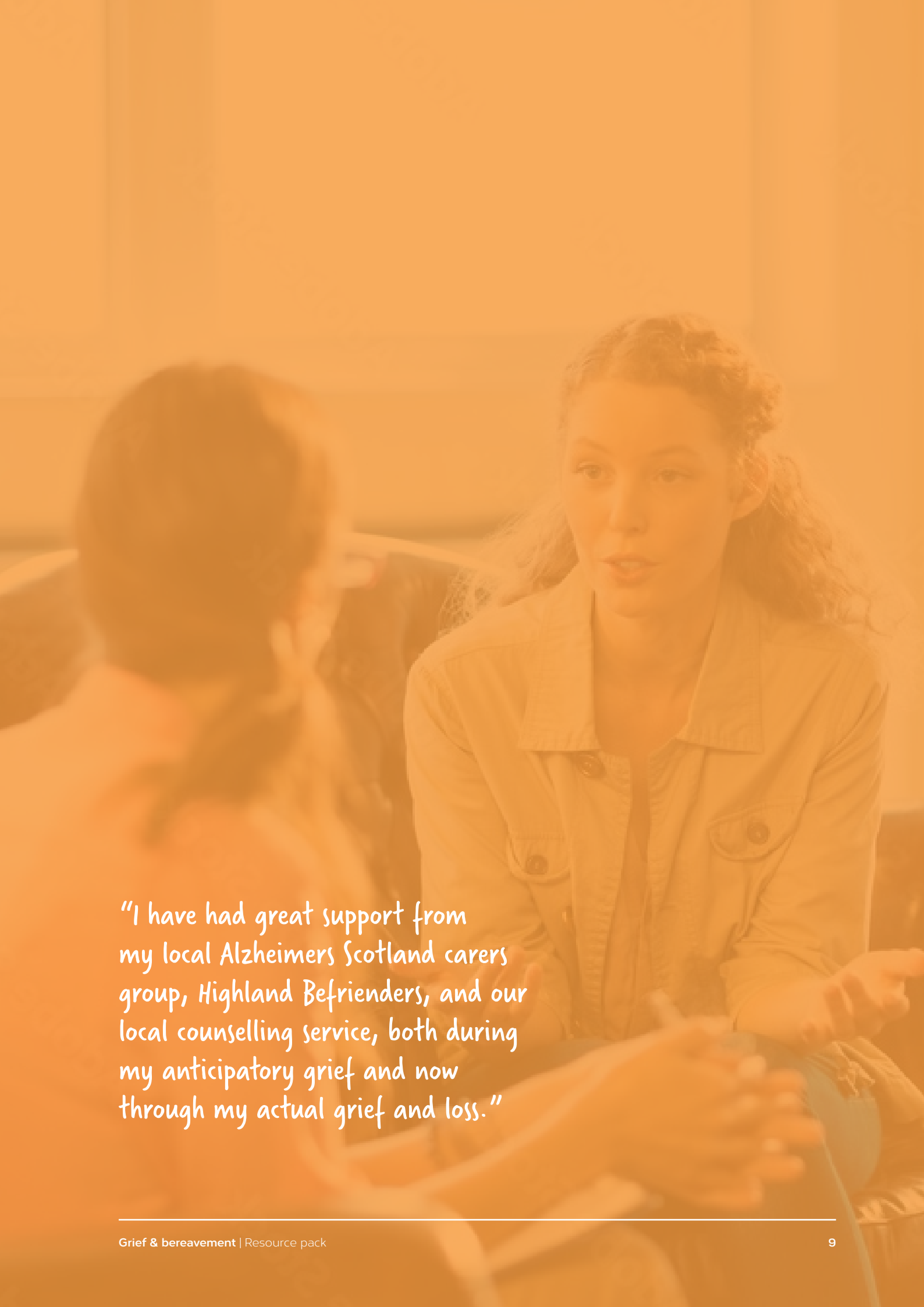
www.samaritans.org/?nation=scotland

Helpline: 116123

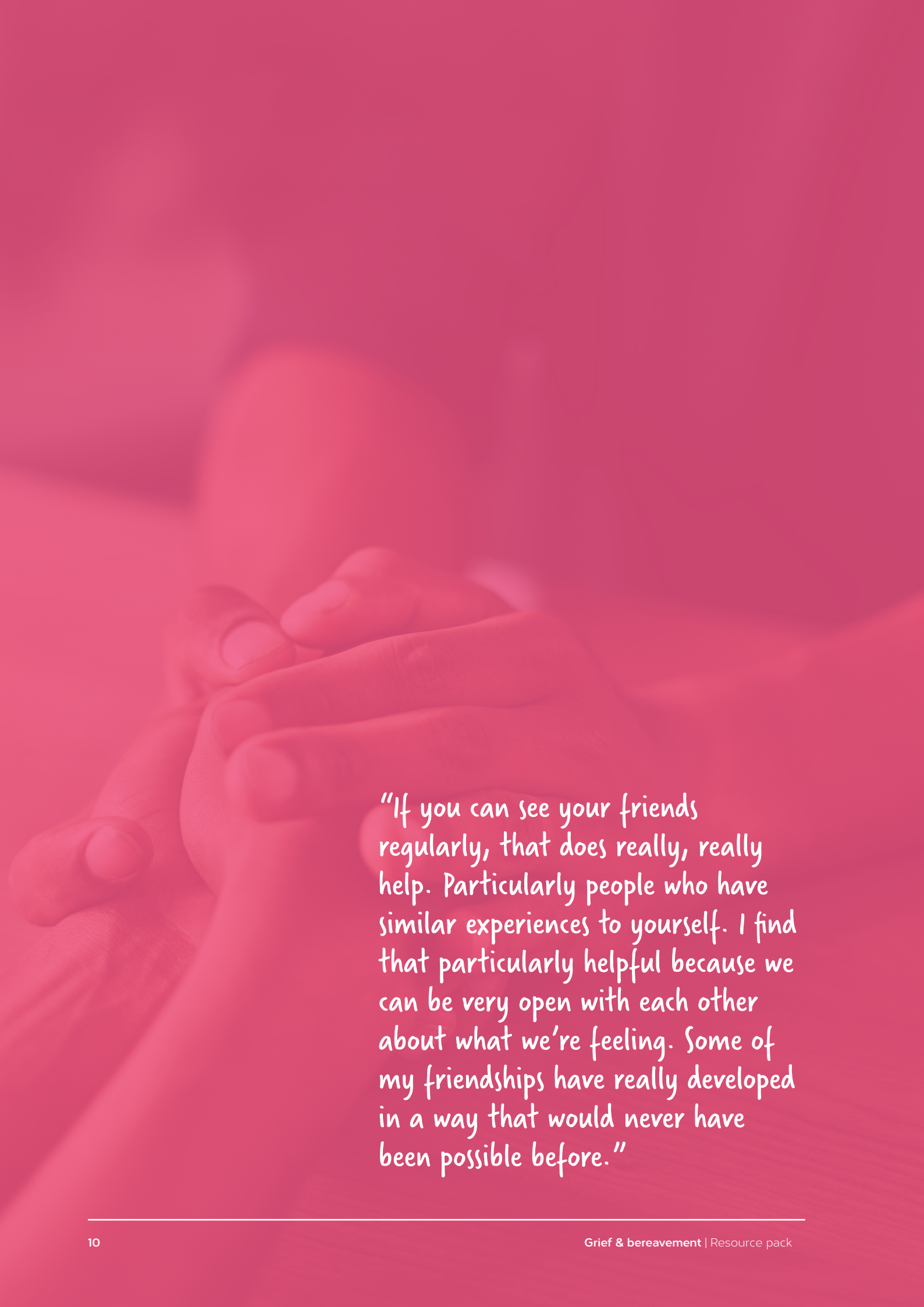
- **Alzheimer Scotland 24 hour Freephone Dementia Helpline: 0808 808 3000**

Alzheimer Scotland can provide a counselling service. We also run a course called "You, Me & Grief." This is a 6-session support programme which provides peer and professional support and information. To find out more please contact your local Dementia Advisor or visit our website.

www.alzscot.org/living-with-dementia/getting-support/find-support-near-you/you-me-grief-online



"I have had great support from my local Alzheimers Scotland carers group, Highland Befrienders, and our local counselling service, both during my anticipatory grief and now through my actual grief and loss."



"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."

Coping techniques

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. Allow reflection time to ask yourself what is working for you and what is not.

It is important you find what coping technique works for you, below is a list of what others have found helpful.

- Finding a befriending service
- Talking to friends and family
- Joining community or peer support groups
- Talking about your loss and the person
- Being kind to yourself
- Listening to your body
- Reading self-guided books
- Journalling, poetry, creative writing
- Mindfulness
- Art therapy
- Focusing on a project
- Exercise – going for a walk, setting a challenge etc.
- Relaxation – a hot bath, a massage, or visiting a spa
- Animal therapy

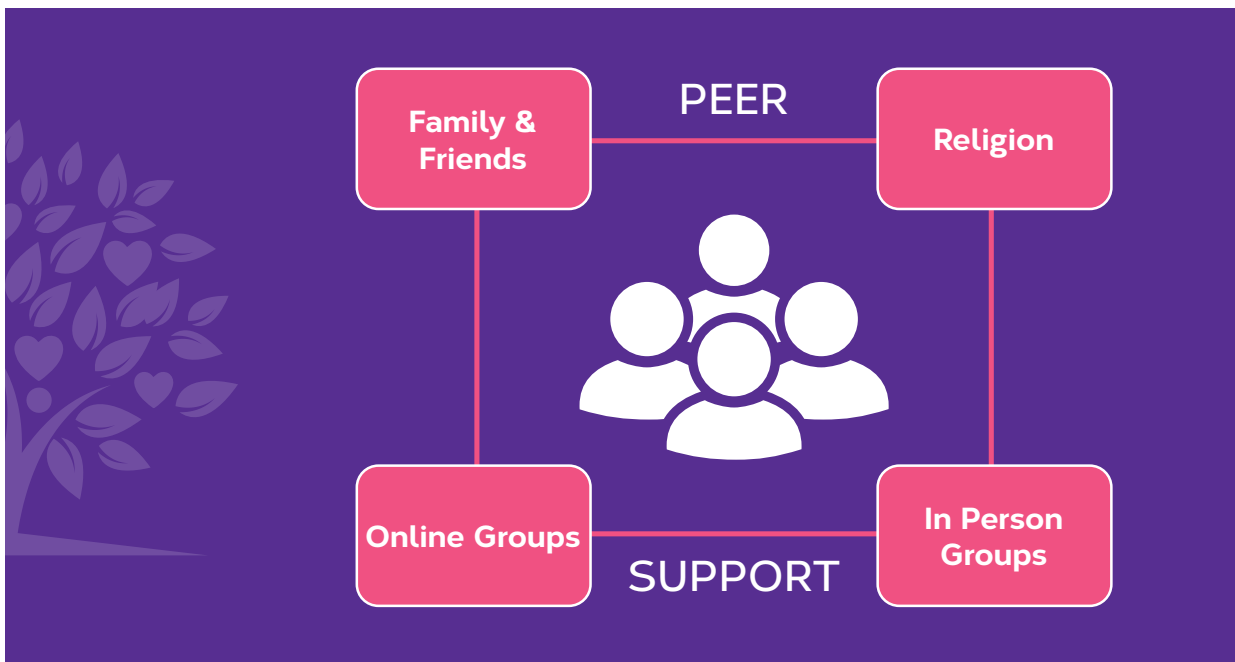


Coping techniques

Peer support

Peer support occurs when people provide knowledge, experience, emotional, social or practical help to each other. Though grief rarely looks the same for everyone, it can be healing to share stories and struggles with those who have been through something similar.

Peer support can be gained from many different areas, such as friends and families, your religion, online groups and in person peer support groups.



Some evidence...

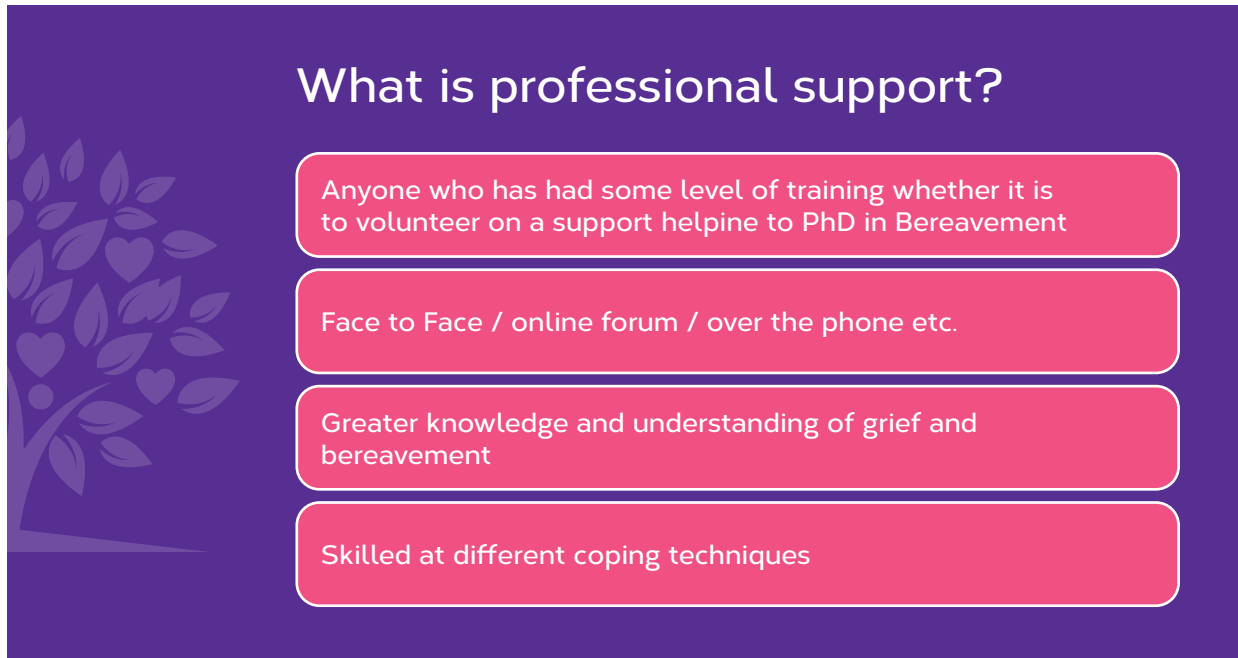
Of the 32 studies meeting all inclusion criteria, most showed evidence that peer support was helpful to bereaved survivors, reducing grief symptoms and increasing well-being and personal growth.

Studies also showed benefits to providers of peer support, including increased personal growth and positive meaning in life.

Several studies addressed the growing trend on internet based peer support programmes, finding that these are beneficial in part due to their easy accessibility.

Coping techniques

Counselling – Professional support and guidance



What is professional support?

- Anyone who has had some level of training whether it is to volunteer on a support helpline to PhD in Bereavement
- Face to Face / online forum / over the phone etc.
- Greater knowledge and understanding of grief and bereavement
- Skilled at different coping techniques

A professional is anyone who has had some level of training. This could be a volunteer on a Helpline, a qualified counsellor or someone who has a PhD in Bereavement. Professional support can be delivered online, face to face or over the phone. Professionals have a greater knowledge and understanding of grief and bereavement and are able to offer coping techniques and a safe space to talk at your own pace.

Why might you seek professional support?

You might be struggling with your emotions and feelings of grief. This might be overwhelming, or you might feel like speaking to someone outwith your circle would help.

Support is personalised to you, your loss and experiences. It is a confidential and safe space to talk openly about your experiences with a trained professional. It is likely that a professional will not tell you what you need to do but help you understand your grief and reflect on what is working and what is not working for you.



Why seek Professional Support

- Personalised support for your grief
- Confidentiality and anonymity
- Don't feel like you can express fully your emotions to family and friends
- Complex grief

It is ok to ask for help, it is ok not to feel ok.

Adjusting to change & looking after yourself

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 consistently, even if it's something small.
- Get enough rest. If you are struggling to sleep, mindfulness can help focus your mind or speak to your GP.
- Give yourself space and time to grieve. Many carers refer to dementia as the long goodbye. It is important to take your time.
- Take things slowly, one step at a time. Don't be afraid to ask for help and support if you need it. Tell people what you need and how you feel. It can be hard for others to support you through your grief, therefore it is important that you tell people how you feel and what your needs are. Most people are trying to help, and some guidance can be helpful for both parties.
- Keep busy. Try to do things with other people. You could take up past hobbies again, consider starting new ones or learn a new skill.

Family dynamics when grieving

Family grief is as unique as an individuals and no two families will change in the same way after a loss. Some families will change in a way that everyone had predicted and other times the changes that happen are completely unexpected. It is important to remember every family member will experience grief in their own way. You may have different needs in your grief than others in your household or family circle. You might feel your grief is more significant than others. It is important to remember:

- Everyone is grieving
- Everyone grieves differently
- Things will continue changing



Adjusting to change & looking after yourself

Looking after yourself

Grief can affect some or all of your behaviour, your appetite, or your sleep pattern. You may feel that you are experiencing many emotions in one day. You might find yourself taking a step back from activities you once loved or socialising. It is important that you look after yourself.

You might feel like you have lost some control and it can help to add some structure back into your daily life.

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

It is important that you make time for 'me time'. This doesn't mean you should spend time by yourself - rather doing something for yourself. It could be spending time with loved ones, a hobby you enjoy doing or watching your favourite film. Me time can improve mental health, spark creativity, boost self-esteem and reduce stress.

Self-care

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

Pay attention to your inner voice. You may experience a stage of grief in which your inner voice might be punishing. You may feel you 'should' or 'ought' to have done more or done things differently. This can lead to you feeling stuck in grief and wondering what to do with your feelings of anger, guilt and shame. Be kind to yourself. Allow yourself time to reflect on your experiences. Listen to your body and what it needs.



You, Me & Grief

You, Me & Grief

You, Me & Grief is a programme of support for carers who have recently lost a loved one with dementia. The 6-session programme will offer support and professional advice alongside peer support and community connections. This programme has been developed alongside carers with lived experience and will be delivered in an intimate group setting. The programme offers a safe and confidential space to meet others in a similar situation.



“During the course I realised I was not alone in what I was feeling. I felt my input seemed to help others in the same situation as me.

Each week I was made welcome by complete strangers which was very nice.”

The topics of the course include:

Coping with grief, practical support, adapting to change and the importance of self-care. Short taster sessions of some activities will also be included. This course is available online and in person throughout the year, please contact your local Dementia Advisor for more information.

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Phone: 0131 243 1453

Email: info@alzscot.org

www.alzscot.org

Making sure nobody faces dementia alone.



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