



Development of an acceptance-based bereavement support website to enhance coping and quality of life after bereavement.

MAIN Launch webinar

10th June, 2025

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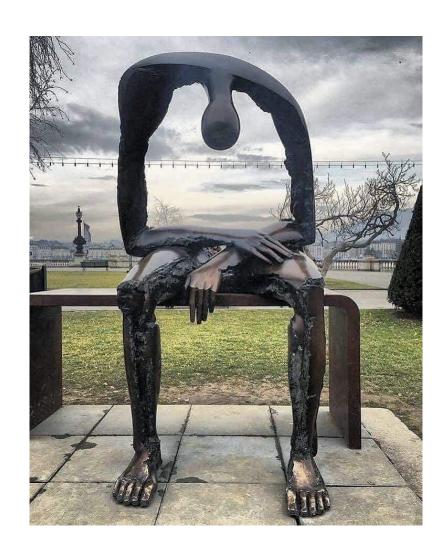
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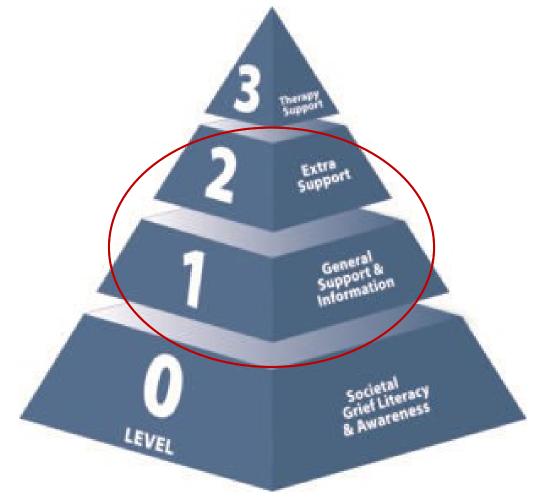
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Bereavement support needs in the UK

- Est. 3.5m people bereaved each year
- 10% need specialist support (Level 3)
- 30% may benefit from extra support (e.g. volunteer led/Level 2)
- Many adjust well with support from friends and family
- HOWEVER normal grieving was disrupted during the pandemic.



Developing online bereavement support interventions



Gaps in the provision of bereavement support exist



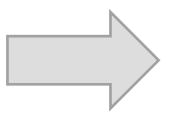
Need is greater than can be met by existing services



Access to support at the right time



Evidence-based interventions.





 Online bereavement support based on Acceptance and Commitment Therapy

ACCEPTANCE AND COMMITMENT THERAPY (ACT)

Aware

Be present

Psychological flexibility

Open up

Acknowledge and make room for thoughts and feelings

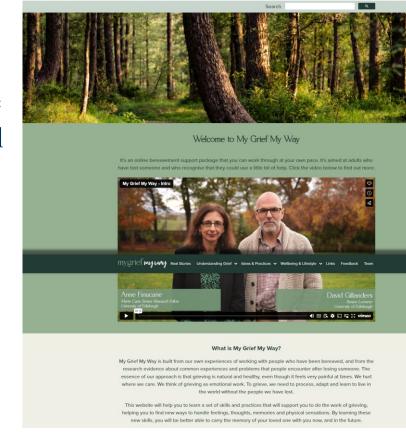
Engaged

Do what matters

Development of an online ACT intervention to improve ability to cope and quality of life after bereavement

Aim

- To develop a **programme theory** and **logic model** to illustrate how an online ACT-based bereavement support resource could lead to improved outcomes
- To design, test and refine a prototype intervention/resource.









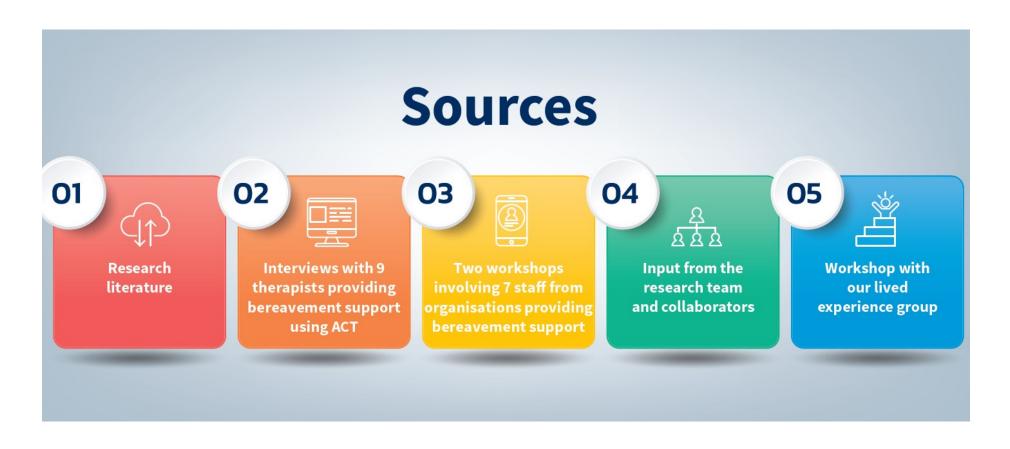








My Grief My Way (MGMW) development



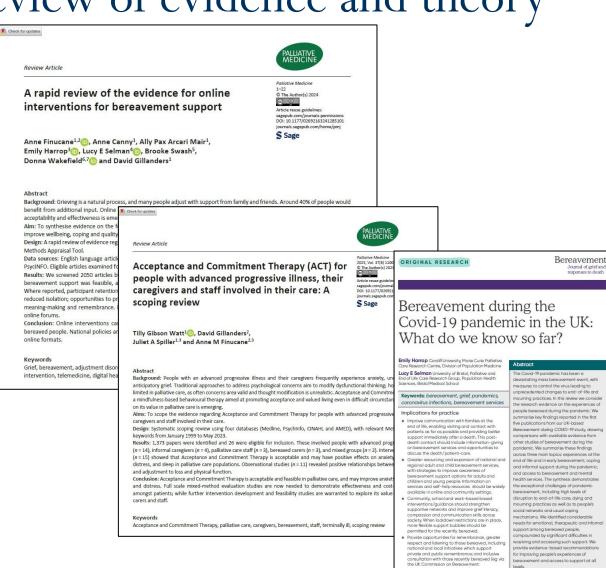
Logic model development: Review of evidence and theory

• A Rapid Review of Literature on Online Bereavement Support

• Scoping review on ACT in palliative care

Knowledge of existing theory

• Other relevant evidence





Logic model development: Qualitative work

Willi et al. BMC Palliative Care (2024) 23:59 https://doi.org/10.1186/s12904-024-01390-x **BMC Palliative Care**

RESEARCH

Open Access

Practitioner perspectives on the use of acceptance and commitment therapy for bereavement support: a qualitative study



Abstract

Background There is currently a high demand for bereavement support coupled with inconclusive findings as to the efficacy of existing approaches. Acceptance and Commitment Therapy (ACT) aims to improve human functioning and has shown efficacy across a wide range of conditions. ACT may be a promising means of supporting bereaved people, yet evidence on the use of ACT for bereavement support is lacking. The aim of this study is to explore how ACT is currently used for bereavement support and practitioner perspectives of how it helps following bereavement.

Methods Semi-structured interviews were conducted online via MS Teams with practitioners experienced in using ACT for bereavement support. Data were analysed thematically guided by a framework approach.

Results Nine participants were recruited. Three themes were identified: (i) creating psychological space around grief; (ii) using psychological space for value-directed action in the midst of grieving, and (iii) adapting ACT for bereavement support. Practitioners indicated that ACT improves clients' relationship with distressing internal experiences. Metaphors and mindfulness techniques were used to encourage acceptance of grief responses, taking perspective on distressing thoughts and images, and contact with the present moment. Better relationships with distressing experiences were regarded as less psychologically taxing, improving coping and well-being, while providing the psychological space to engage in value-directed action. Values exploration, sometimes using metaphors and exercises, was seen as supporting the bereaved person to rediscover a sense of purpose and engage in meaningful activities alongside their grief. Practitioners used ACT flexibly, integrating other interventions, and adapted ACT to the perceived sensitivities of bereaved people, and age-related and developmental factors.

Conclusion ACT is used to support people who have been bereaved to live effectively with the difficult thoughts and feelings associated with grieving and to enable them to gradually identify, reconnect with, and act in line with their values after loss.

Keywords Acceptance and commitment therapy, ACT, Bereavement, Grief, Qualitative research, Psychological adaptation, Coping skills, Coping behaviour, Coping strategies, Psychological well-being

Qualitative interviews (N = 9 ACT practitioners)

- Identified problematic grief responses
- Mindfulness
- Defusion and perspective taking exercises
- Sensitivity when talking about values
- Starting point differs
- Useful integration of related therapies.

Logic model development: Key stakeholder engagement

- Meetings with bereavement support organisation staff
- Research team and collaborator meetings







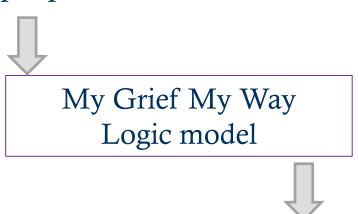
Logic model: Lived experience group

- 5 females and 4 male
- Diverse cultural backgrounds
- Loss of parent, spouse and child
- Expected and traumatic loss
- Time since loss varied
- Single and multiple losses
- Retired, working, care professionals, academia.



Logic model development

- 1. Literature reviews/evidence synthesis
- 2. Qualitative data collection
- 3. Stakeholder meetings
- 4. Research and collaborator team meetings
- 5. Lived experience group input



My Grief My Way Prototype







Known Risk Factors for Higher Grief Support Needs

SITUATIONAL FACTORS

Financial hardship Social Isolation Relationship with health providers around the loss

LOSS FACTORS

Unexpected death
Death of a child
Loss of support system
Unable to say goodbye /
unfinished business

INDIVIDUAL FACTORS

Complex relationship with the deceased Multiple losses History of psychological difficulties

Key:

➡ Informs

Known Indicators of Higher Grief Support Needs

OVERWHELMING EMOTIONS

Sadness, anger, anxiety, regret guilt, shame

LOSS OF MEANING & PURPOSE

Identity disruption Frozen: What do I do now? Spiritual Crisis

BURDEN OF EXPECTATIONS From self and others

SELF CRITICISM

About the death or about grieving

TRAUMATIC MEMORIES
Of how the deceased died or memories involving the deceased

AVOIDANCE

Of emotion, memories, sensations, thoughts

PHYSICALITY OF GRIEF

Concentration, sleep, pain, fatigue

ISOLATION & LONELINESS

Contextual Considerations

TECHNOLOGY FACTORS

Internet access, Familiarity, Navigation, Accessibility

Intervention Components

REAL STORIES

Normalising a range of grief responses, highlighting indicators of higher grief support needs and how people respond

SKILLS TRAINING: OPEN, AWARE & ENGAGED

Videos, audio exercises, imagery, metaphors, worksheets

ENGAGING & SOOTHING

Colour palette, nature imagery, poetry, flexibility of choices, relationship with site

INTEGRATION OF OTHER APPROACHES

Self compassion, continuing bonds, dual process, education

1

Volunteer Support

Relationship, emotional expression, active listening, ACT skills delivery and reinforcement, trouble shooting

Change Mechanisms

NORMALISATION

PROVIDING HOPE

MEANING MAKING

Perspective taking, value / pain connection, unhooking from unhelpful stories

EMOTION REGULATION

Expression, comforting, soothing, distress tolerance

INCREASED PSYCHOLOGICAL FLEXIBILITY

Enhanced openness to emotions Stepping back from thinking Enhanced awareness of influences and consequences of responses Connection with what matters now Engaging in concrete actions to live well with grief.

SOCIAL SUPPORT

Support from volunteer listener Opening up to friends and family Feel part of a grief community

Outcomes

INDIVIDUAL SHORT TERM

Emotion tolerance and regulation, active coping, seeking social support. Increased wellbeing, increased psychological flexibility

INDIVIDUAL LONG TERM

Engaging in things that matter, reconnecting with relationships, making new relationships, Improvements in self care

BEREAVEMENT SUPPORT VOLUNTEERS

Enhanced skills and tools Increased psychological flexibility Greater confidence



Impact

INDIVIDUAL

Everyone who would benefit from bereavement support will have immediate access to evidence based advice and support.

ORGANISATIONAL

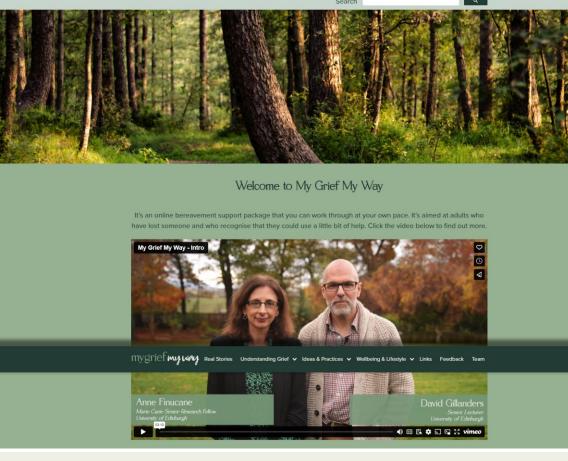
Greater reach, serving more people, safe, effective and cost effective, additional service offering

SOCIETAL

Grief support needs become recognised and validated, greater openness and awareness

mygrief





Audio Exercises

Developing Awareness

Helping you to learn how to be more present and aware of what is happening and how you are dealing with grief





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- Engaging and accessible: video, language, imagery, poetry (from the heart), consistent person / relationship with the site
- Real people's stories edited to show common stuck points of grieving
- ACT skills training videos, worksheets, audio
- Understanding and normalising a wide range of responses
- Specific strategies for self support wellbeing, lifestyle, sleep, cooking, exercise







• Real people's stories

EXPECTATIONS OF SELF AND OTHERS

ACT skills training
 OPEN SKILLS

Poetry
 START CLOSE IN





QUANTITATIVE FINDINGS

- Small n (only 27 participants total, 20 provided both pre and post measures)
- Baseline analysis no difference between those who completed post questionnaires and those that did not
- Time between pre and post mode = 49 days (7 weeks) (Range 41 111 days)

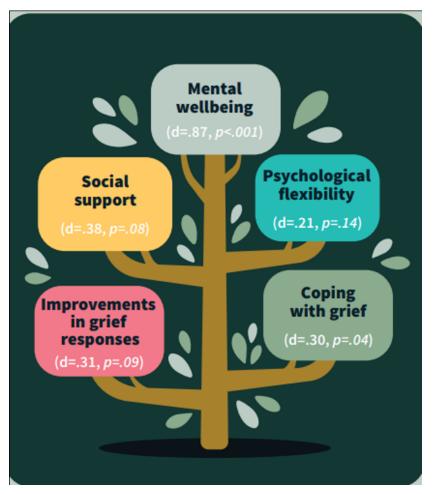






QUANTITATIVE FINDINGS

- Large improvement in wellbeing
- Small effect size changes on other variables
- Suggests indicator of benefit









QUALITATIVE HEADLINES

"Yes, I think it's very user friendly and I think it's easy to access and I think it quite clearly lays out you know, where you can find everything."

"I guess I felt there was people caring for you. So, it did give you that you were caring and that you weren't alone. It was there whenever you wanted it."

"Yeah, I realise how strong I am. And how honest I am with myself. Being open with myself about my feelings and, you know, being aware of the impact of what I'm feeling and how it has an impact on me."

"From 6-7 weeks ago until now... what an improvement and I think that My Grief, My Way has played a big part in that, you know."

My Grief My Way Agency Perspective

Nicola Reed

Director of Client Services



Graphic Source:

You will be Okay, Julie Stokes,
Illustrated by Laurène Boglio



Some Trends ... Changing demand for services

- 50% of our clients have been bereaved < 1 year
- Increasing waiting lists
 - Dip in volunteer numbers post pandemic
 - Triage indicating higher levels of client complexity
 - and some assessed as not needing support ...
- Changed preferences for how support delivered
 - Helpline (phone) to GriefChat (online text based)
 - Higher levels of remote support requested





Our vision is a compassionate Scotland in which the impact of bereavement and grief is properly understood and supported.



Background – University of Edinburgh

1.1 Background

Grieving is a natural process; typically, 60% of people who are bereaved are at low risk of complex grief issues and learn to adjust with support from family and friends. For three in ten people, additional support provided by volunteers or peer support groups is helpful; and for one in ten people specialist support provided by mental health professionals is needed. Despite this need, access to support is inconsistent.





Our involvement – Cruse Scotland

- Stakeholder meetings
- Involvement of client / bereaved individuals
 - Patient & Public Involvement (PPI) group
 - Website materials –resources & videos
- Volunteer involvement
 - Training
 - Website review
 - Client support
 - No intervention / Low / Moderate support needs
 - Self-directed / volunteer-supported
 - Feedback





My involvement

- Director of Client Services
 - Meet current needs of clients
 - Future proofing
- Counsellor
 - Therapeutic basis
 - Foundation grief models
 - Research based
- Trainer
 - Hopeful for what may lie ahead!







The future is bright ...

- Embedded in resource materials
 - Website
 - Literature
- Support options
 - Self directed support
 - Resource whilst on waiting list
 - 'Early support' development
 - Volunteer facilitated counselling support
- Volunteer training & development opportunities
 - Recruitment & retention

