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# My Grief My Way: a development study of an online support package for coping with bereavement

**Submission date**
02/02/2024

**Recruitment status**
No longer recruiting

**Registration date**
07/02/2024

**Overall study status**
Completed

**Last Edited**
12/12/2024

**Condition category**
Other

[X] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[_] Record updated in last year

## Plain English summary of protocol

Background and study aims
This study aims to make a new online support tool called My Grief My Way for people dealing with loss. It can be used alone or with help from a trained volunteer. This will help to check if it's safe and helpful for those with moderate grief support needs. Both interviews and questionnaires will be used to see if the study goals are met.

Who can participate?
People aged 18 years old and over with moderate bereavement support needs, who have contacted Cruse Scotland or Marie Curie Bereavement Support for help

What does the study involve?
In the study, participants will use the My Grief My Way website to learn about grief, develop new coping skills, and adjust to life after loss. They will answer short questionnaires before starting and again after eight weeks. They can use the program independently or with guidance from a trained support volunteer. Participants may also join an interview or focus group to share their experience with My Grief My Way.

What are the possible benefits and risks of participating?
Taking part in the study could bring benefits like better handling of grief, improved well-being, a higher quality of life, and discovering new meaning while coming to terms with grief. No major risks are expected, but learning effective grief coping might be emotionally challenging.

Where is the study run from?
The study is being run by the University of Edinburgh, in partnership with Marie Curie Bereavement Support Service (which is a UK-wide telephone-based listening service) and Cruse Scotland.

When is the study starting and how long is it expected to run for?
The study began in January 2023, with an initial 9 months of literature review, PPI engagement and intervention development work. The intervention part of the study begins in early February

2024. The study expects recruitment to be completed by early August 2024 and to report results by the end of December 2024.

Who is funding the study?
The study is funded by a Marie Curie Research Grant awarded jointly to Dr Anne Finucane and Dr David Gillanders, University of Edinburgh.

Who is the main contact?
The main study contact is a study-specific email address: mygriefmyway@ed.ac.uk

# Contact information


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Scientific, Principal investigator

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# Additional identifiers

**Clinical Trials Information System (CTIS)**
Nil known

**ClinicalTrials.gov (NCT)**
Nil known

**Protocol serial number**
Grant Reference: MC-21-808

# Study information

## Scientific Title
Development of an online self-directed Acceptance and Commitment Therapy (ACT) intervention to improve ability to cope and quality of life after bereavement

## Acronym
MGMW

## Study objectives
1. To develop a programme theory to illustrate how an online ACT-based bereavement support intervention could lead to improved coping, quality of life and well-being following bereavement. (Phase 1).
1.1. What works in bereavement support and what are the theorised causal pathways between ACT and improved coping, quality of life and wellbeing for people who have been bereaved?
1.2. What components of ACT are useful in supporting the well-being of people with bereavement support needs?
1.3. What format and mode of delivery should an online ACT intervention for people's bereavement support needs take?

2. To design, test and refine an online ACT-based psychological intervention to improve ability to cope and quality of life after bereavement (Phase 2)
2.1. What is the acceptability and user experience of an online ACT intervention for people with low and moderate-level bereavement support needs, and are there any differences in acceptability depending on the level of need?
2.2. What are the views of bereavement support volunteers regarding ACT-based bereavement support training?
2.3. What types of health care and non-health care related resource use, costs and benefits are associated with the delivery of an online ACT intervention, from the perspective of the bereaved person, the service provider, and the wider health and social care system?
2.4. What outcome measures are indicated for use in future feasibility and evaluation studies of an online ACT intervention to improve coping, quality of life and well-being for people with bereavement support needs?

## Ethics approval required
Ethics approval required

## Ethics approval(s)
approved 16/11/2023, Clinical & Health Psychology Ethics Committee, School of Health in Social Science, University of Edinburgh (Old Medical School, Teviot Place, Edinburgh, EH8 9AG, United Kingdom; +44 (0)131 651 3969; ethics.hiss@ed.ac.uk), ref: 23-24CLPS003_MGMW HISS

## Study design
Mixed-methods intervention development study

## Primary study design
Interventional

## Study type(s)
Other, Quality of life, Treatment, Safety

## Health condition(s) or problem(s) studied

People with moderate bereavement support needs

## Interventions
The intervention is called My Grief My Way. It is an online psychological intervention for people with mild to moderate problems with grieving / bereavement. It can be delivered as a pure self-help or as a guided self-help intervention. It is based upon Acceptance and Commitment Therapy (ACT), as well as the Dual Process Theory of Grieving and the Continuing Bonds Theory. There is no control condition. The duration of the support intervention is approximately 8 weeks.

The bereavement support resource will be hosted on the My Grief My Way website. Study participants will be provided with the website link. The site will be live so that site usage data can be collected using Google Analytics and will inform intervention development. The landing page will include a disclaimer so, in the unlikely event that the site is found by a member of the public, it will be clear to them that it is part of a research study, and who to contact for further information. The disclaimer will describe the nature of the site and will advise people that the tools and techniques are based on evidence-based psychological therapy principles, but that the use of a self-help website is not a substitute for professional mental health care. The page will signpost people to their primary care physician for further information and support.

Working through the intervention
Self-directed: Participants who are allocated to work through the intervention themselves will be given a link to the My Grief, My Way website and invited to work through the materials at their own pace for a maximum period of eight weeks.

Bereavement support volunteer facilitated: Participants who are allocated to work through the intervention with additional support from a bereavement support volunteer will be given a link to the My Grief My Way website and invited to work through the materials at their own pace for a maximum period of eight weeks. They will also have access to an ACT-trained bereavement support volunteer, who will provide them with regular ACT-congruent bereavement support for a period of up to six sessions. Six sessions are aligned with the current telephone-based bereavement support offered by our key stakeholder organisations. There is no obligation for the participant to complete all sessions, but they will have this option. The sessions will be provided by bereavement support volunteers within each key stakeholder organisation and will be delivered via the usual platforms used by the key stakeholder organisations.

Option to move from self-directed to volunteer facilitated option
If a participant accessing the MGMW resources in a self-directed manner feels the need for 1:1 support as they work through the intervention, they can inform the research team who will in turn inform the relevant stakeholder organisation that identified them originally. The stakeholder organisation will then allocate the person a bereavement support volunteer who will arrange up to six ACT congruent support sessions with them and the research will continue as planned.

## Intervention Type
Behavioural

## Primary outcome(s)
Acceptability and user experience measured using rapid qualitative methods informed by a framework approach, at around 8 weeks after the initiation of the intervention, which is considered post-intervention

### Key secondary outcome(s))
1. Feasibility measure using recording recruitment rate, eligibility, attrition post-intervention: 8 weeks after intervention start
2. Module usefulness measure using website feedback continuously assessed throughout the intervention, participants can provide website feedback at any point they wish. These data will be collated and synthesised after each cohort of fifteen participants has finished the intervention (8 weeks after they begin)
3. Module engagement measure using website analytics continuously assessed as participants use the website. These data will be downloaded and synthesised to see patterns of use after each cohort of fifteen participants has used the website for 8 weeks. There will be three such cohorts of fifteen leading to a total of 45 people user testing and providing experience of the website.
4. The following outcome data are measured pre-intervention and at approximately 8 weeks later:
4.1. Wellbeing measured using the Warwick Edinburgh Mental Wellbeing Scale
4.2. Coping with grief measured using the Adult Attitude to Grief Scale and the Inventory of Daily Widowed Life - Modified version
4.3. Quality of life measured using the EQ-5D-SL and the ICECAP-A (Health economics)
4.4. Social Support measured using the Inventory of Social Support
4.5. Psychological Flexibility measured using the PsyFlex

### Completion date
31/12/2024

## Eligibility

### Key inclusion criteria
1. Bereaved people who are seeking bereavement support via Marie Curie bereavement support services, and Cruse Scotland
2. Age 18 years old and over
3. English speakers

### Participant type(s)
Service user

### Healthy volunteers allowed
No

### Age group
Adult

### Lower age limit
18 years

### Sex
All

### Total final enrolment
27

### Key exclusion criteria
1. Individuals who are judged to have complex bereavement support needs (Nice Level 3)
2. Individuals who are currently or may require specialist mental health input

### Date of first enrolment
09/02/2024

### Date of final enrolment
08/07/2024

## Locations

### Countries of recruitment
United Kingdom

Scotland

Wales

### Study participating centre
**Marie Curie Support Line and Peer Support Service**
Marie Curie, 1st Floor, Unit 1 Bocam Park
Bridgend
United Kingdom
CF35 5LJ

### Study participating centre
**Cruse Scotland Bereavement Support**
29 Barossa Place
Perth
United Kingdom
PH1 5HH

## Sponsor information

### Organisation
University of Edinburgh

### ROR
https://ror.org/01nrxwf90

# Funder(s)

### Funder type
Charity

### Funder Name
Marie Curie

### Alternative Name(s)
Marie Curie Cancer Care, MarieCurieUK

### Funding Body Type
Private sector organisation

### Funding Body Subtype
Trusts, charities, foundations (both public and private)

### Location
United Kingdom

# Results and Publications

### Individual participant data (IPD) sharing plan
The datasets generated during and / or analysed during the current study are not expected to be made available due to the limited value this data will have to other researchers. The process of intervention development will be fully described in the papers described above.

### IPD sharing plan summary
Not expected to be made available

### Study outputs

| Output type | Details | Date created | Date added | Peer reviewed? | Patient-facing? |
|---|---|---|---|---|---|
| Participant information sheet | version 2 | 18/09/2023 | 06/02/2024 | No | Yes |
| Participant information sheet | version 2 | 18/09/2023 | 06/02/2024 | No | Yes |
| Participant information sheet | Participant information sheet | 11/11/2025 | 11/11/2025 | No | Yes |
| Protocol file | version 2 | 25/09/2023 | 06/02/2024 | No | No |
| Study website | Study website | 11/11/2025 | 11/11/2025 | No | Yes |