



THE UNIVERSITY
of EDINBURGH



Development of an online Acceptance and Commitment Therapy (ACT) intervention to improve ability to cope and quality of life after bereavement

Participant Information Sheet – Bereaved Individual

You are invited to take part in a research study called My Grief My Way. Dr Anne Finucane, Marie Curie Senior Research Fellow, and Dr David Gillanders, Senior Lecturer, at the University of Edinburgh are leading this research. Before you decide whether or not to take part, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Our study involves designing an online bereavement support website to help people cope with grief and to improve quality of life and wellbeing after bereavement.

Why have I been invited to take part?

We are working with Marie Curie and Cruse to develop this resource. We invited you to take part as you recently reached out to Marie Curie or Cruse Scotland bereavement support services regarding your grief. People eligible to take part must be able to speak English and be 18 years or older.

Do I have to take part?

No, it is entirely up to you to decide whether to take part. If you decide to take part, you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect your support from Marie Curie or Cruse Scotland bereavement support services. If you decide to withdraw during the study, you will be asked if the research team can use data already collected about you in their findings. You do not have to agree to this.

What will happen if I take part?

If you do decide to take part, please keep this Information Sheet. You will be asked to complete an online Informed Consent Form to show that you understand your rights in

relation to the research, and that you are happy to participate. You will also be asked to complete a brief online questionnaire, which will give us some information about your current circumstances (e.g., age, gender, relationship with the person who died etc). This questionnaire will take around 5 minutes to complete. We will then invite you to arrange a time with a member of our research team to complete a set of online questionnaires so we can understand how you are coping. Our researchers will talk you through this process by phone or Microsoft Teams. This will take about 15 minutes. After you complete these questionnaires, we will send you a link to our online bereavement support website (called My Grief My Way). This will contain a set of resources, which you will be invited to access in your own times over a period of six to eight weeks. You may do this on your own, or you may do this alongside a bereavement support volunteer. Whether you have access to a bereavement support volunteer will depend on your needs and preferences and will be decided by Cruse Scotland Bereavement Support or Marie Curie before you contact the research team. This decision will be made by them in line with the processes they routinely use to provide bereavement support.

- **Participants using the My Grief My Way online resource without a bereavement support volunteer:** Once you have completed background and baseline questionnaires, our Research Associate will give you the link to our My Grief My Way bereavement website so that you can start to access our grief support materials in your own time.
- **Participants using the My Grief My Way resource with a bereavement support volunteer:** Once you have completed the online background and baseline questionnaires, our Research Associate will give you a link to our My Grief My Way bereavement website so that you can start to access our grief support materials in your own time. The website will be live so that anonymised site usage data can be collected using Google Analytics and will inform intervention development. Our team will also inform Cruse Scotland or Marie Curie that you are ready to start, and they will link you with your bereavement support volunteer. The service coordinator or bereavement support volunteer will get in touch with you to arrange up to six phone meetings and guide you by holding a once weekly or fortnightly (if preferred) grief support conversation with you. Your bereavement support volunteer will be familiar with the My Grief My Way online resource, and will be able to guide you through using some of the materials and support you with your grief in general,

After a maximum of eight weeks, we will invite you to complete the same set of wellbeing questionnaires as you completed before you tried using the My Grief My Way resource. A member of our research team will set a date and time with you to go through these questions. We will also invite you to take part in an online individual or focus group or interview (depending on participant preference) so we can find out what you found helpful/useful about the My Grief My Way resource, and what was less useful. We are also very interested in hearing any suggestions you may have to improve our materials for people who have been bereaved. With your consent, our conversation will be audio recorded so that we have an accurate account of your experience. To enable audio recording on Teams will involve the use of the video function. You may wish to turn your camera off during this time if wished. We will remind you of this option at the beginning of each focus group/interview. Information

you provide will be anonymised so that you will not be identifiable. The audio recording will be erased as soon as key notes have been taken from our conversation and checked by a member of the research team. The interview should take around 45 to 60 minutes to complete whereas the focus group may take longer, approximately 60-90 minutes. Recordings will be transcribed as soon as possible following each focus group/interview, within two to three weeks. Transcriptions will be deleted once checked by a member of the research team, again within a further two to three weeks.

What do I need to take part?

You will require access to the internet and the use of an electronic device capable of downloading website information. Once connected, the website will signpost you to areas that may be of interest and you can work through a series of videos, examples of grief stories and exercises for you to complete voluntarily and at your own pace for a maximum period of eight weeks.

What are the possible advantages and benefits of taking part?

The study will provide you with evidence-based psychological techniques and resources to support you through your grief journey. We hope that these resources will help you cope and help you to maintain a good quality of life. By taking part in this study and providing the research team with your experience of this, you will be helping us create good quality bereavement support materials that many more people could benefit from in the future.

What are the possible disadvantages and risks of taking part?

Facing the pain of loss is part of grieving. It is possible therefore that you may feel emotional or upset when using the resources. Please be assured that this project is designed to help you to grieve safely and you will be supported by your organisation, Marie Curie or Cruse Scotland should you require additional help. The research team will also be on hand to direct you to additional support and resources if needed.

Will my taking part be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws that safeguard your privacy at every stage. We will not share any information about you with any other organisation except if you tell us about a serious risk of harm to yourself or others, in which case we may need to disclose to relevant organisations in order to manage that risk and fulfil our duty of care.

HOW WILL WE USE INFORMATION ABOUT YOU?

We will need to use information from you for this research project.

This information will include your:

- Name
- Contact details (email and phone number if provided)
- Gender
- Ethnicity

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information you share with us, safe and secure.

Your data will be referred to by a unique participant number, rather than name. You will be provided with this number by a member of our team once you consent to taking part, and you can use this number when completing questionnaires. That way, any personal information is not directly linked with your name. During the study, the research team will create a separate secure file with your name and unique participant number, just so we have it in case you forget it. This file will be destroyed by the study leads once data has been analysed.

If you consent to an online interview or focus group, this recording will be held in a Microsoft Teams folder accessed only by the research team and person responsible for writing down the words of the interview. Recordings will be deleted after they have been transcribed. All interview data will then be stored on a password-protected computer file save in a secure location in the University of Edinburgh Data Store. Your consent information will be kept separately from your responses to minimise risk.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no one can work out that you took part in the study. The anonymised data from the study will be stored for a minimum period of 3 years and may be used in future ethically approved research. Identifiable information will be retained for a period of one year. We will also use anonymised quotes from participants in research reports and papers (individuals will not be identified).

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- At <http://www.ed.ac.uk/records-management/privacy-notice-research>
- by asking one of the research team
- by sending an email to the University of Edinburgh Data Protection Officer at dpo@ed.ac.uk

The University of Edinburgh is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Edinburgh will keep identifiable information about you for 1 year after the study has finished and your anonymised data for a minimum of 3 years.

What will happen to the results of the research study?

Results of the study will be distributed to Marie Curie and Cruse Scotland bereavement support services. Findings will also be presented at national and international conferences. The study will be written up for publication in peer-reviewed, open access journals. You can request a copy of the results from the research team if you wish by contacting core team members at the end of this information sheet. This summary will be sent to participants by email. The results of the study and the data produced may be used in educational presentations, and may be used to train future students in research methods. **You will not be identifiable in any presentation or publication from this study.**

Who is organising and funding the study?

This study has been organised by Drs Anne Finucane and David Gillanders from the School of Health in Social Science at the University of Edinburgh who will co-lead the research team. The research is sponsored by the University of Edinburgh. This study has been funded by Marie Curie (www.mariecurie.org.uk/).

Who has reviewed the study?

The study proposal has been reviewed by the Clinical Psychology Ethics Committee at the School of Health in Social Science, University of Edinburgh.

We are very grateful to a group of bereaved individuals who are also involved in this research, and are providing feedback on this research at key stages, including the materials that will be seen by participants.

What happens now?

You do not need to do anything. If you have given Cruse Scotland or Marie Curie permission to share your contact information with the research team, a research member (Anne Canny) will be in touch with you to answer any questions you may have before you decide whether you want to take part. If you decide to take part, you will be asked to complete a consent form and a set of online questionnaires before accessing the My Grief My Way resource.

What if there are any problems?

If you have concerns about any aspect of the study or experience any problems, please do not hesitate to contact your bereavement organisation or core members of the research team listed at the end of this information sheet.

If you have any further questions about the study, please contact our team

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Anne Finucane: a.finucane@ed.ac.uk

David Gillanders: david.gillanders@ed.ac.uk

Study telephone number: 07752229606

Study email address: mygriefmyway@ed.ac.uk

If you would like to discuss this study with someone independent of the study, please contact: School of Health in Social Science Director of Research, Dr Angus MacBeth,
Angus.Macbeth@ed.ac.uk

Complaints.

If you wish to make a complaint about the study, please contact: Prof Matthias Schwannauer, Head of the School of Health in Social Science: headofschool.health@ed.ac.uk

Thank you for taking time to read this information sheet