



PARTICIPANT INFORMATION SHEET

Do funeral factors influence post-bereavement outcomes?

You are being invited to take part in a pioneering research study which considers whether there are any aspects of a funeral that influence the way that people feel after they have been bereaved.

Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about how the study is being conducted.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

Part 1

What are funeral factors?

Funerals are made up of lots of different things. These are things that might take place before the day of the funeral itself, during the funeral and afterwards, and sometimes even a long time afterwards. The funeral includes activities, physical objects and perceptions, for example, about levels of control or involvement. At the moment, we don't know which of these different aspects of the funeral (which we will be calling 'factors') are most important to people feeling that a funeral went well.

Part of the research, then, will ask a small number of people some detailed questions about their experience of a recent funeral, to help us define what the most important factors are.

What are post-bereavement outcomes?

In medical terms, an 'outcome' is how people feel, in the longer term. We want to find whether a funeral going well or going badly influences how people feel in the longer term. A second part of the research will be to use our understanding of funeral factors to create a structured survey, so we can ask many more people about their experiences. We will be using a standard wellbeing survey that is used in hospitals to measure how people feel. We can use the survey to compare measurements taken at different times, and by different people.

What is the purpose of the study?

It has been stated for many years that a "good" funeral can help people but there is very little research that has explored this assertion. This study aims to establish whether funeral factors do indeed influence how people feel.

Furthermore, if the results support the view that funeral factors do influence post-bereavement outcomes then this will provide an initial evidence base to determine the best way for funeral directors and cemetery and crematorium managers to support bereaved people and will provide direction for further research into this area.



Why have I been chosen?

You have been chosen to participate in this study because you have attended the funeral of a close relative and feeling willing and able to discuss your experience without this causing you any undue distress or anxiety.

Do I have to take part?

No. It is up to you to decide whether to take part. If you do, you will be given this information sheet to keep and asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or decision not to take part, will not affect and support that you may require from us in the future.

What will happen to me if I take part? / What do I have to do?

If you agree to take part in this research, we will ask you to answer some questions with one of our researchers. This can take place over the telephone, or face-to-face, depending on what you prefer (and where you live) and can take place at your home, or at Full Circle Funerals in Guiseley. This initial interview is likely to take between one to two hours and be recorded on an encrypted recording device. This means that we can concentrate on the conversation and be able to write the detail down accurately afterwards.

This study will take place over a long period of time (two years) and in most cases, you will also need to complete a short questionnaire about how you are feeling after six months and approximately one year after the funeral has taken place. This questionnaire can either be emailed to you for you to complete and return or can be completed over the telephone with a member of the research team.

What are the possible benefits of taking part?

This study will improve our understanding about the influence that funeral factors have on post bereavement outcomes and ultimately aims to increase our understanding of how funeral directors (and allied professionals) can support bereaved people in the best possible way.

What are the possible disadvantages and risks of taking part?

There are no specific risks to participating in this study. However, as with all bereavement and funeral related research, you may feel upset when answering the questions as they ask you to discuss a funeral, and your feelings about certain aspects of it, in some detail.

What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. It will not be used in any way or for any other purpose other than those stated. More detailed information on this is given in part 2.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice at all times and all information about you will be anonymised and handled in confidence. However, if you were to divulge information that could potentially lead to prosecution or may expose children, vulnerable adults or the general public to serious risk then this information may need to be reported. In these unlikely circumstances, all efforts would be made to discuss this with you before any information is disclosed.

Expenses and Payments

No payments will be provided to participants in the study. It is not expected that any expenses will be incurred.



What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time and this will not affect any future support that you may request from us.

What if there is a problem?

If you have a concern about any aspect of this study, we will want to know. Please speak to the researchers who will do their best to answer your questions (see contact numbers given). If you remain unhappy and wish to complain formally, you can do that by contacting Fran Hall from The Good Funeral Guide.

Full Circle Funerals – 01943 262626

Fran Hall (CEO Good Funeral Guide) – 07866 596234

Will my taking part in this study be kept confidential?

Your participation is voluntary, and all information will be kept confidential and anonymous. All information will be kept strictly confidential and will be held a password protected electronic file. Instead of using your name you will have a unique research number.

The initial interview will be recorded using an encrypted recording device. After the interview, this recording will be used to create a written interview summary, detailing the relevant points from the interview. This document will have unique research number but will not contain any personal identifiers (such as names or places). Once the interview summary has been created, the recording of the interview will be permanently destroyed.

Data linking your unique research number to your personal details will be stored securely, in a password protected electronic file. This information is needed to send you the two follow-up questionnaires mentioned above. The results from the follow-up questionnaires will also be anonymous and kept with the written interview summary.

What will happen to the results of the research study?

The results from this study will be published as a written document, and possibly published in a scientific journal. The results will also be presented at conferences. In all instances, your details will remain anonymous and all information remains confidential.

Who is organising and funding the research?

The project is being carried out by the Full Circle Funerals (an independent Funeral Director based in Guiseley, West Yorkshire). There is no funding in place for this study.

Who has reviewed the study?

Full Circle Funerals is receiving support from an advisory committee, including representatives from the University of York, Leeds Beckett University, ICCM (Institute of Cemetery and Crematorium Management), GFG (Good Funeral Guide), SAIF (National Society of Allied and Independent Funeral Directors).

Thank you for taking the time to read this information sheet, please keep it for your future reference.



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