



PARTICIPANT INFORMATION SHEET

Care of the body: what do Experts by Experience expect?

Overview

You are being invited to take part in a research study which considers bereaved people's ideas, concerns and expectations how a body is cared for after someone has died (we have described this as personal care). The study also considers how people decide whether to spend time with someone after they have died, and how they reflect on this afterwards. The study seeks to understand people's experiences prior to the Coronavirus pandemic in 2020 and therefore participants will be asked to discuss experiences of funerals from 2019, or before.

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.

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.

Further information

What is personal care?

Person care of the body refers to all the actions that are performed on or to the body of someone who has died. This might include where they are located and activities such as washing, dressing and embalming (sometimes called hygiene treatment).

The research team will ask a small number of people some detailed questions about their thoughts and reflections about how someone is cared for after they had died. We will ask these questions in the context of a funeral that you have arranged or been closely involved with.

What is an "Expert by Experience"?

An "Expert by Experience" is someone who has personal experience of using health and/or social care services.

In health and social care research, the perspective of people with this lived experience is increasingly being prioritised and used to understand how to deliver and improve services. This is regarded as a positive move away from only asking professionals (such as funeral directors) for their opinions.

What are decisions about spending time with someone?

The research will ask whether you decided to spend any time with the person who had died, after they had died. You will be asked open questions about how you decided whether this was something that you wanted to you and then asked to describe this experience and how you felt about it then and now.



What is the purpose of the study?

A recent research study (report can be found at <https://fullcirclefunerals.co.uk/learning-together/research/>) highlighted that it is important to bereaved people have different views regarding spending time with someone who has died but that the important factor is that their individual needs are understood and met. During this study, we did not specifically ask people for their ideas, concerns or expectations about how the body had been cared and this current study seeks to understand that further.

Different funeral directors have varying ways of practicing and caring for people who have died. The funeral industry has been criticised for not being open and transparent with the people who use their services and this research group feel that this also applies to care of the body. The findings of this study will be used to make recommendations for good practice to funeral directors and allied health and social care professionals.

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 via video interview depending on your preference. This interview is likely to take between half an hour and one hour 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.

What are the possible benefits of taking part?

This study will improve our understanding about what is important to bereaved people regarding personal care and spending time with someone after they have died. This research 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.



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 and this will then be transcribed. 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 will only be kept beyond completion of the study if you have specifically consented for this to take place, as you would like to be informed of opportunities to be included in research studies carried out by Full Circle Funerals in the future.

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 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, 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.

Contact for further research information:

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