

When someone dies: experiences and perspectives of bereaved people and professionals

Workstream 2: Interviews Information Sheet – Bereaved people

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Name of Researcher: Glenys Caswell (Chief Investigator)

I am a researcher from the School of Health Sciences at the University of Nottingham and I would like to invite you to take part in my research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. **Please ask me if there is anything that is not clear.**

What is the purpose of the study?

To find out about:

- the views of bereaved people about their experiences when one or more family members, friends or neighbours died
- the views of bereaved people about the significance of being with the person when they die
- whether or not it is important for bereaved people to know when the person they cared about died

Why have I been invited?

You have been invited to take part in this study because you had a friend, relative or neighbour who died.

You may have seen one of the adverts seeking participants and contacted me to ask for more information, or have visited the study webpage. I am inviting 10 people who have experienced a bereavement to take part.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part you are still **free to withdraw at any time** and without giving a reason. This would not affect your future legal rights.

What happens if I take part?

If you decide to be included in the study you will be asked to sign a consent form to indicate that you agree to take part in **an interview which will last for about an hour**. This can take place in your home or at another location of your choice.

The interview will be **about your experiences** when a member of your family, a friend or neighbour was coming to the end of their life. I would like to find out:

- what your experiences were when spending time with someone who was dying
- how you felt about that experience

With your permission I would like to audio record the interview. However, you can still take part in the study even if you do not want me to do this.

What are the possible benefits of taking part?

I cannot promise the study will help you directly but the information collected may help understanding of peoples' views and experiences about death, dying and end of life care. I hope participants will find involvement in the study to be an interesting experience. Some people find it helpful to have the opportunity to reflect on, and share, difficult experiences such as the illness of those close to them with someone who is not directly involved.

What are the possible disadvantages and risks of taking part?

I understand that talking about issues relating to the death of someone you care about may be difficult and upsetting. I ask you to consider very carefully how you would feel about sharing this experience with the researcher. It is important that you understand what is involved and discuss this fully with the researcher before you decide to take part. It is possible that you may feel upset at times during the interview. However, you will never be under any pressure to answer questions or talk about topics that you prefer not

to discuss. You can stop the interview, take a break, or withdraw from the study, at any time.

Expenses and payments

Participants will not be paid to take part in the study. Travel expenses will be offered if you decide to be interviewed somewhere other than your home.

Will my taking part in the study be kept confidential?

I will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study information collected from you during the course of the research will be used. This information will be kept strictly confidential, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and read our privacy notice at:

<https://www.nottingham.ac.uk/utilities/privacy.aspx>.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Where information about you leaves the University of Nottingham it will have your name and address removed and a unique code will be used so that you cannot be recognised from it. By signing the consent form you agree to the above.

Your contact information will be kept by the University of Nottingham for 3 to 6 months after the end of the study so that I am able to contact you about the findings of the study (unless you advise me that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years.

After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

The only circumstances under which confidentiality would be broken would arise if the researcher was made aware of actions or situations resulting in serious risk of harm to yourself or others. The researcher would discuss this with you and consider the need to raise the matter with the appropriate authorities.

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

Your participation is **voluntary and you are free to withdraw at any time**, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far, including any personal identifiable data, will not be erased from the secure University of Nottingham server. Anonymised data may still be used in the project analysis.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions. The researcher's contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you should then contact the Research Ethics Committee Administrator, c/o University of Nottingham, E41, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: louise.sabir@nottingham.ac.uk

What will happen to the results of the research study?

A report will be prepared for the British Academy, which has funded the study. The results of the research will be made more widely available through professional and academic journal **publications and conference presentations**. With your permission, we may include direct quotations from the interviews. However,

these will not include your name or any personal details. You will not be identified in any report or publications resulting from the research. All participants will be sent a summary of the findings at the end of the study if they would like to receive this.

With your agreement, we may use the data collected in this study to support other research in the future, subject to ethical approval. In this case the data may be shared anonymously with other researchers.

Who is organising and funding the research?

This research is organised by University of Nottingham and funded by British Academy.

Who has reviewed the study?

All research involving people as participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by the University of Nottingham's School of Medicine and Health Sciences Research Ethics Committee.

What do I have to do?

Please let the researcher know if you are interested in taking part in the study, or would like to discuss this further. You can contact her using the details given below by email, by phone or by post. The researcher will contact you directly to discuss the study further.

Further information and contact details

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