
PARTICIPANT INFORMATION SHEET AND CONSENT FORM

For Families who have engaged a Death Doula

Title: 'The role of Death Doula in End of Life Care'

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Description of the study

This project will investigate the role of Death Doula in End-of-Life care in Australia. This project is supported by Flinders University, College of Nursing and Health Sciences under the auspices of the Flinders University Research Centre for Palliative Care, Death and Dying

Purpose of the study

This project aims to investigate the views and experiences of family or friends of people who have died and where a death doula has previously been engaged to provide support at least 3 to 6 months ago.

Benefits of the study

The sharing of your experiences will help to contribute to ongoing research into the role, in developing an understanding of the benefits and drawbacks to employing a death doula when someone is at the end of life

Participant involvement and potential risks

If you agree to participate in the research study, you will be asked to participate in a one-on-one recorded interview about how it was for you to engage and work with a death doula.

The interview will take approximately 1 hour and your participation is entirely voluntary. You will be asked to sign a consent form prior to the interview. To thank you for your time you will be provided with a \$30 gift e-voucher.

The researchers are aware that this may cause you some distress as you will be telling or recalling your experience of someone close to you who has died. If you experience feelings of distress as a result of participation in this study, please let the research team know immediately. You can also contact the following services for support:

- Lifeline – 13 11 14, www.lifeline.org.au
- Beyond Blue – 1300 22 4636, www.beyondblue.org.au

Withdrawal Rights

You may, without any penalty, decide not to take part in this research study. If you decide to take part and later change your mind, you may, without any penalty, withdraw at any time. You do not need to provide an explanation. To withdraw, you can refuse to answer any questions or tell the interviewer to stop. Any data recorded during the interview will then be destroyed.

Confidentiality and Privacy

The researchers listed on this form have access to the individual information provided by you. Privacy and confidentiality will be assured at all times. The research outcomes may be presented at conferences, written up for publication or used for other research purposes as described in this information form. You will not be named and nor will your doula, instead we will use a pseudonym (fake name). Your individual information will not be identifiable in any research products without your explicit consent.

No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without your explicit consent.

Data Storage

The information collected may be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes unless indicated otherwise. All data will be securely transferred to and stored at Flinders University for five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

We will record the interview and then send you a transcript of this interview to read. If you agree that it is a true record of what you said, then we will destroy the recording.

How will I receive feedback?

On project completion, a short summary of the outcomes will be provided to all participants via email on request.

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (project 2590).

Queries and Concerns

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 2543 or email human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet which is yours to keep. If you accept our invitation to be involved, please sign the Consent Form below.

CONSENT FORM

Consent Statement

- I have read and understood the information about the research, and I understand I am being asked to provide informed consent to participate in this research study. I understand that I can contact the research team if I have further questions about this research study.
- I am not aware of any condition that would prevent my participation, and I agree to participate in this project.
- I understand that I am free to withdraw at any time during the study.
- I understand that I can contact Flinders University's Research Ethics & Compliance Office if I have any complaints or reservations about the ethical conduct of this study.
- I understand that my involvement is confidential, and that the information collected may be published. I understand that I will not be identified in any research products.
- I understand that I will be able to withdraw my data and information from this project. I also understand that this data **will not be used** for this research study.

I further consent to: *delete/add boxes as required*

- participating in a one-on-one interview
- having my information audio recorded
- sharing my identifiable data with other researchers

Signed:

Name:

Date: