

**The Cairnmillar Institute**

**Plain Language Information Statement**

**Date:** 3 July 2022

**Project Title:** *Palliative care volunteers' lived experience of past grief and bereavement in the context of their volunteering role*

**Project Number:** 2022050901

**Principal Researcher:** Dr Zoë Krupka (Senior Lecturer, Cairnmillar Institute)  
[zoe.krupka@cairnmillar.edu.au](mailto:zoe.krupka@cairnmillar.edu.au)

**Student Researcher:** Dr Florence Chiew (Honours Psychology student, Cairnmillar Institute)  
[12171@cairnmillar.edu.au](mailto:12171@cairnmillar.edu.au)

**Contact Number:** 03 9813 3400

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**To Participant:**

This Plain Language Information Statement contains information about the research project. Its purpose is to explain to you the procedures involved in this project so that you can make a fully informed decision regarding your participation.

**Why is this research being conducted?**

Across Australia, palliative care volunteers play an important role in providing a range of support to terminally ill clients and their families. For some volunteers, a personal encounter with death and dying has been a motivating factor for freely offering to spend time with people approaching the end of life.

The aim of this study is to explore how volunteers who have had lived experience of grief and bereavement make sense of their past grief in the context of their volunteering role. We are particularly interested in hearing from volunteers who feel that their personal experience of death and dying has informed their decision to take on voluntary work in a palliative care setting.

**Who can participate in the study?**

This research study is aimed at palliative care volunteers who meet the following criteria:

- 1) any gender, aged 18 years and above,
- 2) received training in palliative care volunteering and been working as a palliative care volunteer for at least 2 years,

- 3) experience of the death of a close person with a period of at least 12 months since bereavement.

We are interested in understanding how a personal encounter of grief and loss is experienced in the context of volunteering in palliative care.

### **What does participation involve?**

If you meet the eligibility criteria and decide to participate in the study, you will be invited to an individual interview with the student researcher, Dr Florence Chiew. The interview contains questions that explore your lived experience of past grief in the context of your volunteering role in palliative care.

Examples of questions you may be asked include:

- What have been the most enriching aspects of being a palliative care volunteer?
- How do you make sense of how you have come to choose a volunteering role in palliative care?
- Has your understanding of grief and loss changed since spending time with palliative care clients? In what ways?

If you agree to participate in the study, you will be invited to an online interview via Zoom. The interview will take approximately 1 hour, with additional time to address any questions you may have. To facilitate data collection and data analysis, the researcher will request that the interview be audio-recorded.

Participation in the study is entirely voluntary and you retain the right to withdraw from the study at any time up until the data from the study has been analysed in preparation for writing up. Every effort will be made to protect the confidentiality of any identifying information from your responses.

### **What will happen to the information I provide?**

Dr Zoë Krupka and Dr Florence Chiew will have access to the information you provide and the transcripts of your interviews may be viewed by other researchers at The Cairnmillar Institute once your identifying information has been removed. We will take every precaution to ensure that your information cannot be identified, including changing your name and the names of anyone else you speak of in your interview, removing details of your location, specific workplace and any specific experiences which may be unusual or unique. Any information provided will be secured on password protected computers. Once data collection and analysis has been completed, the data will be imported to the Cairnmillar Institute server where it will be stored securely. The audio-recordings of interviews will be deleted shortly following publication of study findings. De-identified transcripts will be retained for 5 years, after which they will be deleted by the primary researcher.

The results of the study will be disseminated in the student researcher's Honours thesis, and potentially also in a peer-reviewed academic journal. However, no identifying information will be included in the publication of research findings.

Researchers may have to provide information if it is ordered by a court or required by legislation such as in the case of a search warrant or subpoena. The researchers may also be required to disclose information in some circumstances; for instance to prevent serious harm to the participant, another person, or the community. For further information on these limits to confidentiality, please see the [Australian Privacy Principles, section 6](#).

### **Possible benefits**

As there may not be many opportunities to openly talk about and share learnings from past grief experiences, you may derive benefit from reflecting on your lived experiences. By participating in this study, you are contributing to a deeper understanding of the personal factors that motivate individuals to volunteer for palliative care.

### **Possible risks**

In recalling past grief experiences, participants may occasionally experience some sadness. If you are concerned about your mental health or wellbeing in relation to the study, you are encouraged to make use of the free counselling services available through the Cairnmillar Institute Clinics. These services will be provided by provisional psychologists under supervision. If you would like to access these free counselling services, please contact the primary researcher, who will arrange for an appointment at the Clinic.

All palliative care volunteers also have access to bereavement counselling services provided by their local palliative care health network. In addition, participants have access to telephone counselling services through Lifeline (13 11 14), Beyond Blue (1300 22 4636), the National Carer Counselling Program (1800 242 636) and Griefline (1300 845 745).

This study has been approved by the Human Research Ethics Committee at The Cairnmillar Institute and will comply with the *National Statement on Ethical Conduct in Human Research* (National Health and Medical Research Council of Australia, 2007).

### **Who can I contact if I have any questions?**

If you would like further information regarding this project, please contact the student researcher or principal researcher (see contact details provided above). If you decide to participate in this study but later change your mind, you may also contact the researchers involved in the study.

If you have any concerns or complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may also contact the Secretary to the Human Research Ethics Committee. Please ensure to include the **project name**, **project number** and the **name of the Principal Researcher** in any correspondence when contacting the Secretary of HREC. (You can find these details at the top of this document).

The contact details can be found below:

Secretary to the HREC  
The Cairnmillar Institute

391-393 Tooronga Road  
Hawthorn East VIC 3123  
Phone: 03 9813 3400

Email: [hrec@cairnmillar.edu.au](mailto:hrec@cairnmillar.edu.au)

**If I agree to participate, how do I get started?**

If you would like to participate in the study, please get in touch with the student researcher, Dr Florence Chiew, via email ([12171@cairnmillar.edu.au](mailto:12171@cairnmillar.edu.au)). In your email, please attach a signed copy of the consent form. The researcher will then contact you to organise a suitable time for an interview.

**The Cairnmillar Institute****Consent Form**

**Full Project Title:** *Palliative care volunteers' lived experience of past grief and bereavement in the context of their volunteering role*

**Principal Researcher:** Dr Zoë Krupka

**Student Researcher:** Dr Florence Chiew

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I have been invited to participate in a Cairnmillar Institute research project detailed above and agree with the following statements:

- ☐ I have read and understood the Plain Language Information Statement provided to me by the researchers and consent to participate in the research project
- ☐ I consent for my data to be used as outlined in the Plain Language Information Statement
- ☐ I understand my participation is completely voluntary and that I can withdraw from the project at any time up until the interview data is ready for write up
- ☐ I consent to have my interview audio-recorded

Name of Participant:

Participant Signature:

Date:

# ARE YOU A PALLIATIVE CARE VOLUNTEER WITH A PERSONAL GRIEF STORY?

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## Study on lived experience of grief in palliative care volunteering

Across Australia, palliative care volunteers play an important role in providing support to terminally ill clients and their families.

The aim of this study is to explore how volunteers who have lived through a grief experience make sense of their past grief in the context of their volunteering role.

We are particularly interested in hearing from volunteers who feel that their personal experience of death and dying has informed their decision to take on voluntary work in a palliative care setting.

### **Who can participate in this study?**

Palliative care volunteers who are:

- of any gender, aged 18 years and above,
- received training in palliative care volunteering and been working as a palliative care volunteer for at least 2 years,
- experience of the death of a close person with a period of at least 12 months since bereavement.

Eligible participants will be invited to a 60 minute one-on-one interview with a member of the research team.

If you meet the above requirements and are interested to participate in the study, please get in touch with the student researcher, Florence Chiew:

**12171@cairnmillar.edu.au**