

Caregiver participant information sheet

Understanding how young adults living with cancer in rural and remote settings experience and navigate their cancer journey: a phenomenological study.

Invitation:

You are invited to participate in a PhD research study that will explore how young adults living with cancer in rural and remote settings experience and navigate their cancer journey from the perspective of the young adults themselves.

The study is being conducted by:

Investigator: Jessica Hammersley, Lecturer in Nursing, RN, GradDipN, MCN, BEd(Prof Hons), PhD Candidate, University of Tasmania.

The study will be supervised by:

Chief Investigator: Dr Elaine Crisp, PhD, Lecturer, University of Tasmania

Co-Investigator: Dr Kathleen Tori, PhD, Professor in Nursing, Charles Sturt University

Co-Investigator: Dr Karen Francis, PhD, Professor in Nursing, Charles Sturt University

'What is the purpose of this study?'

The purpose of this study is to understand how young adults residing in rural or remote areas experience and navigate their cancer journey, from their perspective. The research team will draw upon the findings to help understand the supportive care needs of patients and their families, inform healthcare professionals working in the area of oncology, and add to the body of knowledge in this area.

'Why have I been invited to participate in this study?'

You have been identified as having knowledge and experience in caring for the young adult (18-39 years) who is experiencing an illness of cancer while residing in a rural or remote area.

'What does participation in this study involve?'

If you agree to participate in the study, we will ask you to do the following:

You will be asked to take part in an in-depth focused interview face-to-face (depending on geographical location), or via zoom, telephone or facetime. The interview will last approximately 60 minutes; this interview will be digitally recorded and transcribed. The questions you will be asked will relate to your experience as a provider of care. If you would like to bring along a piece of work or personal item such as a visual image which you believe captures your caregiver experiences, please feel free to share. With your consent, a photo will be taken of your chosen personal item.

When participating in this study, your identity will remain anonymous, and all information obtained will be treated in a confidential manner. It is important to understand that your participation is completely voluntary. Signed consent forms, original audio recordings, interview transcriptions and a photograph of your personal item (if applicable) will be retained securely in the office of the Student Investigator within the School of Nursing at the University of Tasmania, Domain Campus until five years after the completion of the PhD thesis. After this time, the data will be permanently destroyed.

‘Are there any possible benefits from participation in this study?’

It is not anticipated there will be any direct benefit to you by taking part in this study, except the opportunity for your experiences to be heard. However, your experiences make you an invaluable source of information about the current support system, and the results arising from this study will increase knowledge and help to improve the care of future patients who live in rural or remote settings.

‘Are there any possible risks from participation in this study?’

There is a risk that you may experience some distress sharing your experiences of providing care to the young adult experiencing a cancer illness. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. The researcher will be sensitive to your needs if you choose to proceed or finish the interview at any point. Prior to your commencement of the interview, the researcher will provide you with a flyer which includes appropriate helplines to contact should you become upset or distressed as a result of your participation in the study. Any counselling or support provided will be qualified staff who are not part of the research team.

‘What if I change my mind during or after the study?’

If you change your mind about being involved in the research, you may alert a member of the Research Team of this. You are free to suspend, cancel or postpone your involvement at any time, including up to eight (8) weeks after the interview has been conducted.

How will the results of the study be published?

The final results of the interviews will be integrated into a PhD thesis, to be published in approximately 2026. Results may also be included in oral and visual presentations made by the Research Team at relevant conferences and in associated presentations. However, confidentiality will be maintained at all times and your identity will always remain protected. The PhD thesis will be printed in hardcopy as well as digitally and stored at the University of Tasmania Library. If you would like to receive an overview of the research once it is complete, please let our Student Investigator know.

‘What if I have any questions about this research?’

If you would like to discuss any aspect of this study please feel free to contact Dr Elaine Crisp via email elaine.crisp@utas.edu.au, or Jessica Hammersley via email: janewett@utas.edu.au. We would be happy to discuss things with you further.

This study has been approved by the University of Tasmania Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, you can contact the Executive Officer of the HREC on (03) 6226 6254 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H0020347.

Thank you for taking the time to consider your participation in this study. This information sheet is for you to keep.