



Participant Information Sheet

Study title:	Perceptions and experiences of informal caregivers supporting patients to engage in physical activity after cardiac surgery		
Principal investigator:	Name Department Position	Dr Emily Gray School of Physiotherapy Lecturer	Contact phone number: 0800 687 489

Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate, we thank you. If you decide not to take part, there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project?

Engagement in physical activity (any movement during work, active transport, self-cares, household activities and exercise) following cardiac surgery has many physical and psychological challenges, including pain, fatigue, fear and uncertainty. People who have had cardiac surgery often say how much they need and value physical assistance and psychological support from their spouse and/or whānau / family to help them engage in physical activity after they leave hospital. Shorter hospital stays currently compared to 30 years ago mean that people who have undergone cardiac surgery need to be cared for by whānau/family members at home for a greater duration of their recovery. However, previous studies have shown that caregivers often feel unprepared and lack knowledge about how to care for and support their whānau member following cardiac surgery.

The aim of this research project is to 1) explore the perceptions and experiences of informal caregivers (i.e spouses, whānau/family members or friends) of supporting someone to engage in physical activity following cardiac surgery; and 2) explore caregiver's views about the type of information and support that could be provided to equip caregivers with the knowledge and skills to do this. The findings of this

research may contribute to changes in health service delivery regarding how people are prepared to care for and support their whānau/family member who has undergone cardiac surgery.

This project is being undertaken by Shanelle Ward as part of the requirements for her Bachelor of Physiotherapy Honours degree. The project is supervised by University of Otago academic staff members at the School of Physiotherapy, Dr Emily Gray and Professor Leigh Hale.

Who is funding this project?

This project is being funded by internal research funds available within the School of Physiotherapy.

Who are we seeking to participate in the project?

We are seeking people who acted as the primary caregiver for their spouse or whānau/family member after having cardiac surgery. Ideally, their surgery would have taken place during the past two years but not less than three months ago and could include coronary artery bypass (heart bypass) surgery, heart valve replacement surgery, or both. You will need to be able to converse in English.

If you participate, what will you be asked to do?

Should you agree to take part in this project, you will be asked to take part in an interview of approximately 40 minutes duration. The purpose of the interview is to explore your experiences of caring for and supporting your whānau/family member to engage in physical activity following their cardiac surgery, the kinds of challenges that you faced when providing them with assistance and support, and your views on what information and support should be provided to caregivers in order to prepare them to support their whānau/family member following their discharge from hospital.

The interview will be undertaken by the student researcher, with the support of her supervisor Dr Emily Gray. If you live in Dunedin the interview will take place either over the phone, via Zoom or face to face either in your home or at another place such as the School of Physiotherapy or a local community venue, depending on your preference. If you live outside of Dunedin, the interview will take place over the phone or via Zoom, depending on your preference. You are welcome to have a support person/whānau present during the interview if you wish. This person does not have to be the person that you cared for following their cardiac surgery if you think that having them present during the interview could cause distress to them or yourself.

You will be able to request a copy of your interview transcript for you to check, add information to and/or amend if you desire. Once we have analysed the data, you will be provided an opportunity to view an initial summary of the results which outlines the main findings, and you will have an opportunity to comment on these findings if you so wish. If the research team does send you a copy of your transcript or the initial themes, you will have up to two weeks to comment and send back any feedback to the researchers. Following the interview, you will have the option to withdraw any data relating to yourself. After all the study data has been analysed and themes developed, it may be difficult to

withdraw any specific data relating to yourself once it has been grouped in with the other study data. However, if you do decide to withdraw from the study, no quotes from your interview will be used in the reporting of the study findings.

There is no reimbursement being offered for participation in this project. Food/kai will be provided at any interviews conducted in person.

Is there any risk of discomfort or harm from participation?

The precise nature of all of the questions that will be asked have not been determined in advance, but will depend on the way in which the discussion develops. Consequently, though the University of Otago Health Ethics Committee is aware of the general questions and areas to be explored in the interview, the Committee has not been able to review the precise questions to be used. If the line of questioning does develop in such a way that you feel hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) without having to provide a reason.

Because you will be sharing personal information about a major event in the life of your spouse or whānau/family member, it is possible that recalling and sharing this information may make you feel anxious, uncomfortable, or distressed. Please note that if at any time during the interview you feel uncomfortable or hesitant about answering any questions you do not have to. It is entirely up to you what you tell us, and you may also withdraw from the project at any stage without disadvantage to yourself of any kind.

What data or information will be collected, and how will they be used?

You will be asked to provide information such as your age, gender, ethnicity and living locality (e.g urban or rural). This information will be used to describe participants in the study as a whole group and you will not be able to be identified personally in the reporting of this information. Only the named researchers will have access to this data which will be stored on a secure password protected computer for at least five years. Any personal information (such as contact details) will be destroyed at the completion of the study.

All interviews will be audio-recorded and subsequently typed out word for word by one of the research team or a professional firm who specialise in doing this confidentially. Your name and any other personal information that could identify either yourself or your whānau/family member who had cardiac surgery will be removed from the interview transcript prior to any analysis of the data. Once the interviews have been transcribed, the audio-recordings will be permanently deleted from the computer. The de-identified transcripts will be kept for five years on the researchers' secure password protected computer. Any notes taken during the interview will not contain any personal identifying information to protect your anonymity. The study findings may be published and be available in the University of Otago library.

What about anonymity and confidentiality?

As previously stated, all information that could identify you or your whānau/family member personally will be removed from the interview transcripts prior to being analysed. All personal data that could identify you such as contact information will be securely stored on the password protected computer of one of the research team members and will be destroyed at the completion of the study. No material that could personally identify you will be used in outputs from this study (e.g., publications in academic journals or conference presentations).

If you agree to participate, can you withdraw later?

You may withdraw from the project, before its completion without any disadvantage to yourself.

Any questions?

If you have any questions about the study now or in the future, please feel free to contact either:

Name	Shanelle Ward	Contact phone number:
Position	Honours Student	0800 687 489
Department	School of Physiotherapy	
Name	Dr Emily Gray	Contact phone number:
Position	Lecturer	0800 687 489
Department	School of Physiotherapy	

For cultural support:

To ensure ongoing cultural safety, the Southern District Health Board encourages those who identify as Māori, and who are participating in health research or clinical trials, to seek cultural support and advice from their own Kaumātua or Kuia in the first instance, or please contact:

Wendi Raumati & Eleanor Russell Kaiāwhina Te Ara Hauora – Māori Health Unit Dunedin Hospital Phone: (03) 474 0999 ext 58649	Andrea Jerry Kaiāwhina Te Huinga Tahi Māori Health Cultural Support Southland Hospital Phone: (03) 218 1949 ext 48509
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This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.