

INFORMATION SHEET

(For women with cancer-related lymphoedema)

Title: Distress and self-compassion among women with cancer-related lymphoedema.

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Description of the study:

We are interested in understanding self-compassion, body acceptance and sexual functioning in women with cancer-related lymphoedema. Self-compassion is the ability to accept oneself, or show self-directed empathy, when experiencing difficulties. This study is part of the project entitled "Distress and self-compassion among women with cancer-related lymphoedema".

Purpose of the study:

This project aims to find out how lymphoedema is affecting how you feel about yourself, your body, your appearance and sexual functioning.

What will I be asked to do?

You've been invited through the database kept by the Lymphoedema Research Unit or you have received the information from your therapist or local support group because of your cancer-related lymphoedema. Unfortunately you are not eligible to participate if you do not have access to email and the internet or if you live outside of South Australia.

We ask you to complete questionnaires online that will take about 20 minutes. Your involvement is completely voluntary. After the completion of the questionnaires you will receive general information about managing your lymphoedema. You may be asked to participate in a writing exercise in which we ask you to write about how you feel about your lymphoedema.

We will ask you to complete the same set of questionnaires one week later and again after 3 months and 6 months.

Example of multiple-choice questions would be:

- "Have you been feeling self-conscious about your appearance?"
- "Over the past 4 weeks, how satisfied have you been with your overall sexual life?"

If you have any questions or concerns about this research you can contact Dr Malou van Zanten on 7421 9959.

What benefit will I gain from being involved in this study?

With sharing your experiences we will be able to understand how much lymphoedema is affecting females after cancer treatment in general. You may not benefit directly from your involvement in the study but you will be providing a valuable contribution toward the development of measures that health professionals can use in the future to assist people to make health decisions and manage their health as well as possible.

Will I be identifiable by being involved in this study?

No. When you enter the study online your name will automatically be transferred into an ID number. All data collected in this study will be stored on Flinders University password-protected computers for 15 years in accordance with guidelines. Under Australian privacy law, all information collected about you must be kept confidential, unless you agree to it being released. If you consent to take part, the data collected in the study will be looked at by the researchers involved in this study. All these people will have a duty of confidentiality to you as a research participant and no information that could identify you will be given to anyone else.

Are there any risks or discomforts if I am involved?

There are not expected to be adverse effects from participating. However, the nature of some questions relating to cancer and your lymphoedema may cause some mild distress. You are free to withdraw from the study at any time. If you do experience any distress or concerns after participating in the study, you can contact one of the following:

- Your General Practitioner (GP)
- Lifeline (Phone: 13 11 14). Local call cost, 24 hours per day, 7 days per week. Offers anonymous access to trained counsellors, crisis support, and suicide prevention.
- Cancer Council (Phone: 13 11 20). Local call cost, Monday to Friday, 8.30am to 5.30pm. For support and information, practical assistance and understanding to anyone affected by cancer.
- Mental Health Triage Service (Phone: 13 14 65). Local call cost, 24 hours per day, 7 days per week. For assistance in a mental health emergency.
- If you feel you need emotional support for your lymphoedema concerns please consider contacting the Lymphoedema Support Group South Australia (lsgsa.adelaide@gmail.com).

How do I agree to participate?

Participation is voluntary. You may answer 'no comment' or refuse to answer any questions and you are free to withdraw from the study at any time without affecting your rights or responsibilities. However, the data you have completed up until the withdrawal date may be included in the final analysis. If you would like to participate in this study, you can find the study through this website <https://tinyurl.com/my-lymphoedema>. You will be directed to consent to participate for the study prior to starting. The consent form is also attached to this information letter for your information. You do not need to return the paper based version, only the online version is sufficient.

How will I receive feedback?

On project completion, outcomes of the project will be accessible to all participants via a website that will be emailed to you upon completion of the study and analysis of the data.

What will happen to information about me?

The outcomes of this study may be published in scientific journals and presented at relevant scientific conferences. If the results of this study are published or presented, you will not be identified by name. The researchers participating in this study will not personally gain from undertaking this study.

How is this study funded?

The proposal of this study has received funding from the Flinders Foundation Seeding Grant to be able to undertake this study.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7638). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au