

Participant Information & Consent Form

CancerCare Manitoba Online Support and Discussion Groups

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Sponsor:

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Background

You are being asked to take part in a research study. This form will give you information to help make your decision. Take your time to review it. Talk with the research coordinator about any questions you may have. Ask the research coordinator to explain any words or information that you do not clearly understand. You may take your time to decide about taking part in this study. You may discuss it with your family and friends before you decide.

Purpose

Having a diagnosis of cancer brings many challenges. We are doing this research study as part of our efforts to help those who may be experiencing cancer related distress.

The purpose of this study is to evaluate online support groups for people with cancer and their family/support persons. If you decide to take part in this study, you will join a professionally led support and discussion group that is delivered “on-line” through the Internet.

Who can participate?

You **can** participate in this study if:

- You fully understand the project and give your informed consent to participate by signing this consent form
- You live in Manitoba
- You are a CancerCare Manitoba patient or a family member caring for a person diagnosed with cancer who has received treatment at the CancerCare Manitoba
- You are familiar with computer usage and have access to the Internet in a private area where you will feel comfortable entering personal information
- You have the ability to read and write in English
- You can commit to the weekly time requirement
- You do not have a history of serious psychiatric disorder
- You see yourself as having at least moderate distress because of your cancer experience

You **cannot** participate if:

- Any of the points above do not apply to you.

How we will do the study

If you agree to take part in this study, you will be asked to fill out a series of questionnaires online. The forms will be completed at the following times:

1. Prior enrollment into the online support group
2. At the end of the online support group (8 weeks from start)

You will be sent an email with a link and password to access the forms. Each time you complete the forms it will take approximately 30 minutes.

After you have completed the first set of forms you will be enrolled in the online support group. You will participate in a 1½ hour online group with a CancerCare Manitoba counselor, once a week for 8 weeks.

You will be telephoned by the Research Coordinator and provided with instructions for logging onto the online group.

After the end of the study, you will be contacted for a follow up interview.

If you have any questions about the research procedures, please feel free to contact the Principal Investigator, Jill Taylor-Brown at 787-1325.

Benefits

There may or may not be a direct benefit to you from participating in this study. We hope that the information we learn from this study will benefit people in the future.

Risks

There are no known medical risks to participating in this study. It may however be stressful to participate in the support groups. If you experience increased distress over the course of the study, you may request to speak with a counselor individually. She can refer you to a suitable professional in your area.

In the online support groups, there may be risks associated with the electronic information. As with any online interaction, it is possible that third parties could view the electronic information through interception or misdirection of network transmissions. As well, information could be directly viewed on a participant's computer or from printed copies of the session transcripts. However, no personal information could be linked to potential viewings. The following measures will be taken to ensure that confidentiality in the online support groups is maintained:

- Your privacy on the online support groups will be protected through the use of security features that include study code numbers, first names only, file encryption and password protection.
- Questionnaire information that is used will be stored offsite in the United States. This information will be identified with a first name only. It will be stored in a secure site that supports other medical internet communication applications.
- Electronic transcripts of the online groups will be stored in a secure site in the United States and within the offices of Patient and Family Support Services at CancerCare Manitoba. This information will use first names only, and will not include identifying information such as contact information.
- Participants will be made aware of the need for physical privacy during the online sessions and the need to protect any printed copies of session transcripts.

These measures safeguard the privacy of participants to the best of our ability. However, we cannot guarantee absolute privacy of electronic data. The confidentiality risks involved in this study are the same as with other online exchanges.

Confidentiality

The information gathered from this research study may be published or presented to the public. Your name, or other information which could identify you, will not be used and

would only be disclosed if required by law. Information collected from you will be given a code number. Your name will not be placed on any of the questionnaires. Research records that have your personal information will be treated as confidential as set out by the Personal Health Information Act of Manitoba. The University of Manitoba Health Research Ethics Board may review the study records to assure quality of the research.

All records will be stored in a locked secure area in the offices of Patient and Family Support Services at CancerCare Manitoba. They will be kept for five years. After that, the written records will be destroyed in a secure manner. Only people directly involved with the research study will be able to see these records. Electronic files will be kept on the password- and security-protected Cancercare Manitoba computer servers and backed-up and stored at a secure off-site location (Iron Mountain).

Everything discussed online is to be held in confidence by you and the other participants.

Compensation

There will be no financial cost to you for taking part in this study. You will receive no payment for taking part in this study.

You will not waive any of your legal rights for compensation by participating in this study.

Questions

Feel free to ask any questions that you may have about the study or your rights as a research participant. If any questions come up during or after the study, please ask the research coordinator at 1- 800 523 2885 ext 4505 or contact the Principal Investigator, Jill Taylor-Brown at (204) 787-1325.

For questions about your rights as a research participant, you may contact the University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not agree to participate in this study until you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

- I have read this consent form. I have had the chance to discuss this research study, with Jill Taylor-Brown or her research staff. I have had my questions answered in language I understand.
- I do not feel forced to take part in this study because of anything a study team member said or did.
- I understand that I can print a copy of this consent form for my records.
- I understand that taking part in this study is voluntary and I may choose to withdraw at any time.
- I understand that my name, address, and other information that can identify me will be kept confidential to the extent permitted by applicable laws.
- I give permission for the University of Manitoba Research Ethics Board to review any of my health records that relate to this study to assure quality of the research.

- I understand that I have not given up any of the legal rights I have as a participant in a research study.
- I understand that I may ask questions about this study in the future.
- I understand that I may be contacted after the study.
- I consent to participate in the online support group research study.

Choose the **I Accept** option if you are agreeing to participate in this study. If you are no longer agreeing to be in this study, choose the **I Decline** option and contact the Research Coordinator at 1-800-523-2885 ex 4588. Once you choose the **I Accept** option, you will be prompted to start completing the questionnaires right away.