



Truce: A Support Program for Young People Who Have a Parent with Cancer
Information Sheet for the Participating Parent or Caregiver of a Young Person who has a Parent or Caregiver with Cancer

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Invitation

You are invited to participate in a research project about Truce, a new group support program for young people (aged 14-22 years) who have a parent or caregiver with cancer. This program also includes some modules for parents or caregivers and you are being invited to participate in those modules.

A team of researchers led by CanTeen, are conducting a study to determine how effective Truce is at helping young people who have a parent or caregiver with cancer improve their mental wellness, how they deal with difficult thoughts and feelings, and how they communicate with people, especially in their family.

Before you decide whether or not you wish to participate, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and talk about it with others before you make a decision.

Why have I been invited to participate in this research?

The research is being done to measure the effectiveness of a new program for young people who have a parent or caregiver with cancer. Research done by CanTeen has helped us to understand some of the issues that young people face when their parent or caregiver has been diagnosed with cancer. Because of this we have developed a group program just for them. We need to test how effective it is, that is, how well it works, by having some young people go through the program. You have been invited to participate because you have a child who has a parent or caregiver with cancer. You do not need to be the parent or caregiver with cancer yourself; you just need to

have an on-going relationship with the child who is considering participating in the study.

The support programs will be held in Melbourne, Wollongong, Sydney, Newcastle and Brisbane.

Your participation in the study is completely voluntary (so you don't have to do it if you don't want to).

What will participation involve?

If you agree to participate in this research, you will be asked to sign and return the Consent Form at the end of this information sheet.

To evaluate the program most effectively we need to split people into two groups, one group will do the program straight away, while the other group will need to wait until later (around 4 months) to do the program (this is called a waitlist control). We will send a CanTeen book for young people who have a parent or caregiver with cancer, to the young people in the waitlist control group to read during this time. However, anyone displaying extreme distress will be withdrawn from the study and directed to the regular CanTeen Counselling Services.

We will ask everyone (both groups of young people and all the parents or caregivers) to do three surveys. We will repeat a similar survey at the end of the Truce program and again 2 months later. Each survey will take around 30 minutes of your time. After the 2 months, those people who have been waiting will now have the opportunity to participate in the Truce program. If they don't want to they don't have to do it.

The Truce program itself involves 7 weekly sessions each for about 2 hours for the young people. Parents/caregivers will attend one combined session for parents/caregivers and young people, and receive a psycho-educational booklet. The sessions will involve games, talking, drawing, and moving activities. They will cover topics such as values and goal setting, unpleasant thoughts and feelings, and recognising emotions. The purpose of the combined session and psycho-educational booklet is to help parents/caregivers understand what their child has been learning so that they can better support them and to also to better understand some of the issues facing young people who have a parent or caregiver with cancer.

What if I don't want to take part in this research, or if I want to withdraw later?

Whatever you decide to do – participate or not participate – it won't affect your relationship with CanTeen or any of the other hospitals or universities involved in any way. If you decide to take part, you can withdraw at any time without having to give a reason.

Even though the study goes for a few months and involves repeated testing we understand that sometimes people don't want to finish a study. We hope that you do – but we have allowed for some people to withdraw in our planning.

If you decide to withdraw please contact the research team 1800 234 007 or at truce@canteen.org.au. You can elect to have all of your completed surveys destroyed or let the research team use them for analysis.

Please note that if your child decides to withdraw then you will need to withdraw as well.

Who is paying for this research?

This research project is funded by a Rotary Mental Health Grant.

Are there any risks or benefits of being involved?

Participating in the research will provide us with valuable information that CanTeen can use to help other young people who have a parent or caregiver with cancer. This project will help us to finalise the program Truce. We intend to make Truce available for use both inside and outside CanTeen to help young people who have a parent or caregiver with cancer. Whilst you may not benefit directly from your participation you may feel a sense of satisfaction in being able to do something that will help others. We can not guarantee that you will benefit from participating in the Truce program, but we do expect that those who do participate in Truce will experience improved mental well-being and learn new skills to assist with coping with their experience with cancer.

On the other hand, participating in Truce will involve you committing your time and it is possible that discussing your thoughts and feelings may be upsetting. The people running Truce are all trained psychologists and counsellors and will always work in pairs. You should be able to discuss any issues raised with them. If you have any further issues that you feel you can not discuss in the group please call:

Lifeline on **13 11 14**. Lifeline is staffed by trained volunteer telephone counsellors who are available 24 hours a day, 7 days a week.

Cancer Council Helpline on **131120**. Cancer Council Helpline can provide information on cancer, as well as emotional and practical support. Its hours are 9am to 5pm Monday to Friday.

Parentline on **1300 30 1300 (QLD), 132289 (VIC), (1300 1300 52 (NSW))**. Parentline provides confidential, professional counseling and education to support parents and carers of children. Its hours are 8am to 10pm (QLD), 8am to midnight (VIC), 24 hours (NSW), 7 days a week.

How will my privacy and confidentiality be protected?

The information you provide will be kept confidential and will be stored securely within CanTeen. All surveys will have your name removed from them. Results from the study will be presented with CanTeen and other organisations and published more widely. When this is done, nothing about you personally will be published, only average information about the group will be used.

Information collected about your child will be kept confidential and not provided to you.

Will taking part in this research cost me anything, and will I be paid?

Participation in this research will not cost you anything, nor will you be paid.

Who should I contact if I have any questions about the study?

If you have any questions about this research, you can contact the research team on 1800 234 007 or truce@canteen.org.au.

Please also see the Truce website for further information: www.truce.org.au

Who should I contact if I have any concerns about the study?

This project has been approved by the Human Research Ethics Committee (Social Science, Humanities and Behavioural Science) of the University of Wollongong. If you have any concerns about your rights as a participant in this research, or if you have a complaint about the way in which this research is conducted, please contact the University of Wollongong Ethics Officer on (02) 4221 4457.

**Thank you for taking the time to consider this study.
If you wish to take part in it, please sign and return the attached consent form.
This information sheet is for you to keep.**



Consent Form for Parents or Caregivers of Young People who Have a Parent or Caregiver with Cancer

Truce: A Support Program for Young People Who Have a Parent with Cancer

Participant consent

I,, have read and understood the Information Sheet about the research project to evaluate the effectiveness of Truce, a support program for young people who have a parent or caregiver with cancer, and provide my consent to participate in the research project. I understand why I have been invited to participate, what the research will involve, that my decision to participate is voluntary and that I may withdraw at any time without impacting my relationship with CanTeen or any of the hospitals or universities involved in the study.

I understand that the risks to me in this study are minimal. I also understand that the study involves allocation of participants to two groups, for parents/caregivers, one group will receive a psycho-educational booklet and participate in a combined session lasting approximately 2 hours and the other group will be wait-listed and be given the opportunity to participate in the program after approximately 4 months. Both groups will be expected to complete 3 sets of questionnaires.

I understand that I will not be provided with access to data in relation to my child's participation in the study. In signing below, I give consent for the use of the information collected to be used for the purposes of evaluating Truce and for publication of group data in internal and external reports. I understand that in any publication of the information collected I will not be identified.

Signature of participant: Date:

Please turn over the page

Please provide your contact details:

Preferred contact
method (*please tick*)

Address:
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.....

Contact number:

Email address:

<p>If you have a complaint about the way in which this research is conducted please contact the University of Wollongong Ethics Officer on (02) 4221 4457.</p>
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