


Understanding Children's Experiences of Parental Cancer Study




Hi,

My name is Rhea and I wanted to introduce myself.

I am a mum to two little girls, who are similar ages to you! We love searching for secret waterfalls together, especially after a big storm 

I am also researching at a University where I am talking with families and children similar ages to you about having a mum, dad or someone who cares for them that has cancer.

We don't know much about how children understand their mum/dads cancer and what is important for them during this time. We hope your views will help us understand more about what is important for children and how best adults can support them.

I work in a team who also love to talk with children just like you! The people I work with are Ursula, Jordana and Melvin - you can see our pictures below 

Would you like to share your feelings about mum or dads' cancer? If you do, please let mum / dad know and I can lock in a time to talk with you. Maybe you can tell me about your favourite things to do, and if you like searching for waterfalls too?

Best wishes,
Rhea

The Study Team:




Rhea Felton

 [@rhea_felton](https://twitter.com/rhea_felton)



Dr Ursula Sansom-Daly

 [@usansomdaly](https://twitter.com/usansomdaly)



Dr Jordana McLoone

 [@jordanamcloone](https://twitter.com/jordanamcloone)



Dr Melvin Chin



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T: (02) 9382 3114 (Direct line: Dr Ursula Sansom-Daly)
F: (02) 9382 1789

Participant (CHILD VERSION) Information Sheet

Study Title	Understanding Children’s Experiences of Parental Cancer Study	
Principal Investigator/s	Rhea, Ursula, Jordana and Melvin	
Contact Details	Ursula = (02) 9382 3114 ursula@unsw.edu.au Behavioral Science Unit University of NSW (UNSW)	Rhea = +61 403857 715 r.felton@unsw.edu.au Behavioral Science Unit University of NSW (UNSW)



This information sheet has been put together to help you choose if you would like to take part in our research study about how children understand their parents/carers cancer diagnosis.

1. What is this study about?

We are researchers at the University of UNSW. We are trying to find out about how children understand and make-meaning of their parents/carers cancer. Finding out these things will help us understand what supports children need during this tough time. You can find out more about the study and what is involved here = (ADD BSU WEBSITE URL HERE WITH STUDY OVERVIEW VIDEO).

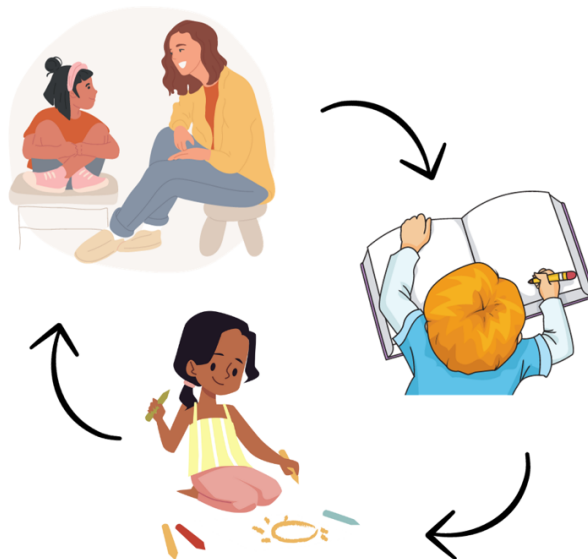
2. Do I have to be in this study?

No, you don't. If you say no, that is ok. You and your parents/carers will decide if being in this study is the right thing for you.

Even if you take part at the beginning and change your mind later and don't want to be a part of the study anymore; that is okay as well. All you need to do is tell the researcher or your parents/carers that you don't want to take part anymore.

3. What will happen to me in this study?

We would love for you to take part in one conversation with Rhea, this will happen after we speak with your parents/carers. Our chat will last no more than 1 hour. In our conversation we will do different games like drawing or writing, and ask you some questions about you, your family and your parents or carers health. You can keep your drawing at the end of the chat too!





4. Is there anything that could make me upset if I take part in the research?

If anything you talk about during the research does make you upset you can stop the research. Your parents/carers will be told and you will be given the names of people you can talk to about what is making you upset, if that is what you want to do. The researchers can help you do that.

You can also call the Kids Helpline (for kids aged 5 years and up) at any time. Their telephone number is 1800 551 800.

5. What will happen to my information?

Your information will only be used by the researchers. You can tell them whatever you want and no-one will know that it came from you. The only time the researchers would have to tell someone is if anyone hurt you or upset you in any way. The researchers would also have to tell someone if you said you might hurt yourself or someone else.

If you think of things after the chat with researchers, you can add things or change things. If you want to add anything different you can speak with Rhea on +61 403 857 715.

6. What will I get for being part of the study?

Rhea hopes to publish a children's book series and would love to gift you the books when they are released! These children's books will discuss what the study found in a way children can understand. Let Rhea know if you would like to be sent a copy of these children's books.

7. Who can answer my questions?

If you have any questions, you can talk to **Rhea** on **+61 403 857 715**.

You can also ask your parents/carers to talk to us too!



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Local Health District



8. How do I agree to participate?

If you would like to participate, please let your parent/carer know. They can sign the consent form below.

The ethical aspects of this study have been approved by the South Eastern Sydney Local Health District (SESLHD) Human Research Ethics Committee 2023/ETH01697. Should you have any concerns about the conduct of this project, you are welcome to contact the SESLHD research support office on 02 9382 3587 or SESLHD-RSO@health.nsw.gov.au



This information sheet is for you to keep.

Consent Form - Participant (Child)

Project Title: Understanding Children’s Experiences of Parental Cancer

Name of Parent/Carer: _____

Name of Child: _____

Name of Investigator: Rhea Felton

Supervisory Team: Dr Ursula Sansom-Daly, Dr Jordana McLoone and Dr Melvin Chin

1. I consent to my child participating in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.
2. My child can review and/or edit their responses prior to data analysis and publication. I can contact the researcher, Rhea Felton on r.felton@unsw.edu.au to do this.
3. I understand that my child’s participation will involve participation in discussion with the researcher and I agree that the researcher may use the results as described in the plain language statement.
4. I consent to participating in a discussion with the researcher and I agree that the researcher may use these results as described in the plain language statement.
5. I acknowledge that:
 - a. The possible effects of participating in the workshops have been explained to my satisfaction. I understand that a resource kit is available that can help me provide support to my child, should that be appropriate;
 - b. I have been informed that my child is free to withdraw from the workshop at any time without explanation or prejudice and to withdraw any unprocessed data provided;
 - c. The project is for the purpose of research;
 - d. I have been informed that the confidentiality of the information provided will be safeguard subject to any legal requirements;
 - e. I have been informed that with my consent the interview will be audio-taped and I understand that audio-taps will be stored securely on the UNSW OneDrive Folder and will be destroyed after 15 years or when the youngest participant turns 25 years.
 - f. The name of my child will be referred to by a pseudonym in any publications arising from the research;

I consent my child’s voice to be recorded during our conversation **yes** **no**

I wish to receive a short report about the research findings **yes** **no**

I wish to receive the children’s book series once published **yes** **no**

Parent/Carer signature: _____ Date: _____

Investigators signature: _____ Date: _____



(PARTICIPANT'S COPY)

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(INVESTIGATOR'S COPY)