

Plain Language Statement for Adolescents and Parents

Centre for Mental Health
School of Population and Global Health



Project: Determining how to best help bereaved adolescents: A Delphi consensus study

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Introduction

Thank you for your interest in participating in this study. My name is Karl Andriessen, and I am the responsible researcher. The next few pages provide detailed information about the study. They explain to you as clearly as possible all the procedures involved before you decide whether or not to take part. Please read this information carefully and feel free to ask any questions.

Who can participate in this study?

Adolescents (aged 16 or older):

You can participate if you (i) have lost a close person such as a family member or a friend through suicide or other cause when you were aged between 12 and 18 years old, and (ii) have experienced the loss between 6 months and 10 years ago. You can participate whether or not your parent or guardian participates.

Parents/guardians:

You can participate if you are the parent or guardian of an adolescent child, which meets the above criteria (i.e. the adolescent has lost a family member or a friend when the adolescent was aged between 12 and 18 years old, and has experienced the loss between 6 months and 10 years ago). Parents and guardians can participate whether or not their own child participates.

Clinicians:

You can participate if you have at least 5 years of experience with providing professional help to bereaved adolescents.

What is this research about?

Adolescents who have experienced a death by suicide or other causes may experience short- or long-term problems with their physical, mental or social health, including increased risk of suicidal behaviour. However, little is known of what help bereaved adolescents wish to receive, and if the help that is offered is actually helpful.

This study aims to determine what are the most important features of support for bereaved adolescents, based on expert consensus between bereaved adolescents, parents/guardians of adolescents who have been bereaved, and clinicians who provide bereavement support to adolescents.

The study aims to determine what help is most important for adolescents to receive, including individual and/or group support; face-to-face and/or online help; outreach or self-initiated help; and the preferred timing of the help, being received shortly after the loss, or on a longer-term basis.

The overall research study consists of two phases. Phase 1 was conducted earlier this year and involved interviews and focus groups with bereaved adolescents, parents/guardians of bereaved adolescents, and clinicians who support bereaved adolescents. The focus groups and interviews investigated what kind of help bereaved adolescents wish to receive.

Based on the findings of the interviews and focus groups we have now created an online survey comprising statements about what support helping professionals might provide to help bereaved adolescents. This consensus study will allow us to identify the features of professional support that most panellists think are important.

Based on the findings of this study, and the research literature, our team will develop a support intervention for bereaved adolescents. This will be piloted in a future study.

Participants who took part in a focus group or interview for Phase 1 are also eligible to participate in this current study.

What will I be asked to do?

Should you agree to participate, you will be asked to complete 3 online surveys. Completing the surveys will involve responding to some brief demographic questions (i.e. age, gender, indicating if your experience with adolescent bereavement is personal or professional), and then rating the importance of statements that describe the type of help offered to bereaved adolescents as *essential, important, don't know/depends, unimportant or should not be included*. **You will be able to complete the online surveys in your own time, and over multiple sittings if you desire.** It is estimated that this will take around 2-3 hours in total over a period of roughly 2 months.

What are the possible benefits?

We cannot guarantee or promise that you will receive any direct benefits from taking part in this study. However, by participating you will be able to apply your knowledge and experience and provide valuable feedback and suggestions to inform what help should be provided to bereaved adolescents. Hence, other bereaved adolescents may benefit from your collaboration in this study.

As a reimbursement for your time you will be offered a \$20.00 gift voucher for each round you complete (with a total maximum of three survey rounds).

What are the possible risks?

Reflecting on appropriate help for bereaved adolescents might induce strong feelings during or after survey completion, and it is possible that you will experience some distress. We believe that this risk is small, but if you become distressed while completing the survey, you can stop participating at any time. If you are experiencing distress following the survey round, you can access confidential support by contacting one of the support services listed on the last page of this document.

Do I have to take part?

No. Participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can stop at any time. Withdrawal from the study will not affect your relationship with The University of Melbourne or with the service providers mentioned in this document.

If you change your mind about participating, you are free to withdraw at any time and you may also withdraw your data up to the point of analysis, if you wish, simply by contacting the responsible researcher at the details provided below.

Will I hear about the results of this study?

We will email you a summary of the findings. We will also post a summary in relevant websites or newsletters, such as those of the collaborating service providers and The University of Melbourne. The findings of this study will also be published in a peer-reviewed scientific journal article.

What will happen to information about me?

We fully intend to protect your anonymity and the confidentiality of your responses, within the limits of the law. Your name and contact details will be kept separately from the information that you provide for the study. The study will publish only anonymised data. You will not be identified in any publication.

Any hard copies with potentially identifiable information will be kept in a locked cabinet in The University of Melbourne. Due to research code requirements, all data we collect will be stored securely under password protection on the university network for at least 5 years and only accessible by the named research team. None of your information will be identifiable or be able to be traced back to you.

Given the importance of these data, the researchers might re-use the de-identified data in future studies that are in the same area of research as this study.

Who is funding this study?

The study is funded by the National Health and Medical Research Council (NHMRC ECF APP1157796) and The University of Melbourne (ECR 1202020).

Where can I get further information?

If you would like more information, please contact the researchers:

Dr Karl Andriessen, Email: karl.andriessen@unimelb.edu.au

Who can I contact if I have any concerns about the project?

This study has been approved by the Human Research Ethics Committee of The University of Melbourne. If you have concerns or complaints about the conduct of this study, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 3 8344 2073 or Email: HumanEthics-complaints@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team or the name or ethics ID number of the study (2057689).

If you feel distressed at any time:

Please contact a parent/guardian, or the following services:

Kids Helpline 1800 55 1800 (24 hours, free call from mobile) – www.kidshelp.com.au

Lifeline 13 11 14 (24 hours, free call from mobile)– www.lifeline.org.au

eheadspace 1800 650 890 (9am – 1am AEST, charges apply from mobile) -
www.eheadspace.org.au

For bereavement support, you can contact the following organisations:

The Compassionate Friends 03 9888 4944 or 1300 064 068 -

www.compassionatefriendsvictoria.org.au

Standby – Support after Suicide <http://standbysupport.com.au>

Jesuits Social Services – Support after Suicide <https://jss.org.au/what-we-do/mental-health-and-wellbeing/support-after-suicide/>

Australian Centre for Grief and Bereavement - 1800 642 066 (free calls) - www.grief.org.au