Hello

We are reviewing the support available for young people when someone close to them has died. We are really sorry that you have experienced the death of someone close to you. We hope that you have trusted friends and adults around you to support you.

Bereavement is a tricky subject to talk about. We don’t talk about it often, and many people feel awkward discussing death, dying and bereavement. Many people feel uncomfortable and often don’t know what to say. Many people may have had their own experiences, and talking about a death may mean remembering something they find painful or sad.

We think it’s important that we do talk about it. The new United Kingdom Commission on Bereavement is asking bereaved children, young people and adults what happened when someone close to them died. We want to find out how we can improve help and support for everyone when someone close to them dies.

If your bereavement was in the last three years, we would like to ask you some questions about how it has been for you, and get your ideas about how support can be better for young people in the future – because you are one of the experts. The survey will take you about 25 minutes.

We know that this might be a challenging task. Here are some questions you might have about taking part.

**Do I have to take part?**No – it’s completely up to you. Please don’t take part if you don’t feel up to it – we won’t mind. It might be easier to take part if some time has passed after your bereavement – six months or so.

**What if I get upset?**Taking part might make you feel difficult things as you reflect on your experiences of bereavement. It’s ok to feel those feelings. Check with your parent or carer before you take the survey, and make sure you have someone you trust around as you complete it, so you can talk about any concerns or feelings you have. They can read more about the survey [here](https://bereavementcommission.org.uk/taking-part/children-and-young-peoples-voices/young-people-survey/) It’s fine to take a break, miss out any questions you don’t want to answer, or stop completely.

**What if I need more support?**

If you need more support after taking part, there is information at the end of this survey about places you can speak to. You may already be receiving some help and support from them or places like them. Please do use them if you need to – they are there for you, your family and your friends. We will remind you of this information at the end of the survey.

**What will you do with the things I say?**

We will collate all the responses received, analyse them and highlight ways that support could be improved for bereaved people. The report will contain anonymised information. We hope that government and other organisations will read the report and help improve support for bereaved children, young people and adults in the future.

**Will my answers be private?**Yes, we will keep the things you say private unless we are worried about you or someone else.

We will keep your contact information and answers until the report has been published. We keep these personal data so that we can

* find your answers if you change your mind about taking part
* respond to any safeguarding concerns. All responses to the survey will be reviewed on a regular basis. If a child, young person, or adult shares any information that they themselves or anyone else maybe at risk of harm we will follow this up in line with our Safeguarding Policy and Procedures. If we need to take action to protect a child, young person, or adult at risk we may need to contact you directly or we may need to share your contact information in a referral to the Local Authority/Health and Social Care Board (NI) (safeguarding team).

After the report has been published, we will remove any information from your answers that could identify you, and we will keep this anonymised data until the end of 2023.

**What if I change my mind?**

You can stop doing the survey at any time. And if you decide afterwards that you don’t want to take part, you can email us at ukcb@mariecurie.org.uk by 31 January and we will delete your answers.

**Can I save my progress and return to the survey?**

No**.** There isn’t a way to save the survey and return to it, so if you need more time, perhaps minimise the survey, or put your device down and see how you feel later on.

If you have any other questions, you can contact us at:

ukcb@mariecurie.org.uk

**0800 090 2309**

Thank you very much for your time and your thoughts. We really appreciate it.

If you would like to complete the survey, please tick the boxes below to give your permission

* I have read and understood the information about taking part and I want to do so
* I have someone I trust to support me as I complete it
* I understand that my data will be held and processed securely by Marie Curie on behalf of the UK Commission on Bereavement in line with data protection and GDPR
* I understand that my information may need to be shared with the Local Authority/Health and Social Care Board (NI) in the event of any safeguarding concerns (as above)
* I give permission for my anonymised answers to be included in reports and publications. I understand I will not be named in these.

Name:

Email address:

Address:

Telephone number:

## About the person who died

We are sorry that someone close to you died. We would like to know more about this person and their relationship to you.

Who was it that died? If more than one person close to you has died in the last three years, please tick all that apply:

This could include step or adopted relatives

* My mum
* My dad
* My brother
* My sister
* My grandparent
* My aunt or uncle
* My boyfriend, husband or male partner
* My girlfriend, wife or female partner
* My non-binary partner
* My child
* My cousin or other family member
* My friend
* My classmate
* My work colleague
* Someone else – please state who:

The next answers are about one person who has died. If more than one person has died, please tell us about the person who you were closest to, or choose one person.

Please tell us when they died:

What was the cause of their death?

* Confirmed or suspected Covid-19
* Cancer
* Other terminal or life-limiting condition – please state:
* Other - please state:
* I don’t know
* I don’t want to say

How old were they when they died?

* Under 18
* 19 – 24
* 25 – 29
* 30 – 34
* 35 – 39
* 40 – 44
* 45 – 49
* 50 – 54
* 55 – 59
* 60 – 64
* 65 – 69
* 70 – 74
* 75 – 79
* 80 – 84
* 85 – 90
* 90+
* I don’t know
* I don’t want to say

If the person who died had a terminal illness or long-term condition or disability, were you one of the main people who looked after them?

* Yes
* No
* I don’t know
* I don’t want to say

## Practical bereavement support

Were you involved in any of the following practical and administrative tasks after the death:

* registering the death
* arranging the funeral
* sorting out financial affairs e.g. bank accounts, payments, insurance
* Other practical things, please state:
* No

What helped you to manage these practical tasks?

Have you had any financial difficulties in connection with your bereavement(s) (e.g. caused by loss of household income, cost of funeral etc.)?

* Yes – if you wish, please say more:
* No
* I don’t know
* I don’t want to say

## Experiences during your bereavement

Have any of the following affected you during your bereavement? Please tick any that apply.

* Not being able to spend time with the person before they died
* Not being with them when they died
* Not being able to say goodbye as I wanted
* Not being able to perform ‘last rites’
* Lack of support or unclear communication from healthcare professionals before the death
* Lack of support or unclear communication from healthcare professionals after the death
* Feeling isolated or lonely after the death
* Periods of school/college/university closure
* Funeral restrictions
* Not being able to get together to get support from friends and family
* Media coverage of deaths during the pandemic
* Social media
* Fears of Covid-19
* Other – please state who:

Who helped you after your close person died? Please tick any that apply

* family member
* friend
* neighbour
* people from your faith community
* teacher
* someone else at school, college or university (eg school counsellor)
* someone from the hospital
* someone from the hospice
* colleague
* employer
* GP or other community healthcare professional
* funeral director
* support from a bereavement service
* bereavement support group (via virtual or face-to-face meetings)
* online community support (via written comments e.g. Facebook group)
* no one/none
* someone else:

How well supported by your family and friends have you felt in your bereavement?

* Very well supported
* Fairly well supported
* A little bit supported
* Not at all supported
* I don’t know

Please tell us about the support you received from family, friends and your community:

Please tell us any ideas you have about how families, friends and local communities can support bereaved young people in the future:

How well supported have you felt by your school or educational setting and/or your employer in your bereavement?

|  |  |  |
| --- | --- | --- |
|  | School or educational setting | Employer |
| Very well supported |  |  |
| Fairly well supported |  |  |
| A little bit supported |  |  |
| Not at all supported |  |  |
| I don’t know |  |  |

What was good about the support you received from your school or education provider and/or your employer?

Please tell us any ideas you have about how schools, educational settings or employers can support bereaved young people better in the future:

If you have had support from a bereavement service, please tell us how you first heard about it

* A friend/family member told me about it
* Via the hospital
* Via the hospice
* Via my GP
* I searched online
* Funeral director
* I knew about the support I needed from a previous bereavement
* I can’t remember
* I don’t want to say
* Other, please state:

What was helpful about the support you received?

Please tell us any ideas you have about how bereavement services can support bereaved young people better in the future:

Some people are less likely to access bereavement support services, eg. some people from Black and minority ethnic backgrounds, from the LGBTQ+ community, people living with disabilities. Do you have any ideas about how we can make sure everyone who would benefit from support is able to access it?

Please tell us any ideas you have about how other people (e.g. hospitals, funeral directors) can support bereaved young people better in the future:

## Anything else

Do you have anything else you would like to tell the UK Commission on Bereavement about how young people affected by bereavement could be better supported in the future?

## About you

These questions will help us understand who answered our survey (e.g. different age groups). You won’t be identified as we will combine the answers from all the respondents.

How old are you?

* 16
* 17
* I don’t want to say

Which of these best describes what you are doing at the moment? If more than one applies to you, please tick the main one.

* Full time education at school, college or university
* Full-time paid work (30 hours or more per week)
* Part-time paid work (Under 30 hours per week)
* Unemployed
* Permanently unable to work or be in education due to sickness or disability
* Caring for a family member or loved one
* Doing something else. Please specify:
* I don’t want to say

Which part of the UK do you live in?

* Channel Islands
* East Midlands
* East of England
* Greater London
* Isle of Man
* North East England
* North West England
* Northern Ireland
* Scotland
* South East England
* South West England
* Wales
* West Midlands
* Yorkshire & the Humber
* Currently living overseas
* I don’t know
* I don’t want to say

Is English your first language?

* Yes
* No
* I don’t want to say

If no, please note your first language:

Which of these best describes your ethnic group?

Which of the following best describes your religious or spiritual beliefs?

* Agnostic
* Buddhism
* Christianity (all denominations)
* Hinduism
* Islam
* Judaism
* Sikhism
* Spiritual but not religious
* Other, please state:
* No religious or spiritual beliefs
* I don’t want to say

Some research has found that some LGBTQ+ people have found challenges in getting bereavement support. That is why we are asking people to share their gender and sexual orientation if they are comfortable to do so

Please complete the following. I identify as:

* A girl or woman
* A boy or man
* Non binary / gender fluid
* I don’t want to say
* I identify as:

Is your gender identity the same as the sex you were assigned at birth?

* Yes
* No
* I don’t want to say

Please describe your sexual orientation

* Bisexual
* Gay/lesbian
* Heterosexual/straight
* Other, please state [free text]
* I don’t want to say

Do you consider yourself to have a disability?

* Yes - please describe if you feel comfortable sharing this information
* No
* I don’t want to say

## Signposting to support

Thank you again for your time in completing this survey.

We are so grateful to you for sharing your experiences and ideas. These will help the Commission to understand how we can continue to improve the support offered to bereaved children, young people and adults across the UK.

We know that some of these questions may have been hard to answer. You might like to try one of these ideas on the next page to help you relax.

 If you would like further support around your bereavement, the following services can help. The Childhood Bereavement Network has a searchable map for local services:

<https://childhoodbereavementnetwork.org.uk/if-you-need-help-around-death/finding-support-local-you>

These national charities are also available for help and support.

**Child Bereavement UK** Tel: 0800 02 888 40  [www.childbereavementuk.org](http://www.childbereavementuk.org/)

**Childline:** Tel: 0800 1111 Website: [www.childline.org.uk](http://www.childline.org.uk/)

**Cruse Bereavement Care (England, NI and Wales)** Freephone National Helpline: 0808 808 1677 Website: [www.cruse.org.uk](http://www.cruse.org.uk/)    [www.hopeagain.org.uk](http://www.hopeagain.org.uk/)

**Cruse Bereavement Care (Scotland)** Telephone: 0808 802 6161 Website: [www.crusescotland.org.uk](http://www.crusescotland.org.uk/)

**Grief Encounter** Telephone: 0808 802 0111 Website: [www.griefencounter.org.uk](http://www.griefencounter.org.uk/)

**Winston's Wish** Telephone: Family Line 08088 020 021 Website: [www.winstonswish.org.uk](http://www.winstonswish.org.uk/)

