

# UCL Bereavement Study questionnaire 2010

# Part 1

Thank you for taking part. *To continue to the survey click* **Next** *at the bottom of this page.* 

### Study aims

This survey will help us to understand the impact of sudden bereavement. The results will be used to improve services for bereaved people.

### How to complete the survey

In Part 1 the responses are by ticking boxes and should take about 5-10 minutes. In Part 2 the responses are given in free text boxes for you to provide as much detail as you wish, and usually takes between 5 and 15 minutes.

# How to save progress and take a break

Clicking the Save button gives you instructions on how to return later. The program asks for your email address to send you a 'return ticket' link. Your email address will not be added to the data and this protects your confidentiality.

# Anonymity

The survey is anonymous. We can't link answers to you unless you give your name. If you do give your name or email we will not pass this to any organisation outside our research team. All data will be collected and stored in accordance with the Data Protection Act 1998.

# In case of difficulty

Completing this questionnaire may not be easy for some people and some questions may evoke difficult memories. For a list of sources of support please bookmark the study website: www.ucl.ac.uk/psychiatry/bereavementstudy

### **Further information**

If you have questions about the questionnaire click on <u>this link</u> (to email address: <u>bereavementstudy@ucl.ac.uk</u>) to contact us.

# 1.1.1.1 Consent to participate:

Question 1

Before you start this study we need to check that we have your informed consent to participate. Once you have read the UCL Bereavement Study information sheet and consent form (at this <u>hyperlink</u>) please tick the box below if you agree with the following statement.

I understand the aim of this study and agree that its anonymised results are to be used for scientific purposes and further analyses.

 $\Box$  Yes – I agree

Question 2

This survey has been sent to you by (*name of higher education institution from list of 37 participating*).

Which one of the following describes your connection to (insert name of HEI)? a student at (*HEI name*) a member of staff at (*HEI name*) □ a member of staff at (*HEI name*) who is also registered there as a student □ None of the above (branch to end of questionnaire thanking respondent for their interest)

## 1.1.1.2 Demographic information

These first few questions in Part 1 are to find out some of your characteristics. It will help us compare your answers with those of other people who are similar to you.

<u>Question 3</u> What is your gender?  $\Box$  Male

□ Female

Question 4 What is your age? (drop-down ages 18-40) □ My age is outside this age range. (branch to end of questionnaire thanking respondent for their interest and reminding them of inclusion criteria)

Please note that the age range for this study is 18 to 40. This in no way implies that bereavement has a lesser impact in other age-groups, but allows us to focus on a specific sub-group which has tended to be under-represented in work of this kind. If your age is outside this range we cannot use your responses in the data analysis, but thank you for having volunteered your time.

For a list of support services, and for further information on the progress of this study, see the <u>UCL</u> <u>Bereavement Study website</u>: link to <u>www.ucl.ac.uk/psychiatry/bereavementstudy</u>

#### Question 5

What is your work status? Please tick one of the options below.
full-time paid work (> 30 hours per week)
part-time paid work (< 30 hours per week)</li>
full-time student
full-time student with part-time job
part-time student with part-time job

 $\Box$  Other - please state

Question 6

Over the last 12 months how many days have you been absent from work, study, training or care responsibilities? (space for entering numerals 0-365 days)

Question 7 – for staff

Please state your occupation, including any managerial responsibilities you may have. (Free text: coded into ONS categories)

#### Question 8 - for students

Please state the occupation of your highest-earning parent, or the person who supports you financially. If he or she is retired or unemployed, give their most recent occupation. (Free text: coded into ONS categories)

#### Question 9

What is your highest level of education? Please tick the option which represents your highest level of exam achievement.

 $\Box$  no academic qualifications

- □ lower secondary education (eg. GCSEs, O levels, CSEs)
- □ higher secondary education (eg. A levels, Highers, IB, Access course)
- □ university degree (undergraduate)
- □ higher university degree (post-graduate)
- $\Box$  other please state

<u>Question 10</u> What is your ethnicity? Please tick one of the options below

- White British
  White Irish
  Other White groups
  Asian or Asian British: Indian
  Asian or Asian British: Pakistani
  Asian or Asian British: Bangladeshi
  Asian or Asian British: all other
- $\hfill\square$  Black or Black British: Caribbean
- □ Black or Black British: African
- □ Black or Black British: all other

#### Question 11

What is your religion? Please tick one of the options below.

No religious affiliation but holding spiritual
 Muslim
 Sikh
 Atheist
 Agnostic
 Buddhist
 Christian - Catholic
 Christian - Protestant
 Christian - other Christian group
 Hindu
 Other - please specify in this box

# Question 12

What is your marital status? Please tick one of the options below.

□ single	$\Box$ divorced
□ co-habiting	□ separated
□ married/civil union	$\square$ widowed

#### Question 13

How many children do you have? (space for entering numerals)

Question 14

What is your current living situation? Please tick one of the options below.

- $\Box$  alone
- □ living with spouse/partner
- □ single parent living with children
- $\Box$  living with parents
- $\Box$  living with other relatives
- □ sharing accommodation with non-relatives
- □ student hall of residence or student hostel
- □ temporary hostel or B&B accommodation
- □ homeless
- $\hfill\square$  other please specify

# 1.1.1.3 Social support

The next few questions are about people you feel close to, including relatives, friends and acquaintances.

Question 15

First of all we would like to ask you about the people that you live with. How many adults who live with you do you feel close to?

- □ Mixed race: White and Black Caribbean
- □ Mixed race: White and Black African
- □ Mixed race: White and Asian
- $\square$  Mixed race: all other
- □ Chinese
- $\hfill\square$  Other ethnic groups
- $\square$  Unable to respond

(space for entering numerals 0-99)

### Question 16

Now we would like to ask about people you feel close to who do <u>not</u> live with you. How many relatives aged 16 or over, who do not live with you, do you feel close to? (space for entering numerals 0-99)

### Question 17

How many friends or acquaintances who do not live with you would you describe as close or good friends?

(space for entering numerals 0-99)

#### Question 18

Thinking about all of the people who do <u>not</u> live with you, and whom you feel close to or regard as good friends, how many did you communicate with in the last week? (space for entering numerals 0-99)

We would now like you to think about your family and friends. (By family we mean those who live with you as well as those elsewhere). Here are some comments people have made about their family and their friends. For each statement, please say whether it is not true, partly true or certainly true for you.

Question 19 There are people I know amongst m D Not true	y family and friends who do things to □ Partly true	make me happy. □ Certainly true
Question 20 There are people I know amongst m D Not true	y family and friends who make me fe □ Partly true	el loved. □ Certainly true
Question 21 There are people I know amongst m □ Not true	y family and friends who can be relie □ Partly true	d on, no matter what happens. □ Certainly true
Question 22 There are people I know amongst m needed to be. □ Not true	y family and friends who would see t □ Partly true	hat I am taken care of if I □ Certainly true
Question 23 There are people I know amongst m □ Not true	y family and friends who accept me j	ust as I am. □ Certainly true
Question 24         There are people I know amongst my family and friends who make me feel an important part of their lives.         Not true       Partly true		
Question 25	y family and friends who give me sup	·

### 1.1.1.4 Past bereavements

Question 26

Since you were aged 10 have you experienced a sudden bereavement of someone <u>close</u> to you due to any of the following?

Please tick *all* those that apply to you.

sudden natural death (eg. cardiac arrest, epileptic seizure, stroke) (branch to questions 28 and

sudden un-natural death (eg. road crash, murder or manslaughter, work accident) (branch to questions 28 and 29)

 $\Box$  suicide (branch to question 27)

#### Question 27

We would like to hear more about the impact of your bereavement by suicide.

The rest of the questions in this survey relate to the impact of a suicide on your everyday functioning and other aspects of your life.

If you have been bereaved by suicide more than once please answer the rest of this questionnaire in relation to <u>one person</u> - the person to whom you felt closest.

What gender was this person?

 $\square$  Male

□ Female

#### Question 28

The rest of the questions in this survey relate to the impact of one <u>specific</u> sudden bereavement on your everyday functioning and other aspects of your life.

If you have been bereaved suddenly more than once please answer the rest of this questionnaire in relation to <u>one person</u> - the person to whom you felt closest.

How did this person die?

- □ sudden natural death (eg. cardiac arrest, epileptic seizure, stroke)
- □ sudden un-natural death (eg. road crash, murder or manslaughter, work accident)

□ suicide

Question 29 What gender was this person?

□ Female

<u>Question 30</u> Please give an estimate of how old you were when this person died?

Remember from the website that we are including sudden unexpected bereavements you may have experienced <u>after you reached the age of 10</u>. The survey starts at the age of 10 because children tend to react to bereavement in different ways to adolescents or adults, and because there may be difficulties remembering events in childhood.

(drop-down ages 10-40).

 $\Box$  I was under 10 at the time of that person's death (branch to end of questionnaire thanking respondent for their interest and reminding them of inclusion criteria)

If the bereavement was before this age we will be unable to include your responses in our analysis but thank you for having volunteered your time. For further information on the progress of this study see: www.ucl.ac.uk/psychiatry/bereavementstudy

<u>Question 31</u> About how long ago did this person die? (space) years ago

<u>Question 32</u> Approximately how old was this person at the time of their death? (space) years old In the case of infant death please use this space to give their age: (Free text)

#### 1.1.1.5 Your relationship to the person who died

#### Question 33

What relation was this person to you? Please tick one of the following options. i.e. He/she was my...

□ brother	$\Box$ close colleague or client
□ sister	$\Box$ cousin
□ father	$\Box$ niece or nephew
□ mother	$\Box$ uncle or aunt
□ son	□ uncle by marriage or aunt by marriage
□ daughter	□ brother-in-law or sister-in-law
$\Box$ partner or spouse	□ mother-in-law or father-in-law
$\Box$ ex-partner or ex-spouse	$\Box$ other – please state (Free text)
□ grandparent	
$\Box$ close friend	

Please specify here if they were a half-, step-, or adoptive relative or a relative by marriage: (Free text)

#### Question 34

In the year before their death on average how often were you in contact with them? This would include face-to-face meetings as well as telephone calls, text messages, emails, cards, letters, and contact via social networking sites.

daily
weekly
monthly
every 2 to 3 months

every 6 months
yearly
not at all during that year

## Question 35

Approximately how long before their death had you known this person for? For (space) years

#### Question 36

At the time of their death how emotionally close did you feel to this person?

Not close at all  $1 \Box 2 \Box 3 \Box 4 \Box 5 \Box$  As close as any relationship I've had before or since

Question 37

If your relationship with them had previously been closer or more distant, please try and rate how close the relationship had been previously using the same scale. If the relationship was no different previously you can just click N/A.

Not close at all  $1 \Box 2 \Box 3 \Box 4 \Box 5 \Box$  As close as any relationship I've had before or since  $\Box$  N/A

# 1.1.1.6 The emotional impact of a bereavement

The following questions are to find out about the types of feelings you may have had since the death.

You may find that some of the questions asked do not apply to you. For these you should tick 'Never'.

For those questions that you do identify with please try to judge, as best you can, how frequently you have experienced this feeling since the death.

 Question 38

 How often did you think that people were uncomfortable offering their condolences to you?

 Never
 Often

 Rarely
 Almost always

 Sometimes

Question 39 How often did you avoid talking about the negative or t Never Rarely Sometimes	unpleasant parts of your relationship? □ Often □ Almost always
Question 40 How often did you feel avoided by friends? Dever Rarely Sometimes	□ Often □ Almost always
Question 41 How often did you think that others didn't want you to to Never Rarely Sometimes	talk about the death? □ Often □ Almost always
Question 42 How often did you feel like no-one cared to listen to yo □ Never □ Rarely □ Sometimes	u? □ Often □ Almost always
Question 43 How often did you feel that friends, neighbours and fan Never Rarely Sometimes	nily did not offer enough concern? □ Often □ Almost always
<u>Question 44</u> How often did you feel like a social outcast? Description Never Rarely Sometimes	□ Often □ Almost always
Question 45 How often did you think people were gossiping about y • Never • Rarely • Sometimes	ou or that person? □ Often □ Almost always
Question 46 How often did you feel like people were probably wond you and that person had experienced? □ Never □ Rarely □ Sometimes	<ul> <li>dering about what kind of personal problems</li> <li>□ Often</li> <li>□ Almost always</li> </ul>
Question 47 How often did you feel like others may have blamed you I Never Rarely Sometimes	ou for the death? □ Often □ Almost always
Question 48 How often did you feel like the death somehow reflecte Never Rarely	ed negatively on you or your family? □ Sometimes □ Often

□ Almost always

## **Question 49**

How often did you feel somehow stigmatised by the death? □ Often  $\square$  Never □ Almost always □ Rarely □ Sometimes

Question 50

How often did you think of times before the death when you could have made the person's life more pleasant? □ Never □ Often □ Almost always

□ Rarely

□ Sometimes

#### Question 51

How often did you wish that you hadn't said or done certain things during your relationship with the person?

□ Never □ Often □ Rarely □ Almost always □ Sometimes

### Question 52

How often did you feel like there was something very important you wanted to make up to the person?  $\square$  Never □ Often □ Rarely □ Almost always □ Sometimes

### Question 53

How often did you feel like maybe you didn't care enough about the person? □ Never □ Often □ Rarely □ Almost always

□ Sometimes

#### Question 54

How often did you feel somehow guilty after the death of the person? □ Never □ Often □ Rarely □ Almost always □ Sometimes

#### Question 55

How often did you feel like the person had some kind of complaint against you at the time of the death? 0

$\Box$ Never	□ Often
□ Rarely	Almost always
□ Sometimes	

#### Question 56

How often did you feel that, had you somehow been a different person, the person would not have died? □ Never

□ Rarely

□ Sometimes

□ Often □ Almost always

# Question 57

How often did you feel that you had ma	ade the person unhappy long before the death?
□ Never	□ Often
Rarely	Almost always
□ Sometimes	

Question 58 How often did you feel as though problems you and that person had together contributed to an untimely death? □ Never □ Often □ Rarely □ Almost always □ Sometimes Question 59 How often did you avoid talking about the death of the person? □ Never □ Often □ Rarely  $\Box$  Almost always □ Sometimes **Ouestion 60** How often did you feel uncomfortable revealing the cause of the death? □ Never □ Often □ Rarely □ Almost always □ Sometimes Question 61 How often did you feel embarrassed about the death? □ Never □ Often □ Rarely □ Almost always □ Sometimes Question 62 How often did you not mention the death to people you met casually? □ Never □ Often □ Rarely □ Almost always □ Sometimes Question 63 How often did you tell someone that the cause of death was something different than what it really was?

□ Never	□ Often
□ Rarely	Almost always
Sometimes	

### 1.1.1.7 Accessing help

We are now interested in finding out about the help you received or were offered after the death. If you wish to give more detail there are further questions about this in **Part 2**.

### Question 64

How long after the death did you receive help that was valuable to you?Within a dayWithin a yearWithin a weekOver a yearWithin a monthAt no timeWithin 6 monthsOver a year

#### Question 65

What help did you receive after the death? Please tick all those that apply:

- $\square$  None
- $\square$  Police
- □ Funeral director
- $\square$  Coroner's service
- □ NHS services (doctor, nurse, therapist, counsellor)
- □ Private counsellor or therapist
- □ Voluntary sector services (helpline, counsellor)
- □ Help from friends, family and neighbours

□ Self-help from a website, book or leaflet □ Other – please state: (Free text)

We are now interested in finding out about your emotional health.

#### Question 66

Have you ever, except in the last 6 months, had nearly two weeks or longer when nearly every day you felt sad, empty or depressed for most of the day?

 $\Box$  Yes (branch to question 67)  $\Box$  No

#### Question 67

If Yes, at about what age did these feelings of being sad, empty or depressed first occur? (space) years old

### Question 68

Have you ever, except in the last 6 months, had 2 weeks or longer when you lost interest in most things like work, hobbies and other things that you usually enjoyed?

#### Question 69

If Yes, at what age did these feelings of having lost interest in most things first occur? (space) years old

Question 70

During the last 30 days, about how often did you feel tired out for no good reason?		
$\square$ None of the time	$\Box$ Most of the time	
$\square$ A little of the time	$\Box$ All of the time	
$\Box$ Some of the time		

Question 71

During the last 30 days, about how often did you feel nervous?		
$\square$ None of the time	$\Box$ Most of the time	
$\Box$ A little of the time	$\Box$ All of the time	
$\Box$ Some of the time		

Question 72

During the last 30 days, about how often did you feel so nervous that nothing could calm you?
None of the time
A little of the time
Some of the time
All of the time

 Question 73

 During the last 30 days, about how often did you feel hopeless?

 In None of the time
 In Most of the time

 In A little of the time
 In All of the time

 In Some of the time
 In All of the time

 Question 74

 During the last 30 days, about how often did you feel restless or fidgety?

 □ None of the time
 □ Most of the time

 □ A little of the time
 □ All of the time

 □ Some of the time
 □ All of the time

 Question 75

 During the last 30 days, about how often did you feel so restless you could not sit still?

 □ None of the time
 □ Some of the time

 □ A little of the time
 □ Most of the time

 $\Box$  All of the time

 Question 76

 During the last 30 days, about how often did you feel depressed?

 □ None of the time
 □ Most of the time

 □ A little of the time
 □ All of the time

 □ Some of the time
 □ All of the time

 Question 77

 During the last 30 days, about how often did you feel that everything was an effort?

 □ None of the time
 □ Most of the time

 □ A little of the time
 □ All of the time

 □ Some of the time
 □ All of the time

# Question 78

 During the last 30 days, about how often did you feel so sad that nothing could cheer you up?

 None of the time
 Image: Most of the time

 A little of the time
 Image: All of the time

 Some of the time
 Image: All of the time

Question 79

During the last 30 days, about how often did you feel worthless?		
$\Box$ None of the time	$\Box$ Most of the time	
$\Box$ A little of the time	$\Box$ All of the time	
$\Box$ Some of the time		

### Question 80

In the last month how often have you had intense feelings of emotional pain, sorrow, or pangs of grief related to the person who died?

□ Not at all
 □ At least once a day
 □ At least once a day
 □ At least once a week

# 1.1.1.8 Personality style

The following 8 questions are about your personality - the way you typically think, feel or behave.

Question 81 In general, do you have difficulty making and keeping □ Yes	friends? □ No
Question 82 Would you normally describe yourself as a loner? □ Yes	□ No
Question 83 In general, do you trust other people? Please base your description applies <i>most of the time</i> and in most situation In Yes	•
Question 84 Do you normally lose your temper easily? □ Yes	□ No
Question 85 Are you normally an impulsive sort of person? □ Yes	□ No

<u>Question 86</u> Are you normally a worrier? □ Yes	□ No
Question 87 In general, do you depend on others a lot? □ Yes	□ No
<u>Question 88</u> In general, are you a perfectionist? □ Yes	□ No

# 1.1.1.9 Your day-to-day life

The next 8 questions measure how you currently handle everyday life and relationships.

Each one is presented as a statement. Please look at each statement and tick the reply that comes closest to how you have been **over the last fortnight**.

Question 89 I complete my tasks at work and home satisfactorily. □ Most of the time □ Quite often	□ Sometimes □ Not at all
Question 90 I find my tasks at work and at home very stressful. □ Most of the time □ Quite often	□ Sometimes □ Not at all
Question 91 I have no money problems. □ No problems at all □ Slight worries only	□ Definite problems □ Very severe problems
<u>Question 92</u> I have difficulties in getting and keeping close relations Severe difficulties Some problems	ships. □ Occasional problems □ No problems at all
Question 93 I have problems in my sex life. □ Severe problems □ Moderate problems	<ul> <li>□ Occasional problems</li> <li>□ No problems at all</li> </ul>
Question 94 I get on well with my family and other relatives. □ Yes, definitely □ Yes, usually	□ No, some problems □ No, severe problems
Question 95 I feel lonely and isolated from other people. □ Almost all the time □ Much of the time	□ Not usually □ Not at all
Question 96 I enjoy my spare time. □ Very much □ Sometimes	□ Not often □ Not at all

In relation to your education, have you ever had to drop out of a course at school, college or university?

Ves (branch to question 98)

No

Question 98

If yes was this: □ before the bereavement?

 $\Box$  after the bereavement?

□ both before and after the bereavement?

### Question 99

In relation to your employment history, have you ever:

- been made redundant?
- been disciplined?
- resigned from a job for negative reasons?
- been given notice from employment?

 $\square$  Yes (branch to question 100)  $\square$  No  $\square$  Not applicable

Question 100

If yes was this:

 $\Box$  before the bereavement?

□ after the bereavement? □ both before and after the bereavement?

The following questions are about times in your life when you might have felt low and hopeless, with negative thoughts about your future.

### Question 101

Have you ever thought that life was not worth living? □ No □ Yes (branch to question 102)

### Question 102

If you have ever thought that life was not worth living, was this:

 $\Box$  before the bereavement?

 $\Box$  after the bereavement?

□ both before and after the bereavement?

### Question 103

Have you ever wished that you were dead?

 $\square$  Yes (branch to question 104)

# Question 104

If you have ever wished that you were dead, was this before the bereavement?

 $\Box$  after the bereavement?

 $\square$  both before and after the bereavement?

# Question 105

Have you ever thought of taking your life, even though you would not actually do it? □ No □ Yes (branch to question 106)

# Question 106

If you have ever thought of taking your life, was this:

 $\Box$  before the bereavement?

 $\Box$  after the bereavement?

 $\Box$  both before and after the bereavement?

Have you ever made an attempt to take your life, by taking an overdose of tablets or in some other way?

Question 108

If you have ever made an attempt to take your life, by taking an overdose of tablets or in some other way, was this:

 $\Box$  before the bereavement?

 $\Box$  after the bereavement?

 $\hfill\square$  both before and after the bereavement?

#### Question 109

Have you ever deliberately harmed yourself in any way but not with the intention of killing yourself? □ No □ Yes (branch to question 110)

Question 110

If you have ever deliberately harmed yourself in any way, but not with the intention of killing yourself, was this:

- $\Box$  before the bereavement?
- $\Box$  after the bereavement?
- $\Box$  both before and after the bereavement?

# 1.1.1.10 Seeking help

#### Question 111

If you have harmed yourself since the bereavement did you seek help from anyone? □ Yes (branch to question 112) □ Not applicable □ No

### Question 112

Who did you try to get help from? Please tick all those that apply.

a friend
a member of your family
your GP/family doctor
the local hospital
someone else ? Please specify: (Free text).

The next few questions relate to the psychological health of other people in your family.

#### Question 113

Has anyone in your family suffered from an anxiety disorder, a depressive disorder (including postnatal depression), had drug or alcohol problems, or other psychological or emotional difficulties?

 $\square$  Yes (branch to question 114)  $\square$  No

Please use this box to indicate which members of your family have had psychological or emotional difficulties, specifying whether they were blood relatives or not. If your earlier responses about bereavement related to a family member, and this question applies to that person, please include them here too. (Free text)

### Question 115

Have any of your blood relatives died by suicide? If your earlier responses about bereavement related to the suicide of a relative please tick **Yes** as the computer programme cannot add this information automatically.

 $\Box$  Yes (branch to question 116)  $\Box$  No

#### Question 116

If yes please use the box below to indicate what relative they were to you (e.g. father, grandfather, aunt, etc). (Free text)

These final few questions in Part 1 are about your own psychological health.

#### Question 117

Have you ever had an anxiety disorder, a depressive disorder, drug or alcohol problems, or other mental health difficulties?

 $\square$  Yes (branch to question 118)  $\square$  No □ Don't know

#### Question 118

If you have had psychological or emotional difficulties, have you ever had help for this from any of the following:

- general practitioner?
- practice nurse?
- practice counsellor?
- a psychiatrist in an out-patient appointment?

 $\Box \ Yes$ 

□ No

Don't know

 $\square$  Not applicable

Please use the free text below if you wish to give further details: (Free text)

Question 119 Have you ever been an in-patient in an acute mental health ward? □ Yes □ No

Please use the free text box below if you wish to give further details: (Free text)

This is the final question in Part 1. To date, at what stage after the bereavement do you feel that you have been most affected by it?

□ immediately afterwards
□ up to a week
□ up to a week
□ up to 3 years
□ up to a month
□ over 3 years
□ up to 6 months

### Part 2

Thank you for your answers so far. Here in **Part 2** the free text boxes are for you to tell us in your own words about the areas of your life that might have been affected.

- Please give as much or as little detail as you wish to.
- If a question does not apply to you, just skip it.
- At any stage you can click Save in order to return and continue at another time.

## 1.1.1.11 Relationships

#### Question 121

In what way, if any, has your relationship with a partner, or with potential partners, changed since the bereavement?

Remember that if this or any other question does not apply to you, just skip to the next one.

#### Question 122

What about relationships with close friends, or with potential close friends?

Question 123

In what way, if any, have relationships within your immediate family (parents, brothers, sisters, children) changed since the bereavement?

#### Question 124

What about relationships with members of the wider family (cousins, aunts, uncles, nephews, nieces, grandparents)?

#### Question 125

If there are other ways in which you have withdrawn from those around you or grown closer to them, please use this space to give details. (Free text)

# 1.1.1.12 Education and work

<u>Question 126</u> In what way, if any, has the bereavement affected your educational progress?

<u>Question 127</u> What about your work performance?

### 1.1.1.13 Other aspects of everyday life

#### Question 128

In what way, if any, has the bereavement affected your drinking habits or your use of unprescribed drugs? (Unprescribed drugs include illicit drugs as well as medications used above their prescribed limits.)

In what way, if any, has the bereavement affected your finances?

Question 130

In what way, if any, has the bereavement affected your spiritual beliefs?

## Question 131

What information about the circumstances of their death, if any, did you not find out about until later?

# Question 132

In what situations, if any, have you avoided discussing the death, or noticed that others avoid the subject?

# Question 133

In what situations, if any, have you hidden your grief to protect yourself and others?

# Question 134

Is the person who died still talked about by those who knew them?

In your answer you may want to consider:

- Whether anyone avoids talking about them.
- Whether anyone has made negative comments about them or the way they died.
- What opportunities you have had to share memories of them.

# Question 135

To what extent has their death made you fear that you may die in a similar way?

# 1.1.1.14 Immediately after the death

# Question 136

If you attended a funeral or memorial service for the person who died, what was your experience of this?

Question 137

If an inquest was held what was your experience of this, and your reaction to the verdict?

Question 138

Please describe any positive or negative experiences you may have had after the death in relation to the following:

- police force
- funeral directors
- coroner's office
- healthcare staff
- press reporting on the death

# 1.1.1.15 Help received

# Question 139

What are your views on any help you were offered or not offered? In your response you may wish to comment on:

- how helpful or unhelpful any support was
- what help you wish you had been offered and at what stage
- why certain people did not offer their support

(Free text)

# Question 140

After the death did it feel as though support was available to other people close to that person but not to yourself? For example this may have been because:

- you hid your grief
- others were not aware that you had a close relationship with this person
- the support you wanted was not available

# 1.1.1.16 Future work and feedback

You have reached the end of the questionnaire. Thank you very much for your time.

We are also inviting some people who have completed this survey to participate in a face-to-face **interview**. This gives us a chance to hear more about your personal experiences of bereavement.

The interview lasts up to an hour. In London these will be held at UCL (Torrington Place, London WC1), but arrangements for sites outside London are to be confirmed. Further information is available on the study website: <a href="https://www.ucl.ac.uk/psychiatry/bereavementstudy">www.ucl.ac.uk/psychiatry/bereavementstudy</a>

#### Question 141

If you would be willing to be contacted about volunteering for an interview please type your email address and/or telephone number in the space below. These details will **not** be passed on to anyone outside this research team.

Please note that if you do volunteer for an interview that you are not committed to this, and can withdraw this decision at any time.

Email and/or telephone: (Free text)

### Question 142 - Future work:

We also hope to conduct a follow-up study in a few years' time to explore whether there are any changes in how people adjust to a bereavement over time.

If you are willing to be contacted about participating in this future study please supply contact details which will be reliable for a period of approximately 5 years.

If your email address is likely to change you may prefer to give a postal address or telephone number. If we contact you by post the envelope will be marked *only* with your name and address, and will be labelled Private and Confidential. If you know your NHS number this is also a reliable way of our team being able to contact you by post.

Volunteering for this follow-up study is entirely optional. If you do provide contact details but later decide not to participate, you are free to withdraw at any time. You do not have to give any reason for withdrawing.

At no point will your name or contact details be passed on to anyone outside the research team. Email/Telephone/Postal address/NHS number: (Free text) Thank you for participating in this questionnaire.

# Question 143 - Communication of the study's results:

Once the results have been analysed they will be available on the UCL Bereavement Study website. If you would like the results to be emailed to you please type your email address in the box below.

Please note that:

1) Your email address will <u>not</u> be visible to others when the study results are emailed out.

2) When the responses to this questionnaire are analysed your email address will be <u>removed</u> so your anonymity is protected.

3) Your name or contact details will <u>not</u> be passed on to anyone outside this research team.

### Email: (Free text)

Clicking on the Finish button (bottom right) will end your questionnaire and bring you directly to the university's counselling service website. This is your opportunity to go back and review your responses if you wish to.