



# THE UNIVERSITY *of* EDINBURGH

## School of Health in Social Science

### **Study Information Sheet**

This study is looking at publicly available social media posts across several platforms to develop a better understanding of neurodivergent experiences of grief and loss. This is a University of Edinburgh project as part of PhD research by Ally Pax Arcari Mair, supervised by Dr Karri Gillespie-Smith, Dr Doug McConachie, and Dr Karen Goodall. This sheet is to help you learn more about the study, increase the transparency of the research process, and give you the information you need if you want to contact the researcher to let them know that you do not wish your posts to be part of this research. Please take the time to read the following information carefully, and if you have any questions, please do not hesitate to ask.

#### **What is the purpose of this study?**

The purpose of this study is to find out more about how neurodivergent individuals experience grief and loss. This will include looking at how neurodivergent people understand, discuss, and are impacted by grief and loss. In this study, neurodivergent refers to having one or more neurodevelopmental disorders, such as an intellectual disability, autism, ADHD, Tourette's, dyspraxia, etc.

#### **What data will be looked at?**

Posts on the following social media platforms related to neurodivergence and grief will be looked at:

- Instagram
- Reddit
- TikTok
- Tumblr
- Twitter
- WordPress

Content from neurodivergent social media influencers, professionals, and activists will be appropriately cited. Public posts which are more personal will be anonymised and not directly quoted in any research output.

#### **Do you have to use my post/content?**

No – it is entirely up to you. If you do not wish to have your posts used in this study, you can email Ally (the researcher) to let her know, or you can fill out this [form](#) and no posts from the username/social media handle you provide will be considered. If you decide later you wish for your posts to be removed from the analysis, you can let Ally know at any point up until the 20<sup>th</sup> of March 2023, by this point all the posts will be anonymised and it will not be possible to remove them.

### **What are the benefits of having your posts inform this study?**

By allowing us to look at your posts and see your experiences of grief and loss, you will be helping the researchers to get a better understanding of neurodivergence and grief.

### **What will happen if you don't opt out?**

You will not need to do anything. There is no active participation to this study. The researcher will access your posts via a public search engine should they meet the study's criteria and search strategy.

### **Are there any risks associated with taking part?**

You will not need to take part directly, only your social media posts/content may be accessed.

### **What if you decide you do not want to take part?**

You can let the researcher know at any point before the 20<sup>th</sup> of March 2023 that you do not wish for your posts to inform this study: the researcher's contact details are at the bottom of this document, and a link to an "opt-out" form is also available [here](#). After this date, it will not be possible to remove the posts from the dataset for analysis.

### **Data Protection and Confidentiality**

The information collected will be collected and processed in accordance with Data Protection Law. All information collected will be kept strictly confidential and data from "posters" (those who are not social media influencers, professionals, and/or activists) will be anonymised to protect their identity; for example, all reasonably identifiable information will be removed, such as names, locations, social media handles, etc. Links to posts will be kept whilst the data is being formatted, described, and/or transcribed, following this the links from posts will be deleted and the data anonymised. Although this information is publicly available by search engine, the data collected and formatted into a cohesive dataset, will only be viewed by the research team. All information will be stored on the University of Edinburgh servers which are password protected.

### **What will happen with the results of the study?**

The results of this study will be used in a chapter of Ally's (the researcher) PhD and will also be used to write a scientific article for publication in an academic journal and/or presented at a conference. Content from social media influencers, professionals, and/or activists may be directly quoted; however, posts from posters will only be paraphrased to protect the poster's identity, but they may be directly quoted if it is a short reoccurring phrase by multiple posters across 2 or more platforms (e.g. multiple posters said "it made me feel sad"). Information will be kept for 5 years in accordance with University of Edinburgh GDPR regulations and then deleted.

### **Who can I contact?**

If you wish to take part in our study, please contact the researcher by email or her project supervisors by phone or email. Furthermore, if you have any questions about the study and if you wish to receive a summary of the research outcomes, contact either:

PhD Researcher

Ally Pax Arcari Mair  
PhD Student in Clinical Psychology  
Department of Clinical and Health Psychology  
School of Health in Social Sciences  
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Or

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If you have any complaints, please do contact the Head of School of Health in Social Sciences:

Prof Matthias Schwannauer  
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We do not expect this study to be distressing, as there is no active participation; however, we understand that the concepts of grief and loss in of themselves can be distressing to read/hear about, and we know it can be a very sensitive topic. So, we have included some resources below should you feel distressed by the content of this study; you may wish to contact your GP or one of the following:

- Samaritans provides confidential non-judgmental emotional support for anyone who is struggling to cope: call 116 123, text 07725 90 90 90, or email [jo@samaritans.org](mailto:jo@samaritans.org)
- Breathing Space is a free, confidential phonenumber service for any individual who is experiencing low mood and depression, or who is worried and in need of someone to talk to: call 0800 83 85 87
- Counselling Directory provides information to help people find a qualified counsellor or psychotherapist in their local area: <https://www.counselling-directory.org.uk/>
- NHS 24 provides urgent health advice out of hours, when your GP practice is closed: call 111.
- Shout 85258 is a free, confidential, 24/7 text messaging support service for anyone who is struggling to cope: text 85258
- Cruse Bereavement Support is a charity which provides support and counselling for those experiencing grief and loss: you can call their helpline on 0808 808 1677 or go to <https://www.cruse.org.uk/>