



PARTICIPANT INFORMATION SHEET

Project:

‘Living alongside an eating disorder’: an exploration of the experiences and perspectives of UK family members of someone with an eating disorder, and charity staff and volunteers.

You are being invited to take part in research on the effect of eating disorders on families. This research is being conducted by Laura Gill, a medical student, at the University of Edinburgh. To help you decide if you wish to take part, the following information describes why the research is being conducted and what it will involve. Please take time to read the following information carefully.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the study is to understand family members’ experiences of having an adult family member with an eating disorder and what kinds of understandings of eating disorders this group of people have. This research is interested in understanding what kind of informal and formal support, or support networks, family members might seek out for themselves and their own wellbeing. (Please note that this research is not an evaluation of specific services.) This research is important because family members’ experiences and perspectives are currently under researched and not well understood. Insight from this project could help in raising awareness about helping families get through these experiences.

The results from this research project will be used in a final year undergraduate dissertation, which can be provided to the participants upon request.

WHY HAVE I BEEN INVITED TO TAKE PART?

You are invited to participate in this study because you are either a family member of an adult person who has, or has had, an eating disorder, or you work within a charity/organisation that supports families affected by eating disorders. All interviewees must also be over the age of 18.

DO I HAVE TO TAKE PART?

No – participation in this research is entirely voluntary. If you do decide to take part, you are free to withdraw at any time until 20th March 2023, without giving a reason. Any data collected up to that point would be destroyed and not included in the research analysis. If you do decide to take part, please keep this Information Sheet and complete the Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate.

If you are a person with a family member who has, or has had, an eating disorder: To participate in this research, it is important that you discuss this research and your potential participation with your family member who has/had an eating disorder, and get verbal consent from them that they are comfortable with you participating. Their identity will be anonymised and they will be given a pseudonym in all research notes. The focus of the interview will be own experience and thoughts, but this step is to ensure that any information you might share about them is to their knowledge, and so that they may put parameters on what information is shared with the researcher during an



interview. Please note that your family member with an eating disorder will not be interviewed and a consent form will not be collected from them.

WHAT WILL HAPPEN IF I DECIDE TO TAKE PART?

Through an informal interview with the researcher, you will be asked to speak about your experiences being, or working with, a family member of someone with an eating disorder. The interview will cover topics such as: wellbeing, health, informal and formal support, family dynamics, and your understanding and definition of eating disorders. The interview would take place either on the University of Edinburgh campus, or via a Microsoft Teams video call, at a time that is convenient to you. If you organise a face-to-face interview, the interviewer can wear a mask if you prefer. The interview will last up to an hour and will be recorded, however recording is not required, and participants can choose to have interview notes to be taken by hand instead. Interviews can be paused or ended at any time at the discretion of the interviewee, and you may choose not to answer any questions you do not wish to.

DATA PROTECTION AND CONFIDENTIALITY

Your data will be processed in accordance with the Data Protection Act 2018, and UK General Data Protection Regulation (GDPR). All information collected about you will be kept strictly confidential and only viewed by the researcher. You will be given a pseudonym and identifying information will be anonymised to protect your identity. All recordings and data will be stored in an encrypted and password protected file, accessible only by the researcher. Your consent information will be kept separately from your responses.

ARE THERE ANY RISKS OR BENEFITS ASSOCIATED WITH TAKING PART?

The hope is that taking part will be interesting for you, however there are no guaranteed or expected benefits to taking part. It is possible that taking part in these discussions could be upsetting or cause you distress, given the sensitive nature of the topic area. To mitigate against any distress, you have the right to stop at any time and withdraw from the study, or pause the interview process. To ensure that you (and your family members) feel safe and comfortable with your participation, your participation will only be allowed with your assurance that you have received verbal consent from your family member who has/had an eating disorder.

FURTHER INFORMATION

If you have any further questions about the study, please contact the lead researcher Laura Gill by email: s2027005@ed.ac.uk.

Concerns

If you have any complaints or concerns about this project, please contact the Social Research Ethics Group (SREG), Biomedical Teaching Organisation, University of Edinburgh. Email SREG@ed.ac.uk and my project supervisor: Dr Lilian Kennedy, Lilian.Kennedy@ed.ac.uk.

You may also wish to contact the Dean, Michael Shipston, Mike.Shipston@ed.ac.uk

For more information on complaints:

<https://www.ed.ac.uk/files/imports/fileManager/WEB%20Complaint%20Form.pdf>

Support Resources

If you wish to seek support from charities during or after the process, the main UK based eating disorder charity is BEAT (beat eating disorders). The student researcher can also offer further advice on regional based charities once you have made contact.

BEAT contact:

Help for England

Helpline: 0808 801 0677

Email: help@beateatingdisorders.org.uk

Help for Scotland

Helpline: 0808 801 0432

Email: Scotlandhelp@beateatingdisorders.org.uk

Help for Wales

Helpline: 0808 801 0433

Email: Waleshelp@beateatingdisorders.org.uk

Help for Northern Ireland

Helpline: 0808 801 0434

Email: NIhelp@beateatingdisorders.org.uk