

Version 2: October 2023
Participant information sheet

Understanding caregiver trauma responses to children/young people (CYP) with eating disorders

We would like to invite you to take part in our study looking to understand the experience of caregivers of CYP with an eating disorder. Thank you for your interest in this research. Taking part in this study is entirely optional and so, before you decide whether you want to take part, we will explain why this research is being carried out.

Please read the following information carefully before deciding whether you would like to be a part of this study. If you have any questions before taking part, please feel free to get in contact using our details below.

What is the purpose of the research?

Some research has found that supporting a CYP with an eating disorder can be traumatic. However, research is limited in this area and the current study seeks to address this. We are interested in understanding how caring for a CYP with an eating disorder affects caregivers. We would also like to find out what aspects influence the distress caregivers may experience. In particular, we are interested in the nature of the child's illness, the caregiver's understanding of eating disorders, and how able they feel to support their child. We hope that this research will help us to understand how best caregivers can be supported.

This research is being carried out as part of two Doctorate theses in Clinical Psychology, at the University of East Anglia (UEA).

Who is being invited to take part?

We are interested in recruiting individuals who satisfy all of the criteria below:

You are a parent or guardian caregiver to a child/young person who is currently experiencing eating-related difficulties or has a diagnosed eating disorder

Your child is 5-25yrs

You are 18 or over

You have a substantial caring responsibility for your child (Substantial care = you consider yourself someone who offers practical and/or emotional support in relation to their eating disorder)

You live in the United Kingdom

You have the ability to comfortably read, comprehend and respond to written information presented in English

What would taking part involve?

Once agreeing to take part, you will be asked to complete an online survey which involves a small number of questionnaires. You can use your phone, tablet, or computer to complete these. You will have as much time as you need to complete these, but we predict it may take around 15-20 minutes to complete all questionnaires.

The questionnaires will ask you for information about: yourself, your child and their eating difficulties and support, as well as your emotions, thoughts, attitudes and behaviours towards your child's eating disorder.

There are no right or wrong answers and so we would appreciate your openness when completing the questionnaires.

Do I have to take part?

No, your participation is entirely voluntary. After you have read this information sheet, you will be asked whether you give your consent to participate in our study.

Can I stop taking part if I change my mind?

Yes. If for any reason you no longer want to continue with the survey, then you can exit from the survey at any time. There will be no consequence of you doing so and you will not need to give any reason as to why. Any answers already given will not be saved or submitted. However, once you have completed the survey, you will not be able to withdraw your responses as all responses are anonymous and we will not collect any personally identifiable information about you.

What are the possible disadvantages or risks of taking part?

This research will ask you questions about the topics described above. It is therefore possible that these could cause you distress either during or after completing the survey. If you become distressed during the study, you can exit the study at any time or come back to it later. You can also consider contacting one of the organizations provided below (you will be reminded of these on completion of the survey), for further support for you and/or your child.

1. *BEAT Eating Disorders*
 - Helpline (open 365 days a year from 12pm-12am during weekdays, and 4pm-12am on weekends and bank holidays):
 - 0808 801 0677 (England), 0808 801 0432 (Scotland),
 - 0808 801 0433 (Wales), 0808 801 0434 (Northern Ireland).
 - <https://www.beateatingdisorders.org.uk> – for resources, and support chat rooms
2. Samaritans are available 24 hours a day to give support to anyone who is struggling on 116 123 or via email jo@samaritans.org. More information is also available on their website <https://www.samaritans.org/>
3. FEAST - A global support and education community for families affected by eating disorders. <https://www.feast-ed.org/>

4. NHS - 111
5. Speak to your GP about accessing support for your own wellbeing
6. If your child has not yet been seen by their GP or local eating disorder service, it is important to contact them to discuss getting support. If they are accessing support and you have concerns, please contact their care providers directly.

What are the possible benefits of taking part?

There are no 'direct' benefits to you taking part in this study, but a £2 donation will be made to an eating disorder charity for your participation as a thank you for your time. We hope that your participation will help lead to a better understanding of the stress caregivers may experience and how best they can be supported.

Will this impact my child's care?

This research is separate to any care your child may currently be receiving or may receive in the future. Their care providers will not be aware of your participation in this study, or of any of your responses. If you are concerned about your child you should contact their GP, local Eating disorder or mental health team providing their care.

What will happen to the information I provide?

You will not be asked for any information that could personally identify you or your child, such as your name, address, date of birth etc. All data collected from the survey will be stored on an electronic file that is password protected and can only be accessed by the primary researchers and supervisor. Following the study, anonymised data will then be stored in a UEA data repository and may be used in further research. It will be stored in line with the Data Protection Act (2018) and UEA Policy and will be deleted after 10 years.

What will happen to the results?

The information collected from this survey will be analyzed and findings will be written up and submitted as part of two Doctoral theses in Clinical Psychology (UEA). The results of this study may also be shared with other researchers, published in academic/research journals and/or presented at conferences. All information is collected anonymously and as a result, anything reported will not allow for personal identification of those involved in the research. Results will also be shared via our social media: [Facebook](#), X/Twitter: @edcare_research.

Who is organizing, funding, and reviewing this study?

This study is organized and funded by the Doctoral Programme in Clinical Psychology at the UEA. The UEA Faculty of Medicine and Health Sciences Research Ethics Committee has reviewed and approved this study (ETH2324-0866).

What if I want to get in touch?

If you have any questions, queries, or concerns – please feel free to contact us using the following details:



Primary researchers:

Rachel Nabirinde (Trainee Clinical Psychologist)

Email: r.nabirinde@uea.ac.uk

Natasha Heal-Cohen (Trainee Clinical Psychologist)

Email: n.heal-cohen@uea.ac.uk

Doctoral Programme in Clinical Psychology, Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ.

Alternatively, please feel free to contact our supervisor, and joint researcher:

Dr. Aaron Burgess (Research Supervisor and Clinical Lecturer in Clinical Psychology)

Doctoral Programme in Clinical Psychology, Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ.

Email: Aaron.Burgess@uea.ac.uk

Or a member of course staff independent to the study:

Dr Peter Beazley, Deputy Programme Director for UEA Clinical Psychology Doctorate programme, Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ. Email: P.Beazley@uea.ac.uk

Please note that these email addresses are not to be used if you are seeking immediate support following survey completion for example, due to distress. It is unlikely that we will be able to respond in a timely manner and do not want you waiting for any support you might need. As a result, please do use the websites and organizations provided above for support.