## Call for contributions to an academic study

## **Express your Experiences**

# of an eating disorder / disordered eating / difficult feelings and actions around eating

Are you living with an eating disorder or a form of disordered eating and are over 16?

## We are interested in your experiences!

**But first of all**: if you are preoccupied with or anxious about your eating, weight, shape, size, training, exercising or muscle mass and you feel it's (becoming) a problem, there is support available for you. This is regardless of your gender, weight, age or any other factors. Support services are listed at the end of this document! Many options are online, free and easy to access.

If you think you might have a type of eating disorder but you are not sure, you can learn more about the different symptoms on this website of eating disorders charity Beat: <a href="https://www.beateatingdisorders.org.uk/get-information-and-support/about-eating-disorders/types/">https://www.beateatingdisorders.org.uk/get-information-and-support/about-eating-disorders/types/</a>

## The aim of this study

How do you express your difficulties around eating or your experiences of an eating disorder? We are inviting you to share with us your own unique stories, texts, poems, dialogues, open letters, song lyrics, artworks, music or any other expressions around the topic – using words or not. Submissions in English or any other language are welcome. We want to hear from you - whether you are diagnosed or self-diagnosed with an eating disorder, or not sure whether any eating disorder 'label' fits you. Any gender, any background, any body – no labels needed – it's about you and your unique story! All submissions are anonymous; but you can sign your work with an artist name if you wish.

We\* are a research team at the University of Nottingham and part of the EDIFY research project (<a href="https://edifyresearch.co.uk/">https://edifyresearch.co.uk/</a>). We want to explore how personal thoughts and unique stories can help healthcare professionals and others in society to better understand what it is like living with an eating disorder / disordered eating / difficulties navigating feelings and actions around food. We are also researching how creative ways of expressing and sharing personal experiences can form a part in self-care, help in recovery and foster hope, greater understanding and better treatment. And we want to give a diverse range of people a platform to start much-needed conversations about the topic, with their own voices. The study has ethics approval from the University of Nottingham.

## How we will use your contribution:

When you upload the file with your text, image, audio or other contribution on our online platform, you will need to consent to and be ok with what is outlined in points 1-7 below. Please take your time to think about it.

- 1. All contributions are made anonymously. Your online submission cannot be traced back to a sender. Please type 'xxxx xxx' instead of your name when prompted on the online submission page. You can sign your text or artwork with an artist name if you wish and we will credit this whenever we use the material. By submitting you are agreeing not to give any full real names (either your own or others') and that you are submitting your own work.
- 2. The anonymous submission means we have no way of knowing who submitted what. This also means that you cannot contact us about any contributions after submission, for example that you have changed your mind or want to alter something.
- 3. When you submit your material, you consent for it to be used for our study. There is no commercial use. The study will engage with all contributions respectfully and professionally, for example by identifying themes that can highlight particular questions for research. We are embarking on our research with an open mind but examples to illustrate possible directions are: highlighting experiences of people who are currently underrepresented (for example men and boys, trans people, people from non-white and/or minoritized backgrounds, and many others); busting myths and stereotypes; identifying differences but also shared problems; looking how help and support can be improved. We will share our research findings in articles, books, at conferences and/or online.
- 4. We may quote parts from your contributions or publicise the whole contribution in our research findings. We may also use parts or your whole work in a recoveryorientated way on our project website, in public exhibitions, via social media or in other ways. We hope that this will help us to increase knowledge about the topic, provide a helpful platform for diverse experiences that are currently not being heard or seen and encourage others to seek help.
- 5. We welcome all contributions and value openness and honesty of expression but please understand that we can only share contributions publicly that are not perceived as triggering to others. We will work with eating disorders charities in this matter. However, every contribution will be read/heard/seen, is important to us, valued and welcome! We will treat every contribution professionally, respectfully and as a voice that is very personal and unique.
- 6. We would also like to work creatively with some contributions (no commercial use). For example, we may work with artists to add music, sound, image or film to your work or record readings of texts or translate them into other languages. We have found that such multimedia engagement can be a powerful way to honour and link individual contributions and engage diverse audiences. You can find previous examples of our work here (poems turned into rap songs, texts turned into video and much more):
  - https://www.nottingham.ac.uk/research/groups/hungry-for-words/creative-writing-and-eating-disorders/poems.aspx
  - By submitting your material, you are consenting to us working with your material in a similar recover-orientated and creative way.
- 7. On our website you can follow what we do with your contributions, trace the progress of our project, find out about publications, events and read about the impact your experiences have on others:
  - https://www.nottingham.ac.uk/research/groups/hungry-for-words

- give us your age range (tick box, two options: 'between 16 and 25', or 'over 25')
- indicate (tick box, five options):
  - 'I have a clinical diagnosis of an eating disorder',
  - 'I haven't been diagnosed with an eating disorder but I think I may have one',
  - 'I am not sure I have an eating disorder but feel the topic affects me personally'.
  - 'I have had a clinical diagnosis in the past but consider myself recovered now'
  - 'Prefer not to say'
- If you are ok with this, please tell us (from a list) what type of eating disorder you are diagnosed with / think you may have. You can also tick 'prefer not to say'.

We collect this information to help us understand more how eating disorders affect different people.

### Who 'we'\* are:

This is an interdisciplinary project combining medicine, science and arts & humanities. Main contact: Prof. Heike Bartel <a href="heike.bartel">heike.bartel</a> at <a href="nottingham.ac.uk">nottingham.ac.uk</a>, Heike Bartel is Professor of German Studies and Health Humanities at the University of Nottingham, Fellow of the Institute of Mental Health and expert in stories of illness, trauma and recovery. The project is supported by Dr Tamsin Parnell, the wider EDIFY research team and the eating disorders charity First Steps ED.

## Supporting you! Resource and Information list

If you require immediate assistance, please use the links below to receive help:

#### NHS

### **England**

Find local urgent mental health helplines
Website:

https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline

## Scotland

Call NHS 24 on **111** 

Website:

https://www.nhsinform.s cot/illnesses-andconditions/mentalhealth/mental-healthsupport/mental-healthservices-at-nhs-24

#### Wales

Call **111** and press

OPTION 2

Website:

https://111.wales.nhs.uk/ encyclopaedia/m/article/ mentalhealthandwellbein

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## 24/7 confidential support

#### Samaritans

Free UK-wide24/7 listening service for adults Website:

https://www.samaritans.

org/

Email: jo@samaritans.org

Telephone: 116 123

#### Childline

Free UK-wide 24/7 listening service for under 18s sign up to use the 1-2-1 counsellor chat service Website:

https://www.childline.org

.uk/

Telephone: 0800 1111

#### **SHOUT**

Free UK-Wide 24/7 confidential and anonymous text support service with trained volunteers
Website:

https://giveusashout.org/ Text SHOUT to 85258

For many their GP practice is the first place to seek support. However, the following specialist resources can also be very helpful with any queries around the topic – by anybody and without a referral from a GP or anybody else ('self-referral'):

## **First Steps**

Website: https://firststepsed.co.uk/

First Steps ED are a specialist eating disorder charity, working nationally to support anyone aged five years and over affected by an eating disorder, eating difficulties or body image concerns.

First Steps ED services are open to all ages, genders, and backgrounds, and you don't need an official mental health or eating disorder diagnosis to access them. You can make a referral to First Steps ED yourself, or a parent, carer or professional can make a referral on your behalf using the following link: <a href="https://firststepsed.co.uk/make-a-referral/">https://firststepsed.co.uk/make-a-referral/</a>

First Steps ED offer a range of services (many of them can be accessed online) and if you are based in Derbyshire, Leicestershire, or Hertfordshire, many of these services are funded and free. First Steps ED also has free self-help resources which are accessible through the following links: <a href="https://www.talk-ed.org.uk/">https://www.talk-ed.org.uk/</a>, <a href="https://firststepsed.co.uk/">https://firststepsed.co.uk/</a> and their online befriending service is available for free to anyone in the UK. For anyone over 16 and outside a commissioned area, First Steps ED offer private psychotherapy (which would require self-funding): <a href="https://firststepsed.co.uk/private-practice/">https://firststepsed.co.uk/private-practice/</a>

## Beat is the UK's largest eating disorder charity and offers a wide range of help and support, many free and online

Website: https://www.beateatingdisorders.org.uk/

Helpfinder: https://helpfinder.beateatingdisorders.org.uk/

Website: https://www.beateatingdisorders.org.uk/get-information-and-support/get-help-

for-myself/i-need-support-now/helplines/

## Telephone:

England Scotland Wales Northern Ireland 0808 801 0677 0800 801 0432 0808 801 0433 0808 801 0434

Webchat support with Beat helpline advisors: <a href="https://www.beateatingdisorders.org.uk/get-information-and-support/get-help-for-myself/i-need-support-now/one-to-one-web-chat/">https://www.beateatingdisorders.org.uk/get-information-and-support/get-help-for-myself/i-need-support-now/one-to-one-web-chat/</a>
You do not need a formal diagnosis to use the one-to-one webchat

### Email Support:

England: help@beateatingdisorders.org.uk

Scotland: Scotlandhelp@beateatingdisorders.org.uk Wales: Waleshelp@beateatingdisorders.org.uk

Northern Ireland: NIhelp@beateatingdisorders.org.uk

## GP Leaflet:

Beat have designed a leaflet to bring along to GP appointments to help people get a quick referral from their GP to an eating disorder specialist. It has guidance for the person who has an eating disorder, for people supporting someone with an eating disorder and for the GP. <a href="https://www.beateatingdisorders.org.uk/resource-index-page/gp-leaflet-first-steps/">https://www.beateatingdisorders.org.uk/resource-index-page/gp-leaflet-first-steps/</a>

You can also use the **Freed** website to find services in England <a href="https://freedfromed.co.uk/#help-and-support">https://freedfromed.co.uk/#help-and-support</a>

### **Further resources**

**YoungMinds** is a UK-based charity for young people's mental health. It provides various links to receive help and support and also provides helpful information on general mental health. https://www.youngminds.org.uk/

https://www.youngminds.org.uk/young-person/my-feelings/eating-problems/

**Talk ED** is a UK peer-led charity supporting anyone affected by an eating disorder or eating distress at any stage of their journey with referrals for tailored services. They also offer long term one-to-one peer recovery support for recovery, support groups and workshops.

https://www.talk-ed.org.uk/

https://www.talk-ed.org.uk/support-services/befriending/

**Support** ED is a Scotland-based charity that works in communities to support people with an eating disorder, families and carers. They offer befriending and support groups as well as information about eating disorders.

https://supportedscotland.org/

https://supportedscotland.org/support-groups-update/

**Eating Disorders Association N.I.** is Northern Irelands dedicated eating disorder charity. They provide peer support for people with eating disorders and their loved ones as well as information and resources about eating disorders.

https://www.eatingdisordersni.co.uk/

**Mind** is an England and Wales-based charity for mental health. They provide various links to receive help and support.

Information for Eating Disorder Recovery <a href="https://www.mind.org.uk/information-support/types-of-mental-health-problems/eating-problems/recovery-self-care/">https://www.mind.org.uk/information-support/types-of-mental-health-problems/eating-problems/treatment-support/</a>

For support for eating disorders/ disordered eating in other English-speaking countries:

**USA:** https://www.nationaleatingdisorders.org/

Canda: <a href="https://nedic.ca/">https://nedic.ca/</a>

Australia: https://nedc.com.au/support-and-services/get-help/

New Zealand: <a href="https://www.ed.org.nz/">https://www.ed.org.nz/</a>