

Distress Guide

Level 1 Mild Distress:

Respondent actions:

- Change in voice tone or volume
- Change in focus
- Hesitancy to answer questions or probes
- Fidgeting
- Use of inappropriate language
- Non-relevant answers

Interviewer actions:

- Pause give respondent time to recover/compose themselves
- Check if respondent wants to continue if they have not already indicated that they would like to stop – terminate interview if necessary
- Change topic/move to next question/topic
- Inform PI
- Offer appropriate helpline numbers at the end of the interview

Level 2: Moderate distress

Respondent actions:

Level one signs plus...

- Long pauses and sighing
- Tearful / crying
- Extreme forms of agitation
- Non-responsiveness
- Nonsensical responses to questions or probes
- Asks for your advice/help
- Says, does not want to continue with interview

Interviewer actions:

- Stop interview and offer helpline numbers
- Inform PI and Operations team lead
- Complete respondent distress report form
- Operations team lead to submit incident report to ERB

Level 3: Severe distress

Respondent actions:

- Mentions suicidal thoughts
- Talks about wishing another person was dead or talks about committing harm to another person
- Respondent asks for immediate help from a health care professional

Interviewer actions:

- Stop interview and offer helpline numbers
- Inform PI and Operations team lead
- Complete respondent distress report form
- Operations team lead to submit incident report to ERB

Helpline telephone numbers and web resources

For help with emotional distress¹:

National Suicide Prevention lifeline #988

Additional resources can be found on the CDC Website:

<https://www.cdc.gov/violenceprevention/>

Resources for Cognitive Health and Older Adults

[Cognitive Health and Older Adults | National Institute on Aging \(nih.gov\)](https://www.nia.nih.gov/health/cognitive-health-and-older-adults)

More Information about Cognitive Health, Dementia and Alzheimer's:

NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center
(www.nia.nih.gov/alzheimers) Phone Number: 800-438-4380

Email: Adear@nia.nih.gov

Alzheimer's Association

800-272-3900

866-403-3073 (TTY)

info@alz.org

www.alz.org

Alzheimer's Foundation of America

866-232-8484

info@alzfdn.org

www.alzfdn.org

The CCQDER operations study team lead **Kristen Gregory-Lee/Amanda Titus** and the study PI will be informed of distress displayed during the interview.

The operations team lead will be responsible for reporting any signs of **moderate or severe** distress to the ERB.

¹ Links and phone numbers updated on: 06/24/2024

Respondent Distress Report form

CASE ID number_____

Interviewer name_____

Name of PI_____

Level of distress (moderate/severe)_____

Distress Description

Interviewer Actions

Date reported to PI and Operations team lead_____

Severe distress

Date reported to ERB_____

Name of operations team lead making report_____