

Participant Information Statement and Consent Form



Resilience Experiences and Perspectives in Autistic Adults The research is being carried out by the following researchers:		
Role	Name	Organisation
Chief Investigator	Dr Melanie Muniandy	Olga Tennison Autism Research Centre, School of Psychology & Public Health
Co-investigator	Dr Lauren Lawson	Department of Psychology, Counselling & Therapy, School of Psychology & Public Health
Co-investigator	Dr Megan Clark	Olga Tennison Autism Research Centre, School of Psychology & Public Health
Co-investigator	Adjunct Professor Amanda Richdale	Olga Tennison Autism Research Centre, School of Psychology & Public Health
Research Assistant	Charlotte O'Brien	Olga Tennison Autism Research Centre, School of Psychology & Public Health
Research funder	This research has received funding from La Trobe University.	

1. What is the study about?

You are invited to participate in a study exploring resilience and how autistic adults cope or recover from challenges and setbacks in life. Through the perspectives and experiences of autistic adults, we hope to understand what resilience means in the context of autism and identify key barriers, facilitators and areas of support that may promote resilience in the autistic adult population.

This project represents a vital step in furthering the understanding of resilience, with potential to inform the design of support options to alleviate the impact of stress on mental health and well-being in autistic adults. This has the potential to contribute towards improvements in quality of life and the reduction of burnout in autistic adults. Results from this project would allow the research team to build valuable connections within the autism community and clinical collaborators to aid in bridging the research to practice gap.

2. Do I have to participate?

Being part of this study is voluntary. If you want to be part of the study, we ask that you read the information below carefully and ask us any questions.

You can read the information below and decide at the end if you do not want to participate. If you decide not to participate this won't affect your relationship with La Trobe University or any other listed organisation.

3. Who is being asked to participate?

You have been asked to participate because:

- You are an adult aged 18 years and older
- You have a formal diagnosis of autism
- You have no diagnosis of an intellectual disability
- You are fluent in English
- You are based in Australia

4. What will I be asked to do?

If you want to take part in this study, we will ask you to provide some demographic information, such as your age, gender and diagnoses. You will then be invited for an individual Zoom interview. The interview questions will centre around your thoughts and experiences of resilience, stressful and challenging events and their implications on your mental health, as well as key factors that may help or hinder resilience. All interviews will be video and audio recorded for transcription purposes, and will be destroyed after this. The interview session will take approximately 1 hour of your

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time. An AI will transcribe your interview audio and the transcriptions will be double-checked for accuracy by a researcher.

5. What are the benefits?

The study will help us further the current research and provide a more comprehensive understanding of resilience experiences in autistic adults. Findings from this study may also help develop an understanding of how to better support autistic adults from a stress and mental health perspective. As a thank you for participating in the study, you will receive a \$50 AUD e-voucher for your time.

6. What are the risks?

With any study there are (1) risks we know about, (2) risks we don't know about and (3) risks we don't expect. If you experience something that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns. We have listed the risks we know about below. This will help you decide if you want to be part of the study.

Conversations or interview questions surrounding resilience, especially in relation to experiences of stress and challenges may be uncomfortable or distressing for some individuals. Please note that it is up to you how much or little you would like to share with us. An overview of questions will be also be provided to you in advance.

If you experience any distress or feelings that you are not sure about after the session, please feel free to contact us using the contact information below so we can discuss possible ways to support you. Some members of our research team are registered or clinically trained psychologists and may be able to provide support if needed.

You can also seek support from one of the national helplines listed below:

- **Lifeline Australia** provides nationwide 24-hour telephone counselling on 13 11 14 (or live chat available through www.lifeline.org.au)
- **Beyond Blue** provides nationwide 24-hour telephone counselling on 1300 224 636 (or live chat available through www.beyondblue.org.au)
- **Sane Australia** provides a telephone and online counselling service operated by professionally qualified counsellors between 10am and 10pm Australian Eastern Standard Time, Monday to Friday on 1800 187 263 (www.sane.org/counselling-support)

7. What will happen to information about me?

The information gathered for the study will be used for research purposes. Results from this study are likely to be reported or published in a thesis, journal articles, research reports or conference presentations. Importantly, when findings of this study are shared, all personal details of participants remain confidential.

We will ask you to complete a demographic questionnaire using a secure database (REDCap). All participants will be allocated an ID number and this data stored on REDCap will be de-identified. Interviews will be digitally recorded for transcribing purposes and participants will be assigned pseudonym during this time. Upon transcription, all videos will be destroyed. Audio recordings will be kept for 7 years after the project is completed. After this time, we will destroy all of your data. All personal information on participants (including the list of ID numbers, pseudonyms and names) will be stored in an online, secure, password-protected folder, only accessible by authorised research team members.

The storage, transfer and destruction of your data will be undertaken in accordance with the [Research Data Management Policy](https://policies.latrobe.edu.au/document/view.php?id=106/) <https://policies.latrobe.edu.au/document/view.php?id=106/>.

The personal information you provide will be handled in accordance with applicable privacy laws, any health information collected will be handled in accordance with the Health Records Act 2001 (Vic). Subject to any exceptions in relevant laws, you have the right to access and correct your personal information by contacting the research team.

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8. Will I hear about the results of the study?

At the end of the interview, you will be asked if you would like to receive a brief summary of the study results once this is available. You will also be able to read about the results of this study on the Olga Tennison Autism Research Centre's blog (<http://otarc.blogs.latrobe.edu.au/>).

9. What if I change my mind?

You can choose to no longer be part of the study at any time until the interview data has been analysed (four weeks after data collection). If you withdraw, we will stop asking you for information and all identifiable information about you, such as your name and contact details, will be withdrawn from the research study. Should you choose to withdraw, you can contact us using the information below. A 'Withdrawal of Consent Form' will be provided to you to complete and return to us. Your decision to withdraw at any point will **not** affect your relationship with La Trobe University or any other organisation listed.

10. Who can I contact for questions or want more information?

If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
Melanie Muniandy – Olga Tennison Autism Research Centre	Postdoctoral Researcher	03 9479 1692	m.muniandy@latrobe.edu.au

11. What if I have a complaint?

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Position	Telephone	Email
HEC23230	Senior Research Ethics Officer	+61 3 9479 1443	humanethics@latrobe.edu.au

This information sheet is for you to keep.