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**Caring for a Young Person with an Eating Disorder**

**Chief Investigator:** Professor Maja Nedeljkovic, Swinburne University

**Co-Investigator:** Dr Jessica Mackelprang, Swinburne University; Ms Inge Gnatt, Swinburne University

**Student Investigator:** Ms Paige Davis, Swinburne University

**Introduction:**

You are invited to participate in a study being conducted by researchers at Swinburne University in partnership with Eating Disorders Families Australia. This study aims to explore the impact of caring for a young person with an ED in addition to caregivers’ needs and experiences. In developing a comprehensive overview, we anticipate that results from this study will inform the development and structure of an intervention for caregivers of young people with an eating disorder.

The participant information statement provides you with all the information on the research project. It explains what your participation in this project will involve, to help you decide whether you would like to take part. Please read this information carefully.

**Project and researcher interests**

This research project is being conducted by researchers at Swinburne University of Technology in partnership with Eating Disorders Families Australia and does not have any specific funding. The project will also form part of the student investigators thesis, to meet the requirements of their Doctor of Philosophy (Clinical Psychology) thesis by publication.

**What does participation in this research involve?**

*Eligibility:*

You are eligible to take part in this research project if you:

* Are aged 18+ years old
* Are able to read English
* Identify as the caregiver of a young person (25yrs or younger) with a current or past eating disorder diagnosis

*Procedures:*

* If you agree to participate, you will asked to fill out an online survey that should take no longer than 45 minutes to complete. This can be completed at a place, date, and time suitable to you. You will be asked to respond to basic questions regarding your demographics (e.g., age, gender, relationship to the affected individual), and to provide basic clinical information regarding your young person (e.g., age, gender, clinical diagnosis). The online survey will also involve a series of measures and questions exploring your experience as a caregiver, the impact of caregiving, and your needs as a caregiver. Upon conclusion of the survey, there will be the opportunity for you to enter your email address to be contacted regarding a follow-up interview and/or trialling the intervention should you be interested.

**Participant rights and interests – Possible benefits to participants**

There will be no direct benefit to you from your participation in this research. Participation may give you the opportunity to reflect on your experience. Findings may also be beneficial in advancing our knowledge and understanding of the caregiving experience and we also anticipate that the findings will help inform the develop of an intervention for caregivers of young people with an eating disorder.

**Participant rights and interests – Possible risks to participants**

Due to the personal nature of some questions (e.g., ‘what degree of impact has caring for the young person had on these areas of your own life? e.g., wellbeing, mental health’), there is a possible risk of psychological discomfort or distress. As such, you may feel that some questions we ask are stressful or upsetting. If you believe answering these questions is likely to cause you any discomfort, you may choose not to participate in this research. If you become uncomfortable during your participation, **it is important to remember that you can withdraw from the study at any time**, with no consequences at all. You may also contact the researchers or the independent support services listed on this project for additional support.

**Participant rights and interests – Free consent/withdrawal from participation**

Participation in this study is completely voluntary. You are not under any obligation to participate and your choice to participate or not will have no impact upon your future or current relationship with Swinburne University, Eating Disorders Families Australia, or the researchers listed on this application. If you agree to participate, you can withdraw from the study at any time. To withdraw from the study, you may simply discontinue participating or close the web browser. However, please note that due to the anonymous nature of the survey, data collected up to the time you withdraw will be retained and may form part of the research project results.

**Participant rights and interests – privacy and confidentiality**

All data collected in this study will remain anonymous and stored on password-protected computers and on password protected OneDrive university servers. Anonymous data will be securely retained for an indefinite period and may be shared with other researchers as part of the Open Science Framework designed to advance knowledge and understanding. It is important to emphasise that the data collected is anonymous and cannot be linked to any specific individual.

**Research output**

Data gathered and obtained from this survey may be published in academic journals, presented at academic conferences and seminars, summarised at community and training forums/ workshops, and used in future masters and/or honours students research projects. This data will also form part of the student investigators Doctor of Philosophy (Clinical Psychology) thesis by publication.

Participants will have access to a summary of the results of this project on request. To request this information and/or be contacted regrading further research, you may email [paigedavis@swin.edu.au](mailto:paigedavis@swin.edu.au).

**Further information about the project– Who to contact?**

For further information about the project, please do not hesitate to contact either:

**Professor Maja Nedeljkovic,** Chief Investigator

Department of Psychological Sciences, Swinburne University of Technology

Email: [mnedeljkovic@swin.edu.au](mailto:mnedeljkovic@swin.edu.au)

Tel No: (03) 9214 4428

**Ms Paige Davis,** Student Investigator

Department of Psychological Sciences, Swinburne University of Technology

Email: [paigedavis@swin.edu.au](mailto:paigedavis@swin.edu.au)

**Support Services**

If you feel you need extra support after participating in this study, participants **within Australia** may contact:

* [**Lifeline**](https://www.lifeline.org.au/) – 24/7 crisis support and suicide prevention service to all Australians experiencing emotional distress.

Phone: 13 11 14

Online Chat: <https://www.lifeline.org.au/crisis-chat/>

Text Support: 0477 13 11 14

* **Beyond Blue** – 24/7 mental health support

Phone: 1300 224 636

Online Chat: <https://www.beyondblue.org.au/support-service/chat>

* **Suicide Call Back Service** – 24/7 phone and online counselling to people affected by suicide.

Phone: 1300 659 467

Online Chat: <https://www.suicidecallbackservice.org.au/phone-and-online-counselling/>

* **Butterfly National Helpline** – 8am to midnight (AEST), 7 days a week. Free phone, email, and web support and referral for individuals experiencing an eating disorder, carers, and professionals.

Phone: 1800 33 4673

Online Chat: <https://butterfly.org.au/get-support/chat-online/>

* **Eating Disorders Families Australia** – National organisation providing support, education, and advocacy services for carers and families impacted by an eating disorder.

Phone: 1300 195 626

Website: <https://edfa.org.au/>

* **Eating Disorders Victoria** – A Victorian organisation that offers services to individuals affected by eating disorders, as well as the families, communities, and professionals that support them.

Phone: 1300 550 236

Website: https://www.eatingdisorders.org.au/

* **Local Health Services** – See your GP for support or to seek a referral to a counsellor or psychologist (this may result in out-of-pocket costs).
* **Appointments for counselling** are also available at the Swinburne Psychology Clinic for a low cost at the Hawthorn campus George Swinburne (GS) Building, 34 Wakefield Street, Level 4. Phone: (03) 9214 8653

Participants located **outside of Australia** may refer to this website for support:

* [www.befrienders.org](http://www.befrienders.org)

If you are experiencing distress and require immediate medical attention, please contact your local emergency services (e.g., 000 for Australia).

**Concerns/complaints about the project – who to contact:**

This project has been approved by or on behalf of Swinburne’s Human Research Ethics Committee (SUHREC) in line with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the conduct of this project, you can contact:

Research Ethics Officer, Swinburne Research (H68), Swinburne University of Technology, P O Box 218, HAWTHORN VIC 3122. Tel (03) 9214 5218 or +61 3 9214 5218 or [resethics@swin.edu.au](mailto:resethics@swin.edu.au)

By clicking next, you indicate that you consent to participate in the project outlined above. You acknowledge that you have been provided a copy of the Explanatory Statement. **It is important to remember, you are free to discontinue the survey at any time with no consequence to your relationship with the researchers, Swinburne University of Technology, or Eating Disorders Families Australia.**