

Feasibility of Care4Carers: A Mindful Parenting Program for Caregivers of Children with  
22q11.2 Deletion Syndrome

Sascha Swanson BPsych (Hons)

This thesis is presented in partial fulfilment of the requirements for the degree of Master of  
Clinical Psychology, School of Psychology, The University of Newcastle, Australia.

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## **Declarations**

### **Statement of Originality**

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library\*, being made available for loan and photocopying subject to the copyright Act 1968.

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### **Acknowledgement of Collaboration**

I hereby certify that the work embodied in this thesis has been done in collaboration with other researchers. I have included as part of this thesis a statement clearly outlining the extent of collaboration, with whom and under what auspices.

Associate Professor Linda Campbell and Doctor Saja Duijff developed and delivered the Care4Carers program. They both contributed to the research design, ethics application and collection of demographic and attendance data. Associate Professor Linda Campbell additionally provided feedback on the qualitative analysis and written manuscript.

I contributed to the development of the research question and database search. I conducted interviews with participants, conducted thematic analysis of qualitative data and prepared the original manuscript.

Mackenzie Matthews assisted with transcription of recorded interviews.

Sascha Swanson (Research Student)

Date: 03.03.2023

Associate Professor Linda Campbell (Primary Supervisor)

Date: 03.03.2023

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I thank the parents who generously took time away from significant caregiving responsibilities and busy schedules to participate in interviews. Their willingness to share their honest thoughts, feelings, experiences, and challenges with a total stranger via video call allowed for collection of rich and informative data. Without them, this research would not have been possible.

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Sascha E. Swanson<sup>a</sup>, Linda E. Campbell<sup>a</sup> & Sasja N. Duijff<sup>b</sup>

<sup>a</sup> The School of Psychological Sciences, The University of Newcastle, Australia.

<sup>b</sup> Centre for Mindfulness, Radboud University Medical Centre, The Netherlands.

**Author Note**

Correspondence concerning this article should be addressed to L. E. Campbell, The University of Newcastle, University Drive, Callaghan, NSW, Australia, 2308. Email: [linda.e.campbell@newcastle.edu.au](mailto:linda.e.campbell@newcastle.edu.au).

This research was approved by the Human Research Ethics Committee (HREC) at the University of Newcastle (H-2022-0038) (see Appendix A) and was carried out in accordance with the World Medical Association Declaration of Helsinki. The authors declared no conflicts of interest with respect to the authorship and publication of this article.

This manuscript is for submission to the Journal of Child and Family Studies. See Appendix B for the submission guidelines of this journal.



### Abstract

Parenting a child with special healthcare needs is associated with significant caregiver stress. Previous research has found that parenting stress and mental health impacts on outcomes for children with chronic illnesses. Despite this, the importance of managing parents' stress is often overlooked in the management of chronic health conditions, such as 22q11.2 deletion syndrome (22q11DS). There is evidence to suggest that providing mindfulness training to parents not only reduces parental stress but can also lead to improvements in child behaviour. This study was designed as a non-randomised feasibility pilot study evaluating a mindful parenting program Care4Carers, specifically designed for those parenting a child with 22q11DS. There were 20 participants recruited to take part, which involved attending online group sessions for 2.5 hours for 8 weeks and practice exercises between sessions. Interviews were conducted with 12 participants after the completion of the program. Using attendance data and thematic analysis of semi-structured interviews, the study aimed to determine if the program Care4Carers would be experienced by participants as feasible and acceptable. Results indicate preliminary evidence of feasibility and acceptability, with adequate retention and themes emerging from interviews highlighting appropriateness of content, delivery and perceived benefits including personal growth, peer support and enhanced coping. 'Barriers to engagement' was also a theme, and possible adjustments are discussed based on participant feedback to further enhance the program. Further research using quantitative measures is required to confirm findings and investigate effectiveness.

*Keywords:* mindful parenting, 22q11.2 Deletion Syndrome, caregiver stress, parenting, special healthcare needs

#### Highlights:

- Delivering a mindfulness-based intervention online is feasible and acceptable to parents of children with 22q11.2 Deletion Syndrome.
- Parents found participating in the mindful parenting group program beneficial, describing lasting experiences of personal growth, peer support and enhanced coping.
- The Care4Carers program should be further tested for evidence of effectiveness, as there is clear need for interventions to reduce stress for parents of children with conditions such as 22q11.2 Deletion Syndrome.