



# Caring for People with Dysphagia Post-Stroke: The Impact on Quality of Life and Support Needs

## Information Sheet

My name is Emily Edgecombe, and I am an honours student in the Bachelor of Speech and Language Therapy Programme at Massey University. I would like to invite you to participate in my research project. My project will explore the impact of caregiver experiences on quality of life for primary non-paid caregivers (e.g., family/whānau members, neighbours, friends, and significant others) of people with dysphagia (swallowing disorder) from stroke in New Zealand. My project will also explore the support needs identified by caregivers. The findings of this research will contribute to a growing body of literature. This will raise awareness of the lived experiences of non-paid caregivers of people with dysphagia and improvements that can be made to accommodate for these caregivers' support needs.

This project is being overseen by Dr Mershen Pillay and Dr Sally Clendon, senior lecturers in the Massey University Speech and Language Therapy Programme.

### Project Eligibility

You will be eligible to complete the survey if you meet the following criteria:

- You do not receive financial compensation for your role as caregiver.
- You are the primary provider of care for a person with dysphagia (i.e., you provide the majority of daily cares such as preparing modified diets).
- The person with dysphagia whom you care for acquired dysphagia due to a stroke.
- The person with dysphagia whom you care for does not have any co-occurring conditions that contribute to their care (e.g., dementia).
- You and the person with dysphagia reside in New Zealand.
- The person you care for was diagnosed with dysphagia by a speech-language therapist or other qualified professional.

### Project Procedures

This study will involve the completion of an anonymous online survey which will require you to respond to questions relating to demographics; impacts on quality of life; current knowledge and practices; and future support needs. Completion of the survey is expected to take approximately 15-25 minutes; however, individual times may vary depending on the depth of the answers provided.

There is a possibility that questions in the survey may induce emotional stress. Therefore, it is recommended that you contact a family/whānau member, kaumātua or support person if required. You will also be able to decline responding to questions that may cause upset.

Completion of the survey, and submission of your responses, implies that you consent to your responses being used in the research project. No identifying information will be collected from participants and responses will remain anonymous in order to maintain privacy and confidentiality. Once you have submitted your responses, it will not be possible to delete or amend your information due to the anonymous nature of the survey.

Electronic data will be stored on password protected devices. The data will be stored for no longer than five years following the completion of this project. After that period, the University confidential waste service will be used to destroy any printed materials.

When the project is finished, the results will be presented in my Honours report. Results may also be presented at conferences or published in journal articles.

### Your Rights

In following ethical procedures for research, I reassure you that you are under no obligation to consent to participate in this study. If you decide to participate, you have the right to:

- Decline responding to any questions that make you feel uncomfortable.
- Contact the research team with any questions regarding the study
- Be given access to a summary of the project findings when it is concluded – email your request to Sally Clendon at [s.clendon@massey.ac.nz](mailto:s.clendon@massey.ac.nz)

### Survey Link

If you are interested in being involved in this project, you can complete the anonymous online survey by following this link:

[https://massey.au1.qualtrics.com/jfe/form/SV\\_6FndKdwZMfPP0IC](https://massey.au1.qualtrics.com/jfe/form/SV_6FndKdwZMfPP0IC)

### Contact Information

Thank you for taking the time to consider this request. Should you have any questions regarding the study please contact:

Emily Edgecombe (Researcher) <a href="mailto:Emily.Edgecombe.1@uni.massey.ac.nz">Emily.Edgecombe.1@uni.massey.ac.nz</a>	Dr Mershen Pillay (Topic Advisor) <a href="mailto:M.Pillay@massey.ac.nz">M.Pillay@massey.ac.nz</a>
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### Low Risk Notification

This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Prof Craig Johnson, Director, Research Ethics, telephone 06 356 9099 x 85271, email [humanethics@massey.ac.nz](mailto:humanethics@massey.ac.nz).