



## **INVITATION TO PARTICIPATE IN A RESEARCH PROJECT**

### **PROJECT INFORMATION STATEMENT**

**Project Title:** The impact of fatigue on parent/s with a child with special needs (disability or chronic illness).

Dear Parent,

You are invited to participate in a research project being conducted by University of Ballarat and the Parenting Research Centre (PRC). This information sheet describes the project in plain, simple language. Please read this sheet carefully and be confident that you understand its contents before deciding whether to participate. If you have any questions about the project, please ask one of the investigators.

#### **Who is involved in this research project?**

The study is being undertaken by Brooke Slater as part of a Masters of Psychology program. The project is being supervised by Dr Louise Hayes through the School of Behavioural Social Sciences and Humanities, University of Ballarat, and Dr Rebecca Giallo through the Parenting Research Centre. This project is being supported by the Parenting Research Centre.

#### **Why have you been approached?**

As a parent of a child with a disability or chronic illness you have been approached to participate in this study.

#### **What is the project about? What are the questions being addressed?**

The aim of this project is to report on parents' experiences of fatigue while raising children with a disability or illness. We are interested in parents' need for information and support to manage fatigue. This project will help us to identify how we can best support parents of children with a disability or chronic illness.

#### **If you agree to participate, what will you be required to do?**

If you agree to participate in this project, you will be asked to complete a survey which will take approximately 30 minutes. This survey will ask questions about your family background, your experiences as a parent, your sleep, and experience of fatigue. You will not be required to complete a consent form, as your consent will be implied when you return the survey. You can opt to complete a hardcopy of the survey, and return it in a reply paid envelope provided, or you can complete it online (see information below about the website security).

#### **What are the risks associated with participation?**

Risks of participation to you are low. While unlikely, the completion of the questionnaire may cause you minimal concern. If you are unduly concerned about your responses to any of the questionnaire items or if you find participation in the project distressing, you should contact Dr. Louise Hayes as soon as convenient. Dr Louise Hayes will discuss your concerns with you confidentially and suggest appropriate follow-up, if necessary. Alternatively, you can ring the Parentline 132055 or 1300301300 should you need further support.

### **What are your rights as a participant?**

Your participation in the project is highly valued. However, your participation is completely voluntary and there is no obligation for you to take part. Whilst completing the survey, you can withdraw from the project at any time. However, the survey is anonymous so it will not be possible to remove it if you decide not to participate after completion.

### **What will happen to the information you provide?**

As your name, date of birth, and contact details are not collected in the survey, it will not be possible for you to be identified from the information that you provide. All surveys collected throughout this study will be kept in a locked filing cabinet (hardcopy) or password protected (electronic), accessible only to the researchers. Only group results will be reported in the student report and any subsequent publications or presentations. It will not be possible to identify individuals. All survey data will be kept for a period of five (5) years, after which it will be destroyed.

### **Security of the data**

No personal information will be collected in the survey so none will be stored as data. This project will use an external site, SurveyMonkey.com, to create, collect and analyse data collected in a survey format. Once we have completed our data collection and analysis, we will import the data we collect to the University of Ballarat and Parenting Research Centre servers where it will be stored securely for a period of five (5) years. The data on the SurveyMonkey.com host server will then be deleted and expunged.

### **Who should you contact if you have any questions?**

If you have any questions or you would like more information please call or email Dr Louise Hayes (0423 770 975, Email: [l.hayes@ballarat.edu.au](mailto:l.hayes@ballarat.edu.au))

**Yours sincerely,**

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**Dr Louise Hayes**  
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**Dr Rebecca Giallo**  
**BSci (Psych)(Hons), PhD**  
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Should you (i.e. the participant) have any concerns about the **ethical** conduct of this research project, please contact the Executive Officer, Human Research Ethics Committee, Research & Graduates Studies Office, University of Ballarat, PO Box 663, Mt Helen VIC 3353. Telephone: (03) 5327 9765, Fax: (03) 5327 9602, Email: [ub.ethics@ballarat.edu.au](mailto:ub.ethics@ballarat.edu.au)