PARENT/GUARDIAN INFORMATION SHEET

Ongoing Pain in Young People with Cerebral Palsy

You and your child are invited to participate in the research project described below.

What is the research about?

This research is about pain in cerebral palsy (CP). Three out of four children with CP experience ongoing pain. For this study ongoing pain is defined as pain lasting 3 months or more and is not pain from recent surgery or recent injury.

In other conditions pain can have a major impact on wellbeing and ability to participate in activities. But in CP, the impact of pain is not well understood. We would like to discover more about the impact of pain on the daily activities of young people with CP and how they cope with pain.

The results of this research may help guide clinicians in the identification and treatment of pain in children with CP. The results will be shared with disability service providers to show the needs of young people with CP in regard to pain management

Who is undertaking the project?

This research is being conducted by Ella Anderson-Mackay and Letisha Carozza. We are undergraduate students selected to do honours in the Bachelor of Physiotherapy degree at The University of Notre Dame. Our supervisors are Alison Kirkman, Jin Ou, Dr Marie Blackmore, Nadine Smith and Prof Sarah Love.

What will my child and I be asked to do?

If you consent to take part in this research study, you will be asked to complete a single survey. It will take about 20 minutes.

There are two options for completing the survey:

1. Your child may complete the survey under your supervision. You may physically enter your child's answers if your child is unable to do so.
2. You may complete the survey on behalf of your child if your child is unable to do so independently.

You can complete the survey online via clicking the link in the email you have been sent from Ability Centre.

Alternatively, you may have been asked to complete the survey in the wait room of an Ability Centre clinic.

What are the benefits of the research project?

There are no direct benefits of this research to your child, but you will be providing us with valuable insight into this under-investigated issue. The information you provide may be used to help improve the experience of pain in other young people with CP.

The results of this study may help to advocate for and direct consumer-directed services for young people with CP with pain.

Are there any risks associated with participating in this project?

There are no significant risks in completing the survey.

If you or your child do become upset or anxious during the survey, please feel free to contact Nadine Smith (Senior Physiotherapist) on 6456 0218 who will refer you on to the appropriate services.

Do I have to participate?

No. Participation in this study is completely voluntary. Even if you begin the survey, you are free to withdraw by simply not submitting it. However, once you complete the survey and submit it back to us, you will not be able to withdraw your response because we will have no way of knowing which one is yours. Although this study is being conducted through Ability Centre, it is separate from Ability Centre's services. Therefore, whether you decide to take part or not will not affect the services you receive from Ability Centre.

What will happen to the surveys?
Completed surveys will be stored securely on a computer with a password known only to the research team. Paper surveys will be stored in a locked cabinet. Only the researchers will have access to this information during the project. The surveys will remain non-identifiable.

Once the study is completed, the survey information will be stored securely in the School of Physiotherapy at The University of Notre Dame Australia for at least a period of seven years. The data may be used in future research but you will remain completely anonymous.

The results of the research project will be published as an honours research paper.

Will we able to find out the results of the project?
The results of this research will be reported back to Ability Centre via in infographic for parents and clinicians by the end of 2020. This will be put on the Ability Centre website and social media.

Who do we contact if we have questions about the project?
If you have any questions about this research, please feel free to contact Letisha Carozza at 20170516@my.nd.edu.au or Ella Anderson-Mackay at 20170565@my.nd.edu.au. We are happy to discuss with you any concerns you may have about this study.

What if we have a concern or complaint?
The study has been approved by the Human Research Ethics Committee at The University of Notre Dame Australia (approval number 019168F). If you have a concern or complaint regarding the ethical conduct of this research project and would like to speak to an independent person, please contact Notre Dame's Ethics Officer at (+61 8) 9433 0943 or research@nd.edu.au. Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

How do we sign up to participate?
If you or your child are happy to participate, please click on the following link to the attached survey, complete the survey and submit it by clicking 'Submit'.

For children (aged 8-12), or child with parent assistance:
https://www.surveymonkey.com/r/childCP
For teens (aged 13-18), or teen with parent assistance:
https://www.surveymonkey.com/r/teenCP
For parents, without child input:
https://www.surveymonkey.com/r/parentCP

Thank you for your time. This sheet is for you to keep.

Ella Anderson-Mackay (Honours student, School of Physiotherapy, the University of Notre Dame),

Letisha Carozza (Honours student, School of Physiotherapy, the University of Notre Dame),

Alison Kirkman (Physiotherapist, Senior Lecturer, University of Notre Dame),

Jin Ou (Senior Physiotherapist, Ability Centre),

Dr Marie Blackmore (Research Coordinator, Ability Centre),

Nadine Smith (Senior Physiotherapist, Perth Children's Hospital) and,

Prof Sarah Love (Physiotherapist, Dean of the School of Physiotherapy, University of Notre Dame)