

# What do I need to know?

- Information for kids and teens



## Ongoing Pain in Young People with Cerebral Palsy

Hello,

We are a team of people (researchers) who would like to learn more about pain in kids and teens with Cerebral Palsy (CP). We are asking you to be in our study because you are a young person with CP who may have ongoing pain. This is pain lasting 3 months or more and is not pain from recent surgery or recent surgery. Pain can make it harder for you to do the activities that you love, like playing with your friends or playing a sport. There may be things you do when you feel pain, for example by asking for help or thinking about happy things. These are ways of coping with pain.

To be a part of this study all you need to do is fill in a survey. This sheet will help you decide if you would like to answer the questions. You can talk to your parent, guardian or carer about it. If you have any questions for us you can email Letisha Carozza on 20170516@my.nd.edu.au or Ella Anderson-Mackay on 20170565@my.nd.edu.au.

### What are the good things about being in the study?

1. You won't get anything for being in the study, but you will be **helping other people with CP** by sharing what you know and your experience.
2. You will be **helping us** do our research. We will be able to find out what activities you find most difficult to do because of your pain.
3. This will **help therapy services like Ability Centre** to plan ways of helping young people like you who have pain.
4. This will also **help other researchers like us** find out how activities can be made easier or less painful for young people like you. We will learn how kids and teens with CP cope with pain. Some ways of coping are better for helping pain than other ways. If we know what you do, then other researchers can see if this could be helpful for other kids with CP.

## What will I be asked to do?

If you say yes, we will ask you to answer questions in one survey with the help of your parent/guardian/carer:

1. Click on the link in the email from Ability Centre at the bottom of this page to open the online survey
2. Read the message about 'Consent' that will appear on your screen. Giving your consent means that you are happy for us to see the answers in the survey.
3. Answer the questions truthfully about your pain in the survey. (It will take you about 20 minutes to complete).
4. Finish the survey by clicking 'Submit'.

Please try to answer all the questions. If you don't want to share some information, that's okay. If you decide you want to be in the study and then change your mind, that's okay. You don't have to submit the survey if you don't want to. Once you've submitted it, you can't change your mind, because we won't know which survey was yours.

## Will anyone else know what I say in the study?

The survey will be anonymous. This means that only you and your parent/guardian/carer will know that your answers belong to you. We will not know who is answering the questions. We don't even ask you your name. Whether you decide to do the survey or not will not affect the services you get from Ability Centre. All of the information that you tell us will be stored in a safe locked place and we will look after it very carefully. We will write a report about the study and show it to other people but only you will know that your answers were included in the report. No one will know that you were in the study unless you choose to tell them.

## Are there any bad things about being in the study?

This study will take up some of your time (about 20 minutes). It might feel hard to be asked to think about pain or things that hurt. If the questions make you feel sad or anxious, please ask your parent or carer to contact Nadine Smith (Senior Physiotherapist) on 6456 0218. You can call this number yourself if that's easier for you.

## Will we be able to find out the results of the project?

Yes. At the end of 2020, we will give the results to Ability Centre to be posted on their website and on social media, so that you can see what we found.

If you are a child aged 8 - 12 click on the link below to complete the survey with parent supervision or help:

<https://www.surveymonkey.com/r/childCP>

For teens (aged 13-18) with parent supervision, or teens with parent assistance:

<https://www.surveymonkey.com/r/teenCP>

For parents, without child input:

<https://www.surveymonkey.com/r/parentCP>

Thankyou,  
Ella Anderson-Mackay,  
Letisha Carozza,  
Alison Kirkman,  
Jin Ou,  
Dr. Marie Blackmore,  
Nadine Smith and,  
Prof. Sarah Love

Honours student, School of Physiotherapy, University of Notre Dame  
Honours student, School of Physiotherapy, University of Notre Dame  
Physiotherapist, Senior Lecturer, University of Notre Dame  
Senior Physiotherapist, Ability Centre  
Research Coordinator, Ability Centre  
Senior Physiotherapist, Perth Children's Hospital  
Physiotherapist, Dean of School of Physiotherapy, University of Notre Dame