

Participant Information Sheet – child

Eat, Sleep, Play – CP: A study on what we eat and how healthy our bodies are

It is OK to say no

Introduction

We know that what we EAT, how well we SLEEP, and how much we do (PLAY), can be important for giving us energy throughout the day, supporting a healthy body weight and for building strong bones. But did you know that the combination of how and what we EAT, and when we SLEEP and PLAY could help even more? This might be especially important for children with cerebral palsy, who may use up the energy that they get from food in different ways, may have trouble sleeping, and who may find particularly activities be harder to complete.

You are reading this sheet because you have cerebral palsy, and because you might be interested in taking part in our study at the University of Auckland. This sheet explains a research study called “Eat, Sleep, Play”, and what would be involved if you decided to take part.

We hope that by learning more about children with cerebral palsy, we can help to give better advice to other children and their families about what kinds of food they should be eating (EAT) around the times that they SLEEP and PLAY to support good health, a healthy body weight and for building strong bones.



EAT

A STUDY ON WHAT WE EAT AND HOW
HEALTHY OUR BODIES ARE



SLEEP



PLAY

What would be involved if you decide to take part?

If you join our study, we will ask you to:

- Complete a diary of what you eat for three days,
- Help your parent/caregiver answer some questions about your health, how you sleep and play, and
- Complete a body scan (called a DXA -pronounced “decsa” scan) that will tell us about how much muscle and fat you have, as well as how strong your bones are. The scan takes around 10 minutes, and you will need to lie still on a bed.

We will ask you to do this **two times**, around 3 months apart. After your first visit with us, we will give you some tips on how you might want to ‘**Eat, Sleep, and Play**’ differently to help your health. We will talk this through with you and your parent/caregiver so that, all together, we can think about ways to do this that suit you. We then won’t see you again until the second visit that will be 3 months later, but in between we will check in with you (probably over the phone) to see how you are going and to see if you have any questions.

Within this study, we will always explain to you what we are doing, and what is coming next. We will also answer as many questions about the study that you can think of!

When the study is over, you will get a certificate to thank you for being in the study- as well as a copy of your results. We will use the information we learn about you, and combine it with other information we learn from other children. We will replace your names with a special code, so no-one will be able to tell that it was you.

Are there any **bad** things that could happen if I take part?

We will ask you to attend the University of Auckland twice, and to allow around an hour and a half each time (though you will likely only take 1 hour). You will be safe during your visits with us at the University, and you will be able to have a parent/caregiver with you during the whole visit.

The DXA scan is like having an x-ray. But the radiation is much lower than an x-ray. In fact, it is one thousandth of all the background radiation you get from one year living in New Zealand (that's a very small amount!). Some people might get worried about the DXA scan being noisy or scary, but it is actually very quiet, and it will be like you are lying on flat bed with a pillow. You will be able to talk to us while you are having the scan so if you get worried, we can help you by talking you through it. You won't feel anything.

Are there any good things that could happen if I take part?

Most of the “good things” that could happen as part of this study will be about helping other children with cerebral palsy by helping us (health researchers, doctors and nutritionist’s) learn more about what could be best for children with cerebral palsy.

But, being in the study could help you learn a lot of new things about your body and how you eat, and this could help you to become healthier and have more energy. As part of the body scan, we will also give you the report, which some kids find quite cool to see what their bodies look like in scan! See the picture → to see what it might look like – and we can help explain what it all means.

You can STOP doing the study at any time.

All you have to do is tell us, or your parent / caregiver that you don't want to do the study anymore- and you can tell us at any time! That means that even if you are halfway through your scan we can press STOP. If you STOP doing the study, nothing bad will happen to any of your regular appointments with other doctors, or therapists. Nobody will be mad with you if you say you want to stop.

Who do I contact for more information or if I have concerns?

If you need more information, you can talk to your mum or dad, or caregiver. You can also talk to us at any time to ask us as many questions that you may have about the study. We will give your parent/caregiver our information so that they can contact us.

Thank you from the **Eat, Sleep, Play- CP** Team!



Maggie (left) and Rebecca (right) are Nutritionists who are completing their Masters research project on the **Eat, Sleep, Play- CP** study to become Dieticians. You will meet both girls through the study as they help you to complete your assessments!

Have you got any questions? Want to get in touch?

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