



Peer support after brain injury

PARTICIPANT INFORMATION SHEET

Invitation

Kia ora

You are invited to take part in research aiming to explore if being supported by someone who has had a brain injury would be helpful for you.

This information sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your taking part would involve, what the benefits and risks to you might be, and what will happen after the study ends. We appreciate your time reading this material.

Please consider:

- Taking part in this study is entirely voluntary—it is your choice. You do not have to take part.
- If you don't want to take part you don't have to give a reason, and it won't affect your rehabilitation services.
- If you do agree to take part, you can change your mind later and pull out at any time.

You do not have to decide today whether or not you will take part in this study.

Before you decide you may want to look at our short videos [see below for links] and talk about the study with other people, such as your family, whānau, friends, or healthcare providers.

We will go through this information with you and answer any questions you have.

If you agree to take part in this study, you will be asked to sign the Consent Form at the end of this document.

See the Video here:

<http://bit.ly/PCR-peer-support-after-tbi>

The study is being carried out by researchers based in the Centre for Person Centred Research at Auckland University of Technology



Principal investigator

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**GISBORNE
TAIRĀWHITI
SERVICE COORDINATOR**

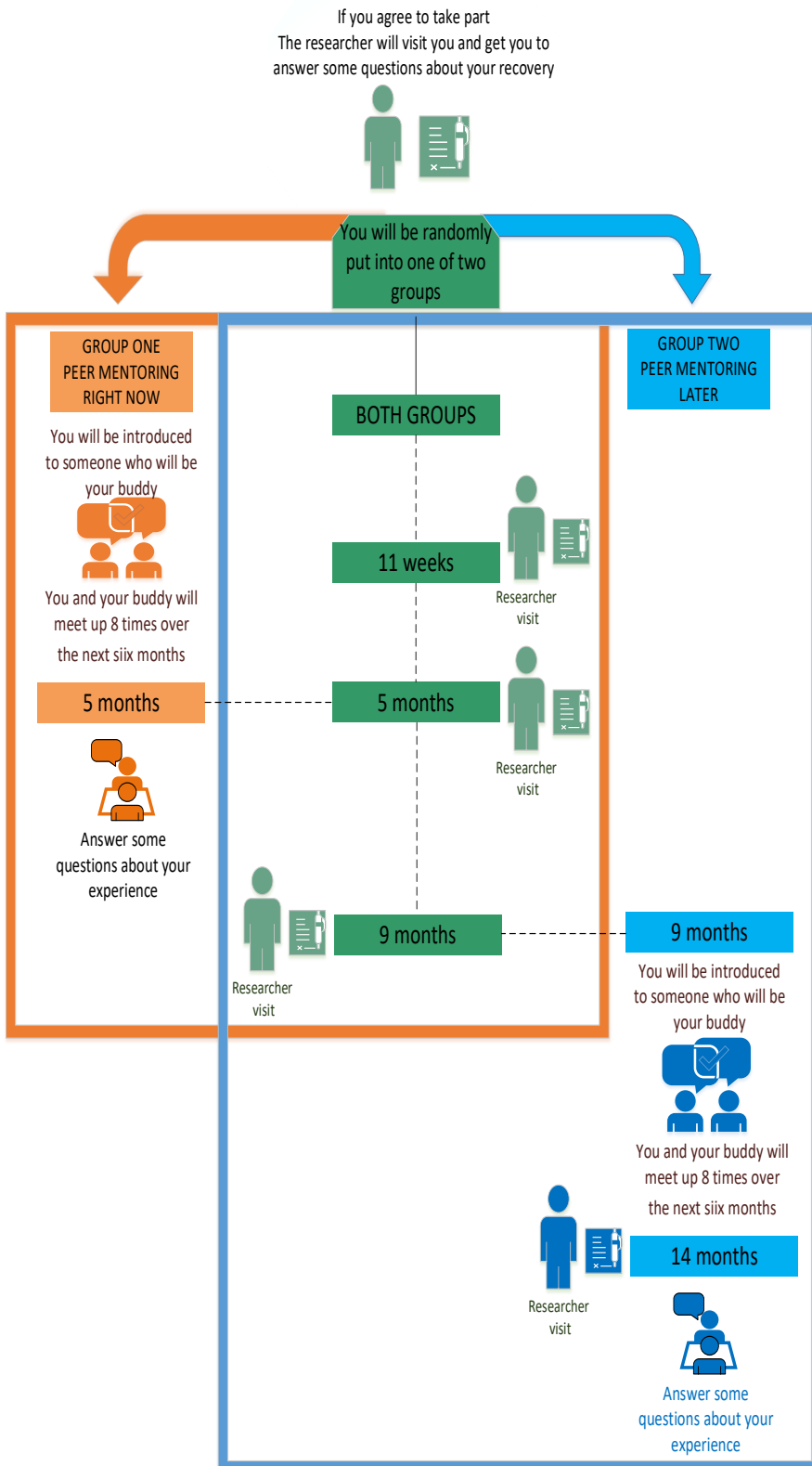
Kathy Gott
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This study is funded by the Health Research Council of New Zealand and has been approved by the Health and Disability Ethics Committee [19/NTB/82 June 2019]

WHAT IS THE PURPOSE OF THIS STUDY?

When people come home following rehabilitation after head injury they can sometimes find it hard to make sense of their recovery and to take part in activities that are important to them. People can sometimes find talking to someone who has had a similar experience about what worked for them, and what didn't, can be helpful. We call this peer mentoring. However, we don't know for certain if peer mentoring really makes a difference to people's recovery. We want to find out if peer mentoring makes a difference to how people recover from head injury.

WHAT HAPPENS IN THIS STUDY?



Who is a mentor?

A mentor (or buddy) is someone who has experienced a head injury in the last six years. People who take on the role of buddy in this research will have had some training in sharing their experiences of recovery and providing support to others with head injury.

Who is able to take part?

You can take part if:
You have experienced a **moderate or severe** traumatic brain injury (TBI),
And it has been no more than 3 years since your injury.

OR

You have experienced a **mild** traumatic brain injury (mTBI) and you are still experiencing symptoms that affect your daily life,
And it has been at **least 6 months** and no more than 3 years since your injury.



What kind of meet ups will we have?

Mostly you will meet face to face (kanohi ki te kanohi) with your buddy but sometimes you or your buddy may decide instead to meet by telephone or video calling.

WHAT KINDS OF QUESTIONS WOULD I BE ASKED?

We want to find out if peer mentoring makes a difference to how people recover from head injury and so we will be asking you questions related to your recovery. This will include questions about your participation, health and well-being. All the questionnaires will be anonymous.

At the end of the study, we may also invite you to take part in a more in-depth interview to learn more about your experiences of peer mentoring. We would like to record the interview so the researcher can listen to you without having to take notes.

We will also ask your permission to collect some health information from your health provider or funder. We will only ask for details about your injury such as the date of your injury, what happened at the time of injury, and how severe your injury was.

We are also interested in seeing if peer mentoring makes a difference to the health services you use. With your permission, we will ask for information from the Ministry of Health's national health data collections to look at how many times you have needed to use these services and any medications you may have been prescribed.

CAN MY FAMILY BE INVOLVED?

You may want to ask your family, whānau or other support person to join you for your mentoring sessions. Or they may wish to meet up with your buddy to learn about their experiences. This is your choice.

At the end of the study we may ask if your family member would like to take part in an interview and share their thoughts about peer mentoring with us.

WHAT ARE THE BENEFITS AND RISKS OF TAKING PART?

There will be no changes to any aspects of your care or rehabilitation if you decide to take part.

We hope you find the sessions with your buddy helpful. You may find the planning and taking part in activities tiring. This is common for people with head injury. Your buddy will ensure that the sessions go at your pace and will vary the length of the sessions if required.

You may find some of the questions we ask challenging. You can have support from your family, whānau or a friend when answering them. The researcher will go at your pace giving you breaks when you need them. You can choose not to answer questions if you do not wish to.

At the end of the study you may want to become a buddy to someone else. We will ask you about that when the time comes.

If we find this kind of support useful for people after traumatic brain injury, ACC are willing to offer this mentoring approach to everyone after a moderate or severe traumatic brain injury throughout the country.

How much time is involved?

This study involves us keeping in touch with you for between 9 and 15 months.

For the peer mentoring you will see your buddy up to 8 times over 5 months. Each session will take about an hour but that can be decided between you and your buddy.

Over the 9 - 15 months a researcher will visit you 4 to 5 times to complete a questionnaire. Filling out the questionnaire will take about one hour each time.

If you take part in an interview at the end of the study, that will take approximately an hour.

Is there any cost involved?

The only cost to you will be your time.

If you incur any travel expenses to meet a member of the study team outside of your home, we will reimburse you in the form of petrol vouchers.

WHAT ARE MY RIGHTS ?

Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive.

You have the right to access information we collect about you as part of the study.

If you agree to take part now, but change your mind later, you can pull out of the study at any time. This won't affect your care.

If your buddy has a concern about your health or safety they will ask your permission to discuss this with someone who might be able to help. However if they have an immediate concern for your safety or that of someone near you they will contact the appropriate emergency service.

Anything you share in your mentoring sessions or in completing the questionnaires will be kept confidential by the study team and your name will not be known to anyone outside the study.

We will not use your name in any reports we write about the study and we will make sure that you cannot be identified.

WHAT IF SOMETHING GOES WRONG?

If you were injured while taking part in this study, which is unlikely, you would be eligible for compensation from ACC just as you would be if you were injured in an accident at work or at home.

WHAT WILL HAPPEN AFTER THE STUDY?

Your peer mentoring sessions will stop after 5 months. The peer mentoring service will stop on completion of the study. However, if we find peer mentoring is helpful, then we will work with health and social care organisations to explore if we can make peer mentoring available to others in the future.

The data we collect will be stored in secure files for at least 10 years after the study has ended.

WILL I BE ABLE TO HAVE A COPY OF THE FINDINGS?

If you would like to receive a summary of our findings you can indicate this on the consent form. These will be sent to you at the end of the study however, they will not be available until about 6 months after the study has ended.

HOW DO I AGREE TO TAKE PART?

The research team will check that you understand the study information and answer your questions. If you wish to take part, then they will ask you to complete the attached consent form.

If you need an interpreter to help you understand this information sheet or consent form please let us know.

Who do I contact for more information, or if I have concerns about this research?

If you would like more information about this research please feel free to contact the Service Coordinator:



Kathy Gott
Kathy.gott@aut.ac.nz
021 205 1948

If you want to talk to someone about how this study is conducted you can contact:
Professor Nicola Kayes
09 921 9999 ext 7309
nkayes@aut.ac.nz

If you want to talk to someone who isn't involved with the study:

You can contact an independent health and disability advocate on:
0800 555 050
advocacy@hdc.org.nz

Alternately, you can contact the Health and disability ethics committee (HDEC) that approved this study on:
0800 4 ETHICS
hdec@moh.govt.nz

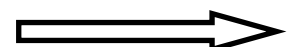


Consent form

Please tick to show that you consent to the following

<input type="checkbox"/>	I have read or had read to me and I understand the information sheet.
<input type="checkbox"/>	I have had enough time to consider whether I want to take part in this study.
<input type="checkbox"/>	I have had the opportunity to talk with my family, whānau or a friend to help me ask questions and understand this study.
<input type="checkbox"/>	I have had the opportunity to ask questions and am happy with the answers I have been given.
<input type="checkbox"/>	I understand that I can decide to withdraw from the study at any time.
<input type="checkbox"/>	I understand that if I withdraw from the study, any information that has already been collected and processed will remain.
<input type="checkbox"/>	I give my permission for the research team to access health information held about me from my health provider or funder to confirm details of my injury.
<input type="checkbox"/>	I understand that taking part in this study is confidential and private, and that nothing that can identify me personally will be used in reports from this study
<input type="checkbox"/>	I know who to contact if I have any questions about the study in general.
<input type="checkbox"/>	I understand what is involved in this study and that I will randomly put into one of the two groups.
<input type="checkbox"/>	I understand that I can choose to include my whānau, family or other support person in sessions with my buddy or the researcher.
<input type="checkbox"/>	I understand my responsibilities as a study participant.
<input type="checkbox"/>	I understand that my GP or an emergency health service will be notified if I disclose any information that suggests that either myself or someone else is at risk of harm
	I agree to the researchers collecting information about my health service and medication use from the Ministry of Health's national data collections: Yes <input type="checkbox"/> No <input type="checkbox"/>
	I am happy to be contacted for a more in-depth interview. I understand that if I take part in an interview that will be audio-recorded and transcribed: Yes <input type="checkbox"/> No <input type="checkbox"/>
	I wish to receive a summary of findings: Yes <input type="checkbox"/> No <input type="checkbox"/>

Please turn over to sign



Declaration by participant:

I hereby consent to take part in this study.

Name:	
Address:	
Phone (landline and mobile):	
Email:	
Alternate contact person name:	
Alternate contact phone (landline and mobile):	
Alternate contact email:	
Participant Signature:	Date:

Do you want to receive a copy of the results of the study (please circile)? Yes No

Do you want to be contacted about any other related research that the Centre for Person Centred Research may be doing? Yes No

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:	
Signature:	Date:

You will be given a copy of this form

The study is run by researchers from AUT and is funded by the Health Research Council.
It has been approved by the Health and Disability Ethics Committee [19/NTB/82 June 2019]