



**PARTICIPATION INFORMATION FOR RESEARCH PROJECT**  
**Evaluating Parkinson's Support groups in rural and regional New South Wales**  
**Caregiver for a Person living with Parkinson's**

**RESEARCHERS**

This study is being undertaken by Vincent Carroll, a Doctor of Philosophy (PhD) candidate at Charles Sturt University. Vincent Carroll is the Chief Investigator conducting this study under the supervision of Associate Professors Rachel Rossiter and Marguerite Bramble. Charles Sturt University (CSU) is a multi-campus public university located across regional New South Wales.

**WHY IS THIS RESEARCH BEING DONE?**

This research will explore the models of Parkinson's support group leadership, what makes and creates an effective Parkinson's support group from the perspective of people with Parkinson's disease (PD), caregivers and support group leaders living in rural and regional New South Wales (NSW). The study seeks to understand Parkinson's support groups and the members who attend these groups.

**WHO CAN PARTICIPATE IN THIS RESEARCH?**

To participate you:

- Must be over the age of 18 years and are currently a caregiver for a person who has been diagnosed with Parkinson's disease; and
- Are an active member of a support group within the limits of what is possible for your group during COVID-19.

For the purposes of this research, a caregiver is described as:

*.....people who provide care to others in need of assistance or support. An informal carer provides this service free of charge and does so outside of the formal care sector. An informal carer will typically be a family member or friend of the person receiving the care, and usually lives in the same household as the recipient of care. As such, many people receive informal care from more than one person. The person who provides the majority of informal care is known as the primary carer. Carers provide care, support and assistance for the consumer living with Parkinson's disease and may or may not be a family member.*

A caregiver can participate in the study with or without the person living with Parkinson's disease being involved or present. Taking part in this research is your choice. Only people who give informed consent will be included (you are encouraged to discuss your participation in this study with someone who you trust). You are encouraged to contact Vincent Carroll if you wish to ask questions before you consent to participate. Whether or not you decide to take part, your decision will not disadvantage you in any way or impact upon your participation or involvement in the support group you attend. If you consent, you have the right to withdraw from the research at any time without penalty or disadvantage by contacting Vincent Carroll by phone or email. Consent can be withdrawn up to 2 weeks after the interview at which time data will be de-identified and combined for analysis.

**WHAT WOULD YOU BE ASKED TO DO?**

If you agree to take part, you will be asked to let Vincent Carroll interview you over the telephone or by video conference, at a time and place that is easily accessible for you. The interview will begin with asking some standard questions about how long you have been caring for a person with Parkinson's disease.

Topics that may then be discussed include:

- Your experience of attending a Parkinson's Support Group
- The role of support groups
- Your perspectives on what makes a successful support group leader.

The interview will be audio and video recorded so that it can be transcribed into writing. It can be stopped at any time if there is any interruption, or if you need a break.

## **HOW MUCH TIME WILL IT TAKE?**

The interview may last between 45-90 minutes. It can be stopped at any time if you need a break and held over 2 or more sessions if required. If you would like to have a transcription of the interview, you can be provided with this after the interview has been transcribed. You have the option to revise your transcription, any requests for change are to be provided to Vincent Carroll within 2 weeks of receiving a copy of the transcription.

## **WHAT ARE THE RISKS AND BENEFITS OF PARTICIPATING?**

There is a potential risk associated with participating in this research. You may potentially find talking about your experience and perspectives of your involvement in accessing and attending a Parkinson's Support Group to be difficult and upsetting. The interview may raise questions which could provoke a range of uncomfortable emotions, such as sadness, anxiety, frustration and fear. If you become upset during the interview or feel uncomfortable, you can stop the interview at any time. The researcher Vincent Carroll is an experienced nurse and will check with you before the interview that you are comfortable to proceed and that you have support available for you after the interview if necessary. If you suffer emotional stress by participating in this study, we advise you to seek further support from one of the following:

- Your local General Practitioner
- Beyond Blue Support Service 1300 224 636 (24 hours 7 days)
- Lifeline 13 11 14 (24 hours 7 days) a crisis support line only

You can nominate a support person to be with you during the interview if you wish. If you have chosen to attend the interview with a Person with Parkinson's disease or a support person your information will not be confidential between you and the researcher as the person attending with you will be privy to the information. You can be assured that the researcher will maintain confidentiality and the participant and their supporters will be encouraged to maintain confidentiality but the researcher cannot guarantee it.

The possible benefits of participating in this research will be that you have the opportunity to have your experiences and perspective heard in a way that could influence the future development support groups and training and development support group leaders.

## **HOW WILL YOUR PRIVACY BE PROTECTED?**

The information that you provide will be kept confidential, and we will not use your real name in any written or verbal reports of this study. All responses will be treated confidentially. All recorded and transcribed data will be de-identified.

You will be given a pseudonym that will be used instead of your real name if anything you tell the interviewer is quoted.

A qualified transcriber will type up the audio recording of your interview, this person will be bound by confidentiality rules. Apart from the transcriber, the only other people to have access to this information will be the research team who are also bound by the same confidentiality rules. All written information, recordings or USB devices will be kept locked in a filing cabinet in the Chief Investigator's office. At the completion of the study, all the de-identified research material obtained from the study will be kept on a CSU campus for a period of 5 years after which it will be destroyed.

## **HOW WILL THE INFORMATION BE USED?**

The results from this study will be included as part of Vincent Carroll's Doctor of Philosophy (PhD) thesis. The findings from this study may also be presented as a conference presentation or a manuscript for publication. Your name will not be linked with your responses and you will not be able to be identified in any of the reported data. If you would like a copy of the final report, you can advise Vincent Carroll, this can be provided when the final report is completed and approved for release by CSU. The de-identified data will be shared with Parkinson's NSW and catalogued on CSU Research Output, an institutional repository that showcases research and scholarly outputs created by CSU staff and students. The de-identified data will be made available for use by other researchers for further research and acknowledged in future work and publications.



### WHAT DO I NEED TO DO TO PARTICIPATE?

Please read this information sheet carefully. If you agree to take part, contact Vincent Carroll to let him know your decision (contact details on the next page). This information sheet is for you to retain so that you have a reminder of what is involved in the research and your rights. It also has the contact details of the researchers and the Research Committee. A consent form will be provided to you if you decide to participate in the research. If you agree to participate:

- i. The consent form will need to be signed prior to your interview and returned to Vincent Carroll by email to [vcarroll@csu.edu.au](mailto:vcarroll@csu.edu.au) or by post in the reply paid envelope that will be provided to you. Alternatively, you can provide verbal consent to participate at the time of the interview, your agreement to participate will be audio recorded.
- ii. You will need to obtain the consent of the person you care for as a condition of your participation. This can be provided by the person you care for signing the consent form, alternatively they can provide verbal consent to your participation at the time of interview, their agreement for you to participate will be audio recorded as well.

### QUESTIONS/FURTHER INFORMATION ABOUT THE PROJECT

If you have any questions or require further information please contact one of the research team below from the CSU School of Nursing, Midwifery and Indigenous Health.

**Vincent Carroll**

CSU Orange

**Mobile:** 0410595795

Email: [vcarroll@csu.edu.au](mailto:vcarroll@csu.edu.au)

**Associate Professor Rachel Rossiter**

CSU Orange

Phone: 02 63657245

Email: [rrossiter@csu.edu.au](mailto:rrossiter@csu.edu.au)

**Associate Professor Marguerite Bramble**

CSU Bathurst

Phone: 0418318122

Email: [mbramble@csu.edu.au](mailto:mbramble@csu.edu.au)

### CONCERNS/COMPLAINTS ABOUT THIS PROJECT

NOTE: Charles Sturt University's Human Research Ethics Committee has approved this project No. H20088. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Governance Officer:

Presiding Officer

Human Research Ethics Committee

Charles Sturt University, Ethics and Compliance Unit

Locked Bag 588.

Wagga Wagga NSW. 2678.

Tel: (02) 6933 4213. Email: [ethics@csu.edu.au](mailto:ethics@csu.edu.au)

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.

Thank you for considering this research project. Please keep this sheet for your information.



**PARTICIPANT CONSENT FORM**

**Evaluating Parkinson’s Support groups in rural and regional New South Wales**

Chief Investigator  
Vincent Carroll  
CSE Orange Campus  
Email: [vc Carroll@csu.edu.au](mailto:vc Carroll@csu.edu.au)  
Phone: 0401595795

Research Supervisor  
A/Professor Rachel Rossiter  
CSU Orange Campus  
Email: [rrossiter@csu.edu.au](mailto:rrossiter@csu.edu.au)  
Phone: 02 6365 7245

Research Supervisor  
A/Professor Marguerite Bramble  
CSU Bathurst Campus  
Email: [mbramble@csu.edu.au](mailto:mbramble@csu.edu.au)  
Phone: 0418318122

The purpose of the research has been explained to me, including the associated risks and discomforts. I have read the attached Participant Information Sheet on the above named study, and understand the purpose and procedures described within it. I have been given the opportunity to ask questions about the research and received satisfactory answers.

I understand that I am free to withdraw my participation in the research at any time without penalty or disadvantage by contacting Vincent Carroll by phone or email. Consent can be withdrawn up to 2 weeks after the interview at which time data will be de-identified and combined for analysis, and that if I do, I will not be subjected to any penalty or discriminatory treatment.

If I have chosen to attend the interview with the person with Parkinson’s disease that I care for or a support person, I understand my information will not be confidential between myself and the researcher as the person attending with me will be privy to the information. I understand that the researcher will maintain confidentiality and other person attending and I will be encouraged to maintain confidentiality but the researcher cannot guarantee it.

Please read the following statements carefully and sign below to agree:

- I have been made aware of any known or expected inconvenience, risk and discomfort and of their implications as far as the researcher currently knows them.
- I understand that data collection will be audio and video recorded during the interview.
- I have the consent of the person whom I provide care to participate in the study. Evidence of this is provided by their signature below.
- I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.
- I have been advised to retain a copy of the Participant Information Sheet.

Name of Participant	Signature of Participant	Date
Name of person with Parkinson’s disease	Signature	Date
Name of Chief Investigator	Signature of Investigator	Date



Charles Sturt  
University

NOTE: Charles Sturt University's Human Research Ethics Committee has approved this project No.H20088. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Governance Officer:

Presiding Officer  
Human Research Ethics Committee  
Charles Sturt University  
Ethics and Compliance Unit  
Locked Bag 588  
Wagga Wagga NSW 2678  
Telephone: 0269334213  
Email: [ethics@csu.edu.au](mailto:ethics@csu.edu.au)

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.