

Participant Information Sheet

Project Title: Young Adult's Lived Experience of ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) & Fibromyalgia: Creative Resource Development Group

About the researcher:

My name is Gipsy Hosking and I am a PhD Candidate with the Centre for Social Change at UniSA. I've had ME/CFS myself for just over 10 years now and I'm interested in learning more about people's lived experience of chronic illness and using this knowledge to educate the public and help others living with ME/CFS and Fibromyalgia Syndrome (FMS).

About the research:

I am conducting my research in the form of an 8 session group in which we will come together and collectively develop a resource based on our stories of living with chronic illness. Together we will decide on the format and focus of this creative resource. It may take the form of a booklet, a website, a video, an art exhibition, a photo essay, a zine, a play script etc. Come with your ideas, your stories and a willingness to work together to develop this thing! You will be the co-authors of this resource and the driving force behind it and behind my PhD thesis. Once it is developed we will look at options for production and distribution.

This group will be taking place as part of my PhD research. So that I remember what we have discussed, and how we came to make the decisions that we did, the group will be recorded. I will also be doing a thematic analysis of the stories of lived experience that you choose to share in the final resource.

What will be expected of you?

To attend 8 group sessions, no more than 2 hours long each time and to be willing and eager to engage in this collective creative process.

Who can participate?

Anyone aged between 18 and 30 living in Adelaide, Australia who has a diagnosis of ME/CFS and/or FMS, or who has a suspected diagnosis of one of these conditions and who has been experiencing symptoms for more than 12 months.

You need no specific creative experience or expertise. I expect this to be a friendly and respectful group welcoming of all genders, sexualities, ethnicities, socio-economic status and abilities.

How will the group run?

I am aiming to make this group as chronically ill friendly as possible and I will be speaking to every participant about how to best support your access needs. The venue in the CBD is wheelchair accessible, with flexible seating arrangements. Refreshments will be provided and carers are welcome to come along.

At our first meeting we will collectively decide the logistics of future meetings. We will decide the frequency (weekly or fortnightly), time and length (up to 2 hours) of the following 7 sessions. Everyone is encouraged to put their health needs first and if you are too ill to travel to a meeting then you can participate via Skype or send you apologies and we will send you an outline of what happened at that meeting. You are also free to withdraw from the group at any time without giving any explanation.

Anticipated risks and benefits

I aim for this to be a fun and empowering experience. You will get a chance to tell your story and to co-author a valuable resource for the community. You may learn new skills, make new friends and have a chance to connect with your community in a chronic illness friendly way. The risks of participating in this research are minimal but you need to be aware that the resource we develop is intended for the public domain. This has some consequences regarding anonymity which are outlined below.

It is also possible that what we discuss in the group may raise emotional or psychological stress for you. For this reason we will have a support worker present at the groups to support all group members in anyway she can.

You can also seek further assistance from the SA ME/CFS Society (includes people with FMS) who can help you find a chronic illness friendly counsellor, psychologist or doctor in your local area. You can phone them on Wednesday from 11-3 or visit the website at www.sacfs.asn.au. Bridges and Pathways is another organisation that can link you into ME/CFS and FMS specific support services and groups, contact them on 0447 133 683 or visit www.bridgesandpathways.org.au.

If you require crisis intervention please contact Lifeline on 13 11 14 or Beyond Blue on 1300 224 636. Beyond Blue also offers online chat between 3pm and 12am or email support, find out more at www.beyondblue.org.au/get-support/get-immediate-support

Authorship and Confidentiality

Complete confidentiality cannot be guaranteed regarding participation in this study. Given the public nature of this group, the confidentiality and anonymity of participants and group discussions cannot be guaranteed. Group participants will be requested to keep information shared in the group confidential. Regarding the resource that we develop, you will have the choice of how you are identified both as a co-author of the whole resource and/or as an individual author of specific material. You can choose to publish under your own name, under a pseudonym or as anonymous. However please be aware that it may be possible to infer your identity based on the details you share for the resource. After the group concludes and the resource is published it will not be possible to change this decision or withdraw you consent. Having your health status known in the public domain may have unforeseen consequences such as future employers knowing about your illness via an internet search.

Further as this group and the resource we develop is part of my PhD research I will be discussing and analysing data from the group and resource in my thesis, in academic journal articles and in conference presentations. If you choose to use your real name in the resource then even if I use non-identifying language during analysis it may still be possible to link my analysis to an individual's story and thus to your name.

Data Collection & Storage

All group meetings (including the initial planning one) will be recorded with video and audio recording materials. This is necessary to allow me to have a record of the group proceedings so I can remember how we came to make the decisions that we did. All records containing personal details will remain confidential and securely stored. The video recording will be destroyed upon completion of my thesis. In line with the policies of UniSA the audio recordings, and any other data gathered, will be stored in the Psychology and Social Work archive room for 5 years after the submission of my thesis and then destroyed using a confidential document destruction service.

Interested?

Know that your participation in this study is entirely voluntary and you have the right to withdraw from the study at any time without giving a reason. If you wish to withdraw from the group you will have the choice of having the contribution you have already made recognised or if you prefer we will not use any of the personal stories you have contributed.

If you would like to know more or if you are interested in participating please contact me at gipsy.hosking@mymail.unisa.edu.au or via the facebook page at www.facebook.com/GHresearch/ or you can text or call me on 0408 266 075

If you have further questions or concerns you can also contact my supervisor Associate Professor Lia Bryant at Lia.Bryant@unisa.edu.au or on 8302 4363

'This project has been approved by the University of South Australia's Human Research Ethics Committee. If you have any ethical concerns about the project or questions about your rights as a participant please contact the Executive Officer of this Committee, Tel: +61 8 8302 3118; Email: vicki.allen@unisa.edu.au'.

Participants or third parties who wish to lodge a complaint about either the study or the way it is being conducted should contact the Executive Officer of UniSA HREC in the first instance, email: humanethics@unisa.edu.au or tel: 8302 3118.