Letter of Information and Consent Form for Caregiver-Employees

Title of the Study**:** Evaluation of Caregiver-friendly Workplace Policy (CFWP) Interventions on the Health of Caregiver-Employees (CEs)

Investigators:

Dr. Allison Williams
School of Geography & Earth Sciences
McMaster University
Hamilton, Ontario, Canada
905-525-9140 ext. 24334
awill@mcmaster.ca

Rachelle Ireson, Research Assistant/Project Coordinator
School of Geography & Earth Sciences
McMaster University
Hamilton, Ontario, Canada
905-525-9140 ext. 28617
iresonrl@mcmaster.ca

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Please read this information form carefully. You have been asked to participate in three audio-taped surveys to assess your health and well-being before and after the implementation of a Caregiver Friendly Workplace Policy (CFWP) intervention at McMaster University. **Each** survey is anticipated to take between 1.5-2 hours of your time. You will also be asked to take part in the CFWP intervention, which is in the form of a face-to-face educational presentation. Your consent is implied by agreeing to this Letter of Information and Consent and the information provided herein. If you agree to this Letter of Information and Consent, please sign where indicated on the final page of this document. If you are receiving this document electronically, please provide an electronic signature on the final page of this document, or sign the document and email/fax it to the contact information above.

Purpose of the Study*:*
The purpose of this study is to look at a Caregiver Friendly Workplace Policies (CFWPs) intervention at McMaster University in order to determine their effectiveness in supporting caregivers in both paid employment and unpaid caregiving, and their impact on caregiver health and well-being. The intervention stage of this study is set to begin in August 2015 and will be completed by August 2016 (12 months). Results for this study and all other studies related to the Gender, Health and Caregiver Friendly Workplaces Chair project will be housed on a website dedicated to the Chair project (http://ghw.mcmaster.ca). Participants may also request a summary report of the findings. Final findings are anticipated to be available by January 2017.

Procedure*:*

The survey

If you volunteer to participate, you will be asked to fill out a brief, anonymous demographics questionnaire (one time only) and a hard copy survey that should take approximately 1.5-2 hours of your time. A member of the research team will meet with you in person while you complete the survey. The surveys will be conducted outside of work hours, and outside of the workplace, scheduled at a location and time of your choice. The researcher will ask you the survey questions, and will manually record your answers on the hard copy of your survey. With your permission, the survey will be audio-taped, as this will give you the opportunity to add more detail to your questions, as well as answer some verbal response questions at the end of the survey. The survey will take place three times, over the period of 12 months. This will allow us to measure any impacts that the intervention has on your health and wellbeing over time.

The intervention

Following the survey, you will be asked to participate in the CFWP intervention, which will be offered to you one-on-one by the researcher. This intervention is in the form of an educational presentation, and is not expected to take more than one hour of your time. The intervention will not take place during work hours, or in your workplace, but rather will be scheduled at a location and time of your choice. You will receive the intervention presentation once, after you have completed the first survey. You do not have to take part in the survey and the intervention presentation in the same session; the researcher will work with you to schedule the survey and intervention. Additionally, the researcher will complete a checklist activity with you as a part of the intervention. This list has 8 tasks that you will be asked to evaluate/assess, after which you will be asked to prioritize 2 tasks to complete. The checklist will be revisited with you at each time point with the researcher.

At the end of the 12-month period and an initial review of the surveys, some of you will be asked if you are interested in participating in a single follow-up interview lasting approximately 60 minutes. This is not mandatory for participation in the study and you are welcome to decline the invitation for an interview. These questions will reflect your experience with the CFWP intervention, how it affected your role strain or caregiver burden, the CFWP intervention(s) areas of strength/weakness, how the intervention met/exceeded/fell short of your expectations, any implications that the experience had for related relationships in your life, and any additional feedback that you have to offer.

Potential Risks:

You may feel uncomfortable (anxious, uneasy) with some of the questions that are asked in the survey, as they address personal stresses and strains that caregivers often experience. In order to mitigate this, the researcher has been trained in a range of caregiver-related issues. Additionally, the researcher will have access to a resource package, which you will receive a copy of when you participate in this study. If you feel uncomfortable at any time, you may choose to end your participation in the study. Your answers will not be saved. Additionally, as a result of the intervention, if you choose to approach your supervisor to discuss your caregiving situation and potential accommodations, there is the risk that co-workers may become aware of your participation in the study (i.e. if you are using flex time or working from home). Your employer is working with us to ease any transitions in workflow or changes to workplace culture to minimize any potential negative perceptions by your peers, or direct supervisor.

Potential Benefits*:*
Potential benefits to participants include: having an outlet to address concerns related to caregivers in the workforce, contributing to knowledge that will assist current and future caregiver-employees, helping to establish a Caregiver Friendly Workplace Policy in your own workplace, personally receiving a form of caregiver support and accommodation for the 12-month period of the study (which may ease the burden of caring, reduce stress, and improve physical and/or mental health), and contributing to scholarship in the field.

Payment or Reimbursement:
For your participation in this study, you will receive an honorarium of $25 for each survey and/or interview you complete. If, for any reason, you decide that you would like to withdraw, even during or after the first survey, you will still receive the $25 honorarium. You will not receive $25 for the intervention presentation.

Confidentiality:
The data that is collected from the surveys are completely anonymous. Although your data will be anonymized, participant's identities are sometimes revealed by the stories they tell. There is no identifying information that will link you to your particular data set and you will in no way be identified in any written publication resulting from the study. In order to ensure your confidentiality, you will be assigned a random participant code. If you agree to allow the survey to be audio- recorded, your participant code will be used if your data is used in future publications. Though your direct supervisor may know that you have participated in the study, they will not have access to any survey/interview data or potentially identifiable information.

The data collected is purely for research purposes. The research team will have access to the data for the purposes of assessing the effectiveness of the CFWP intervention(s) and the anonymous data may be shared with other members of the research team. All data will be stored on a secure server and on the password protected computers of the research team. Hard copies of any notes, surveys, or journals will be kept in a locked filing cabinet in the primary investigators' office temporarily. Hard copies will be scanned electronically to be stored on the secure server, and then will be destroyed through confidential shredding.

Although I will protect your privacy as outlined above, if the law requires it (such as in the case of elder abuse), I will have to reveal certain personal information. Therefore, any promises of confidentiality and anonymity will be waived as abuse will need to be reported to the proper authorities.

Rights of Research Participants:
Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can withdraw from participation for whatever reason up until approximately November 2015. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If there are any questions asked which you would prefer not to answer, you are not obligated to do so. If you have any questions or concerns about the research study, please feel free to contact Rachelle Ireson or Allison Williams at the contact information provided above.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Research Office for Administrative Development and Support
E-mail: ethicsoffice@mcmaster.ca

I_____, consent to participate in *Evaluation of Caregiver-friendly Workplace Policy (CFWP) Interventions on the Health of Caregiver-Employees* conducted by Allison Williams. I understand the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature _____ **Date**
Participant

Signature _____ **Date**
Principal Investigator

1. I agree that the interview can be audio recorded.
   - Yes.
   - No.

2. Yes, I would like to receive a summary of the study's results.
Please send them to this email address
_____

Or to this mailing address:
_____

_____

3. No, I do not want to receive a summary of the study's results.

4. I agree to be contacted to be made aware of future research studies conducted by the investigators, and understand that I can always decline the request.
   - Yes
   - No