

## Healthexperiences

See, hear and read  
people's stories on  
health and illness

### In this newsletter

Update

Website

To visit the website

Happenings

*"If Canada's health  
care system were a  
plant, family  
caregivers would be  
its roots - fragile, vital  
and invisible"*

**Donald Cameron**

# People sharing experiences

## Health Experiences Newsletter – October 2013

*The health experiences research group Canada aims to develop reliable internet information on experiences of people with health and illness. The first Canadian module features the experiences of family caregivers. 39 caregivers across Canada participated in one-on-one interviews in their homes (or preferred location) with a researcher from the St. Mary's-McGill team. The results are published on the internet site [www.healthexperiences.ca](http://www.healthexperiences.ca). We have created this newsletter to keep participants, collaborators and colleagues informed about project developments.*

### Update

We are thrilled to announce the English launch of the module "family caregiving" on the [www.healthexperiences.ca](http://www.healthexperiences.ca) website. On the website you will be able to find summaries of the caregiver's experiences, organized in thematic pages illustrated with video, audio and textual selections from the interviews. The website also has personal descriptions of the caregivers who have participated, as well as a collection of useful resources and information.

We will soon start with the development of a module for breast cancer in women. More information for people who would like to participate will be posted on the website.

At the same time our team is in the process of exploring the options of developing a module on mental health in the future.

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### Website

In October we launched a 'pilot' website. This made it possible for participants to see the results of the caregivers project as well as their own contributions. After the test period the English version of the website was made available to the general public (October 18). We have begun working on the French Translation of the website, and expect the French launch to occur in the very near future. The reactions to the website that we have received from the participants have all been very positive:

*"It is really beautiful! Thank you for the opportunity..... :-)"*

*"I thank you again for having given me a chance to share what I have learned and hopefully it will benefit one person somewhere somehow."*

Your reactions and comments are very valuable to us as they help us to improve the quality and performance of the website. Please feel free to contact us and let us know what you think about the launch of the website, and your experience of participating!



healthexperiences.ca  
experiencessante.ca



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To visit the website: [www.healthexperiences.ca](http://www.healthexperiences.ca)



The website allows you to access information in different ways. On the Family Caregiving home page you can make a choice to read, hear and see other peoples experiences organized in themes in the “topics” section, to read the personal stories of the participants in the “people” section or to access the section with a selection of caregiving information and links. You can also listen to what Dr. Mark Yaffe has to say about caregiving.

## Happenings

Even though the development of the website is one of our main objectives we have also tried to distribute the knowledge on caregivers experiences in different means. This project has been presented in several national and international conferences. A caregivers guidebook has been developed for the Montreal area, based on the experiences and information we gained throughout this project. (you can find this book on .....). We are now working on scientific articles based on the data gathered through the project for publication. And we are exploring possibilities to develop teaching modules for health care trainees from the data we have gathered on the caregivers module. Alexandra, an MSc graduate, is working on a side project and is looking into the experiences of people with a sibling with mental health issues.

The next two modules will focus on breast cancer, and migrant mental health. For the breast cancer module we are collaborating with Germany as well as a researcher from Australia. *For the migrant mental health module, we are collaborating with Australia, BC and Toronto, to learn more about migrant’s experiences with depression and anxiety. We have recently submitted a funding grant, and if successful, we will aim to begin recruiting participants in the Summer of 2014.*

As you can see, we are working hard on lots of exciting developments to enhance the understanding of the experiences of patients and caregivers with health and illness!

Thanks to all our participants for their valuable contribution!



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