

## Healthexperiences

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

# Caregivers share their experiences

## Health Experiences Project Newsletter – January 2013

*The first Canadian module of the health experiences project features the experiences of caregivers that help look after someone with a chronic physical illness. Caregivers across Canada participated in one-to-one interviews in their homes (or preferred location) with a researcher from the St. Mary's-McGill team. The results will be published in May 2013 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. Let us know what you think!*

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### Update

In November 2011, we interviewed the first participant about her experiences as a caregiver. We have now interviewed 40 people (31 women and 9 men from 23 to 88 years old) across Canada who have been very generous about sharing their time, experiences and insights regarding what it is really like to be a caregiver. We are very excited about our progress and the remarkable experiences participants have been willing to share. As a collection, the stories include both common and unique experiences helpful to other caregivers, professionals and researchers. It has been a privilege to meet our participants. We are now analyzing the interviews to identify the 25 most important topics from the participants' perspectives. We will then select video, audio and text clips from the interviews to illustrate each topic.

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### Upcoming website

The website is going to be launched in two separate phases. In the first phase, we will launch the Healthexperiences homepage where you will be able to find information on subjects such as: about us, methodology used but also the expected publication for the caregivers project and other general news. We are planning to launch this in January 2013. We are working with a web company expert in online education to design and launch our website.

The second phase will be the publication of the full caregivers website where you will be able to find the "topic" pages containing the video, audio and text clips. You will also be able to find autobiographies for each of the participants and a resource section with useful Internet sites and organizations involved in supporting caregivers. We are planning to publish this in May 2013.

"We benefit from the  
wealth of knowledge  
and experience  
shared by others and  
hope that we can  
make a contribution  
to this vital  
knowledge exchange"

*Lillian & Michael  
Participants,  
caregivers module*



healthexperiences.ca  
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## What kind of information will I find in the caregivers module?

In the final module there will be a total 250 video clips, audio clips and text fragments extracted from the participants' interviews on the 25 topic pages. This will provide a complete overview of the variety of lived experiences shared with us during the interviews. We have randomly selected 3 quotes as examples of what participants shared with us about their experience of caregiving.



"I knew from 13, knowing that she was just going to get worse with time that I was going to have to sort of buck up in a big way."

*Female, 27 yrs, caring for her mother with MS*

"Nobody's going to be able to look after my mother better than I am so don't even try to offer but if someone can offer to help support me in ways that allow me to continue to do that I would be a fool not to accept that."

*Male, 38 years old, cares for mother*



"You grow up thinking that the home is supposed to be a safe, secure happy place but you know I'm assuming that for most youth caregivers home can really become like a prison because this is what we have to do"

*Male, 28 years old, cared for father*

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## Health experiences evaluation projects

Evaluating the approach and results of initiatives like this is a valuable way to improve research and understand the impact it is having on people. To date, we have started two evaluation projects with healthexperiences.ca. The first project is well under way and aims to explore participants' experiences of participating in an interview for the caregiving study. This is important because it helps us understand the positive and negative effects that our research is having on people who take part in the study. The second aspect of our evaluation work will involve members of the public in the development of our website page. We have held 3 group sessions with potential users of the website in order to develop a greater understanding for how they wish the website to be structured and designed. Considering most Internet users reject health websites simply on the basis of poor design, we feel it is very important to include people's input for the creation of our website! The feedback we receive from these group sessions will be translated back to the website team that is designing and hosting our website.

Thanks to all our participants for their valuable contribution!



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