

## Getting started

On our home page, you can scroll through a brief description of the website content, a short video introduction by the Susan Law, the Health Experiences Team Lead, and a teaser for the caregiving module compiled from some of the video interviews that can be found on this site. Use the navigation arrows found on either side of the homepage to explore its content<sup>1</sup>:



Once you are done exploring the homepage, you can use the menu at the top of the page to navigate through the rest of the site<sup>2</sup>. There is also an expandable menu that you can reveal by clicking on the arrow icon on the bottom left corner of the screen, which will provide links to information about our international collaborations, our first module on caregiving, and our team members<sup>3</sup>.

The content of the website is organized in Modules. A Module is a collection of experiences with health and illness related to a specific condition or situation. These could be for example entitled "family caregiving" or "breast cancer in women". To explore a particular module, please select the one you are interested in from the drop-down menu that appears when hovering over the "Modules" menu item<sup>1</sup>:



## Navigating the Module

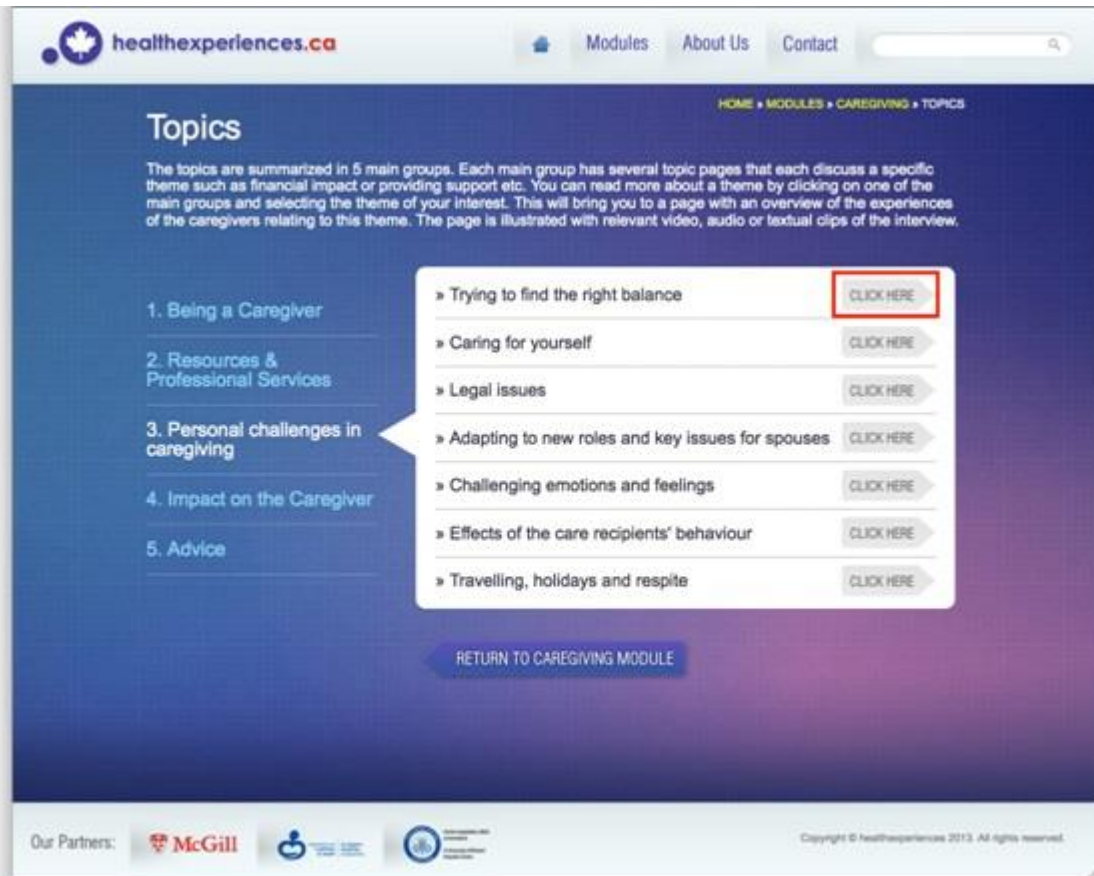
There are many ways of navigating the Module content, starting from the Module's main page:



MODULE MAIN PAGE

### Browse by topics page:

Click on the “VIEW THE TOPICS” icon<sup>1</sup> to get directed to the Topics page menu, where Topics are grouped into 5 main categories. On the topics page you can read about themes that were important to the participants. You will find a summary of the experiences of the participants illustrated with a selection of video/audio and text clips from the interviews. Use the tab on the left to explore all the different categories, and click on one of the topics on the right to see more.



Here you will find a brief description of the topic along with all of the related interview content. Click on the links to the interviews to watch, listen, or read. You may also explore the other related topic pages listed in the menu on the left of the page. At any moment, you can navigate back to a previous page by using the breadcrumb trail found at the top of the screen<sup>1</sup>.

### Browse by People

By clicking the “SEE THE PEOPLE” link<sup>2</sup> on the Module’s main page you will be directed to a list of all the people who have been interviewed for the Module. You can view someone’s profile by clicking on the appropriate link next to their picture. You can also narrow the list by setting criteria found at the top of the page.



healthexperiences.ca




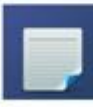


Modules About Us Contact

HOME » MODULES » CAREGIVING » PEOPLE

## People

You can view someone's profile by clicking on their link. On the page you will see the caregivers' personal stories. They explain how they became a caregiver, for whom they are caring, and many other interesting things about their experiences. You will also find links to their clips.

Gender  Age  Recipient  Caregiving time

 <b>Rachel</b> 27 yrs old Cares for her mother <a href="#">VIEW PROFILE »</a>	 <b>Richard</b> 88 yrs old Cared for his wife <a href="#">VIEW PROFILE »</a>	 <b>Donovan</b> 77 yrs old Cares for his wife <a href="#">VIEW PROFILE »</a>
 <b>Sheni</b> 66 yrs old Cares for her husband and son <a href="#">VIEW PROFILE »</a>	 <b>Christiane</b> 61 yrs old Cares for her husband <a href="#">VIEW PROFILE »</a>	 <b>Amazing Alyce</b> 47 yrs old Cares for her husband <a href="#">VIEW PROFILE »</a>
 <b>Lillian and Michael</b> 55 yrs old Care for their son <a href="#">VIEW PROFILE »</a>	 <b>Shoshana</b> 54 yrs old Cares for her husband <a href="#">VIEW PROFILE »</a>	 <b>Rowdyneko</b> 67 yrs old Cares for her husband <a href="#">VIEW PROFILE »</a>
 <b>Matsonia</b> 59 yrs old Cares for her husband <a href="#">VIEW PROFILE »</a>	 <b>Drew</b> 38 yrs old Cares for his mother <a href="#">VIEW PROFILE »</a>	 <b>Mr and Mrs Smith</b> 62 and 64 yrs old Care for mother <a href="#">VIEW PROFILE »</a>

On the profile page, you will see the person's personal story, as well as links to their interview clips. Once again, you can navigate back to previously visited pages by using the breadcrumb trail near the top of the screen.

healthexperiences.ca Modules About Us Contact

# Family Caregiving

Topics People Information & Links

Home » Family Caregiving » People » Rachel

## More clips by Rachel

- Becoming a caregiver
- Challenging emotions and feelings
- Effects of care recipients' behaviour
- Impact on health
- Personal growth and transformation
- Support from family and friends
- Trying to find the right

## Rachel



**Age:** 27-year-old  
**Age at start caregiving activities:** 14  
**Her background:**  
 Rachel is a single 27-year-old woman who works full-time as a lawyer. She has cared for her mother (whom Rachel describes as a proud Caribbean woman) since she was a teenager, when her mother developed multiple sclerosis. Rachel became her caregiver when she was 14 years old. Her mother is now 61 and is semi-independent, living alone across the road from Rachel in an adapted apartment, where she receives daily support from Rachel and several paid caregivers.

Caring for her mother's chronic illness has been an inter...  
 time before her mother was properly diagnosed – Rach...

Finally, from the Module's main page, you can click to view the "Information and Links" section<sup>3</sup> to browse links to useful resources available online that are related to the Module's topic.




### **View the videos, listen to recordings, read the transcripts**

When you click on a video link, a popup window will appear where the video will start to play automatically. You can follow along by reading the transcript below, and you can select other clips of the same person from the menu on the right of the window. You can leave the video popup any time by clicking the X icon at the top-right corner of the window.



Becoming a caregiver



More clips by Rachel [View Profile](#)

- [Becoming a caregiver](#)
- [Challenging emotions and feelings](#)
- [Effects of care recipients' behaviour](#)
- [Impact on health](#)
- [Personal growth and transformation](#)
- [Support from family and friends](#)

It started when I was 13. My mom came in my room and said, "I have something to tell you." She was actually originally diagnosed with Lou Gehrig's disease—with ALS—so I was told that she had ALS and that she would probably die within the next few years. And then I'm not sure exactly when they discovered that she didn't have ALS, [but] she actually had Multiple Sclerosis. And it's never been so happy to hear that you have MS as opposed to something else.

I don't remember when the second conversation was, but she told me at some point, "Oh, I don't have ALS. I have MS." So, we were obviously quite pleased with that result as opposed [to ALS], but the year probably—or two years—leading up to her actually coming to me and telling me that she was falling a lot and having a lot of problems, she'd been going back and forth to the doctors and no one would really listen to her story, and no one would take what she was saying seriously, and they just sort of brushed her off and said, "You're fine, you're fine." But she knew something was wrong. So, I think she actually started being quite adamant about looking into figuring out what it was that was wrong.

So, she finally figured out she had MS. She has primary progressive MS, which is the worst kind you can have. So, I think there was some sense of relief in her knowing what it was that she had. Then, I think immediately thereafter, she started walking with a cane. Her left leg is the part of her body that is the most affected, or was at that time the most affected. So she started walking with a cane immediately, and then I sort of remember thinking—you know when someone doesn't tell you that you have something, you kind of just tough up and say "Oh, I'm fine" and you keep going? And then the minute someone actually tells you what you have you succumb to it a lot? I remember that sort of being the case.

When you click on an audio link, a popup window will appear with the transcript of the clip. To listen to the clip, you must click on the play button on the top left corner of the window<sup>1</sup>. You may also choose other clips to listen to from the same person by clicking the menu on the right.

The screenshot shows a video player window titled "Legal issues" with a close button in the top right corner. In the top left, there are navigation arrows and a "1" icon. The main area contains a transcript with two paragraphs. The first paragraph discusses a person's inability to go back to their apartment and the frustration of not having legal arrangements. The second paragraph explains why the story is important, mentioning the lack of legal arrangements and the person's age. On the right side, there is a sidebar titled "More clips by Rhyannan" with a "View Profile" link. Below this title is a list of five text links: "Legal issues", "Legal issues (2)", "Personal growth and transformation", "Society and caregiving", and "Uncovering why and how caregivers care".

When you click on a text link, you will only be able to read the transcript of the clip, and choose from a selection of other transcripts from the same person from the menu on the right.

We hope you enjoy your visit to our website. Please do feel free to contact us anytime with questions. You can find our contact info by clicking on the "Contact" menu item on our homepage.