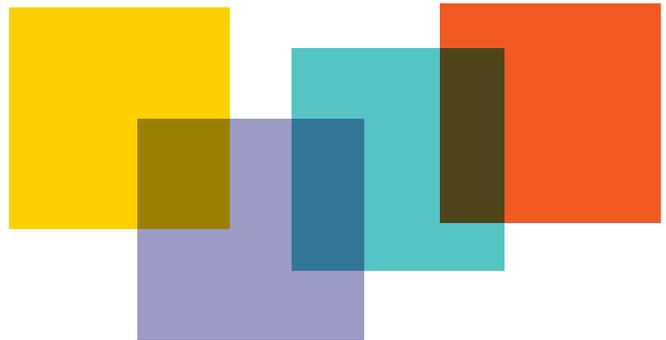
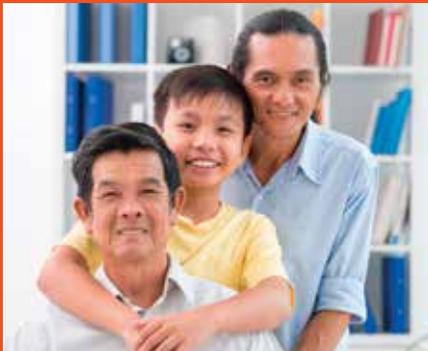


STORIES SHARED, VOICES HEARD:

Ontario's Family Caregivers



About The Change Foundation

The Change Foundation (The Foundation) is an independent health policy think-tank that works to inform positive change in Ontario’s health care system. With a firm commitment to engaging the voices of patients, family caregivers and health and community care providers, the Foundation explores contemporary health care issues through different projects and partnerships to evolve our health care system in Ontario and beyond. Created in 1995 through an endowment from the Ontario Hospital Association, the Foundation is dedicated to enhancing patient and caregiver experiences and Ontario’s quality of health care.

A note on terminology

The term “family caregiver” is used interchangeably with the term “caregiver” in this report for simplicity and readability. We define family in the broadest sense. Both terms refer to the people—family, friends, neighbours—who provide critical and often ongoing personal, social, psychological and physical support, assistance and care, without pay, for people in need of support due to frailty, illness, degenerative disease, physical/cognitive/mental disability, or end of life circumstances.

A word of thanks

The success of The Caring Experience relied on the gracious participation and openness of people who’ve had first-hand experience providing care for someone. The project team would like to express its sincere gratitude to the many caregivers who so enthusiastically gave their time and shared parts of their stories so generously.

There were many other people who contributed to The Caring Experience. Thank you to each of them.

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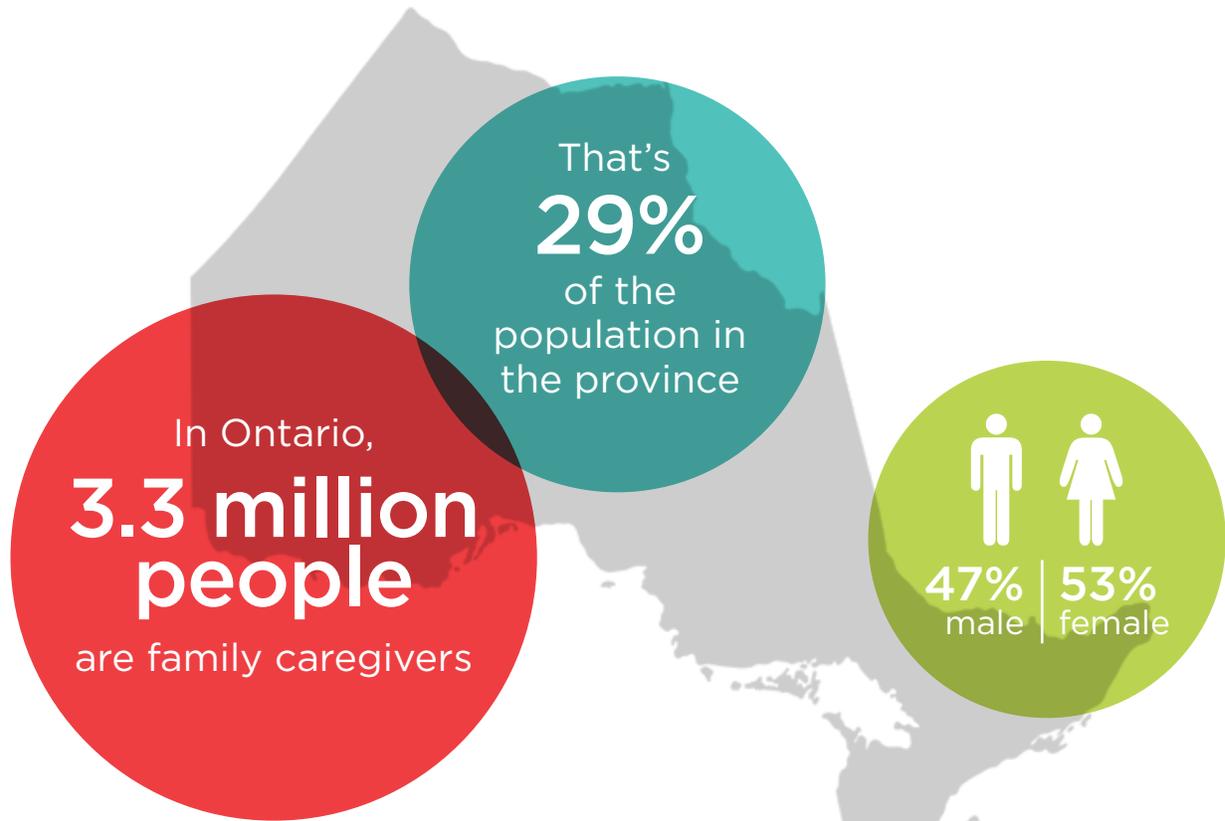
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The story so far...



OF THESE PEOPLE:

29% have one or more children under the age of 14 at home

76% juggle caregiving and paid employment

31% felt they had no choice in taking on caregiver responsibilities

35,000 left their employment (quit or were fired) due to their caregiving duties

With recent evidence and reports that caregiver stress and burnout is on the rise, it's hard to ignore the weight of these facts.

The shift in health care in Ontario to more community- and home-based care means that people now have the greater ability to individually manage their health conditions at home. However, as one caregiver was quick to say, “‘Home instead’ is a dream not available without help at home.” It's only because of family members or friends (family caregivers) that patients can live comfortably out of hospital.

In 2015, The Change Foundation released our *Out of the Shadows and Into the Circle* strategic plan, declaring our interest in understanding the experience of family caregivers as it relates to their direct interactions with health care providers and all aspects of the health care system. For the Foundation, it was an obvious and needed extension of our patient experience work.

Through past projects such as Patients Advancing Transitions in Healthcare (PATH) and PANORAMA, we heard the common refrain that family caregivers were not recognized, valued or included as part of the health care team. We also recognized how intertwined patient and caregiver experiences are—one impacting the other, yet each having distinct differences. It became increasingly obvious to us that family caregivers had to be more formally recognized for the important role that they were taking on, and that they need to be more supported in order to carry out their responsibilities and look after their own health and well-being.

It is our belief that if family caregivers aren't recognized and included, transformation in the health care system can only go so far.



Listening and learning

In our determination to understand and improve the experiences of patients and caregivers, we started by pursuing meaningful ways to listen to, and learn from, family caregivers across Ontario.

The Change Foundation partnered with the Ontario Caregiver Coalition (OCC) to extend our reach beyond our more traditional partners to meet with a wide array of family caregivers. Together, we launched The Caring Experience project to gain a deep understanding of the needs, motivations and challenges of caregivers as they interact with the health and community care system. This report outlines our findings from our caregiver engagements and provides an overview of our process.

To complement our caregiver engagements, we also held sessions with health care providers and staff to understand their perspective on what makes it harder or easier to work directly with family caregivers to support a patient. The findings and process of the provider engagements are outlined in *Stories Shared, Voices Heard: Ontario's Health Providers*.

It is important to note that the focus of The Caring Experience was to better understand the interactions and experiences that caregivers have in the health care system. However, caregiving happens in the context of a complicated, imperfect health care system. Given this broader context, we heard many comments about broader system and societal barriers. These included workplace and employment policies and practices, health system issues, and health policies that create ineffective and inefficient processes that add to caregiver burden. Although The Change Foundation cannot address these broader challenges and issues, we recognize that they exist and that our work will happen within that context.

A summary of our full set of findings from our year of in-depth family caregiver research and engagement, and our strategic plan, are detailed in *Out of the Shadows and Into the Circle: From Listening and Learning to Action*.



CAREGIVER PROFILE

Meet Lisa, mother and caregiver to Chase. She exemplifies how caregiving can be rewarding and challenging, and the all-encompassing nature of her role in Chase's life. <http://www.changefoundation.ca/lisa-chase-cann-caregiving-story/>

Who did we hear from

Between November 2015 and February 2016, we met with and heard from nearly 300 caregivers across the province.

In addition to partnering with the OCC, we hired an engagement company (Overlap Associates) to spearhead many of our caregiver engagements. As part of this effort, Overlap Associates issued a summary report with key insights from The Caring Experience which has helped to inform our findings in this document.

Our formal engagement activities, detailed in Appendix A, included:

- Two province-wide Town Halls, both held on November 24, 2015
- Nine Caregiver Workshops across Ontario
- Journey Mapping with 18 caregivers
- Three online pulse check surveys to caregivers
- Four focus groups
- 30 caregiver interviews

When we set out to engage with caregivers, we were aware of the difficulty caregivers often have in getting away from their caregiving duties. We thought we might have trouble getting a critical mass of caregivers together in one room for our sessions. We were surprised that we had a high retention rate (except when weather was a factor) and that many caregivers said they preferred a face-to-face engagement.

We heard from a wide variety of caregivers—from parents of children with severe disabilities, to spouses caring for their spouse with dementia, to adult children caring for their parents, to friends helping their neighbours, to Indigenous people caring for others in their community.

The caregivers we heard from were living in urban, rural, and remote areas of Ontario. There's no doubt, the stressors for caregivers living in rural or remote locations were more intense.

No matter what way you look at it, family caregivers are not a homogeneous group.

Although we didn't meet with every type of caregiver, we arrived at a point where core themes began to emerge. There will always be unique challenges for different types of family caregivers, as every situation is different, however we found a set of themes that are common to most family caregiver situations.



What we heard

Many caregivers don't immediately identify as a caregiver—they see what they are doing as their role as a parent, sibling, child, spouse, friend or neighbour. However, in a short time, the expectations and demands of the caregiver role extend beyond what we typically expect of a family member or friend.

As with most health care experiences, the large majority of caregivers talked about both good and bad situations. In many cases, when they shared stories of when they felt supported by the health care system as a caregiver, it was simple things that made a difference, things that can be easily implemented and that usually don't require resources or a huge change management process. A positive mind-set towards caregivers—simple kindness, respect and appreciation—went a long way.

Most caregivers said they felt their role was both rewarding and challenging. How they felt changed day by day, situation by situation. For long-term caregivers, the rewarding feeling often wavered over time, because in those caregiving situations, caregiver burnout was at play. As one caregiver explained, sometimes it is important to be recognized as simply who they are to the person they are caring for, and not as their family caregiver.

As we heard the stories of many caregivers, filled with complexities, we listened closely for learnings that related directly to understanding how Ontario's health care system does, or doesn't, recognize and support family caregivers as part of a patient's care team.

This project leveraged findings from journey mapping, caregiver workshops, mini online surveys, caregiver interviews and the Town Halls to tap into the wealth of knowledge and experience of people with lived caregiving experience. The caregiver stories we heard touched on the physical, emotional, mental and spiritual impact of caregiving. Some of what we heard was inspirational; some of it was heartbreaking.

Through this work, we identified four overlapping and interconnected themes that will inform the next phase of our work with caregivers. These four themes can be considered elastic in nature and may not appear in chronological order in any one caregiving journey. Nevertheless, they represent common threads of experience.

Throughout this report, we have used caregivers' own words, quotes and stories in order to paint a picture of the mosaic of caregivers in Ontario.



Speaking from Experience: Meet Francine

Age: 70

Number of years caregiving: 15

Person she cared for: Her husband who had diabetes, post-polio symptoms and neuropathy. Later he also developed kidney failure and required dialysis at home every night. He was in wheelchair because he was a double-leg amputee due to his diabetes.

Husband's age: 53 to 68



About Francine: Francine was the primary caregiver to her husband. He lived at home with Francine, and they ultimately had home care through CCAC for 14 hours a week. At first, she was still working as a teacher, but retired a few years later and had to give up any contract work due to her caregiving demands. She was a constant advocate for her husband, especially when it came to home care hours and support. She trained many home care workers over the years. Francine's husband died in December 2015. Today, she misses her husband greatly, and is embracing her life beyond caregiving, including volunteering and spending more time with her daughter and grandson.

Here is Francine's story, in her own words.

"I had a hard time finding time for myself or to leave the house for a short period of time. During the day, I was like a jumping jack. I couldn't sit still for very long: meals to prepare, blood sugar, pills and insulin to take, trips to the commode, phone calls, dishes, trips to the pharmacy. I could start to relax after his bedtime routine around 9 pm."

"After his discharge from the hospital, I felt like I didn't have the necessary skills and knowledge to provide care for a person who had complex health issues. At the beginning, I felt I lacked confidence and felt unprepared. I was suddenly expected to manage things like administering medications, managing blood sugar and insulin, transferring from bed to commode or vice versa, providing emotional support and comfort and coordinating care and meals with three different diets and numerous restrictions."

"The staff at the nephrology department were the best. They were good listeners, they took the time to listen to us to point out things we did right and to encourage us to continue. They gave the best hugs and always welcomed you with a big smile. We always left feeling good after a visit to that department."

"Caregiving is almost a 24/7 job. The caregivers need respite or time off to refill their well. If not, they will be the next clients of the CCAC."

"I can really say he was a patient patient. That helped in my caregiving for him, but I had moments where I was angry, depressed and felt resentment."

"One PSW was there a lot. She did 600+ hours in two years. She became a good friend. She really engaged with my husband, would colour with him, take him for a walk or to the mall, did all his laundry. She did more than her job description. She even read the eulogy at his funeral."

"I used to hate to speak on the phone especially in English since French is my mother tongue. I had to learn to overcome this difficulty because I was on the phone every day. I had no choice because very few providers could speak French."

Advice to new caregivers:

"Do not be afraid to ask questions. Taking notes of my observations and discussing it with the proper provider was a good way to learn. Do not be afraid to complain if you're not satisfied with a service."

Recognition of the family caregiver role

Overall, there is a lack of recognition of family caregivers and their role in the health care system. The lack of recognition takes two forms.

The first is that many family caregivers don't define themselves as such. They just see what they are doing as their role as a mother, sibling, friend, spouse, etc. They are just stepping up to look after a loved one. As they begin their task, they begin to realize there is a role and it's an important one.

Second, the family caregiver role is often not recognized or respected by members of a patient's health care team. This often means that caregivers aren't treated as a team member. Caregivers told us they do not often feel included in decision making, even though they consider themselves the experts on the needs and preferences of their loved ones.

Many family caregivers said they were looking for basic kindness, respect and acknowledgement from the health providers looking after their family member. Family caregivers want to be seen as a valuable member of the care team, able to offer vital information for care planning.

The voices of caregivers on recognition

Caregivers want to be treated and respected as the person who knows the most about their ill family member. Caregivers spoke of how vulnerable they felt caregiving and that it was upsetting to be overlooked, ignored, reprimanded, and underestimated by the health care practitioners caring for their family member. When caregivers were recognized, it made a big impression.

The mind of a caregiver is rarely at rest.¹ Throughout any given day, caregivers can be found engaged directly in caregiving activities, planning activities related to the care they are providing, trying to maintain a sense of self through this process. Any way you look at it, caregiving quickly becomes all encompassing. Each caregiver experiences the pervasiveness of the caregiving role differently, depending on who they were caring for, and their own situation.

^{1,2} Overlap Associates report for The Change Foundation

Many remarked that caregiving is a lonely job. Caregivers described feeling abandoned—not knowing who to call or where to go for resources—especially in the beginning of the caregiver journey.

In their own words

“We need to be a team. You are the medical professional and I need your help and advice to make my life and the life of my child better. I am the caregiving professional for my child, so listen to what I have to say. I know my child more than anyone.”

“Being a caregiver is like white noise, it follows you wherever you are, whether you are at work, at the gym, driving home, in a meeting with colleagues or lying awake in the stillness of the night. Caregiving is not a responsibility or a job you apply for, it is something that comes unbeknownst to you on a silver platter with a 24/7 commitment.”

“[Caregiving is] a series of steps—planning, preparing, and enjoying a family meal—took upwards of nine hours to complete. Having to go to a new grocery store caused (my) loved one to become upset and anxious, requiring hours to calm down before proceeding.”²

“Caregiving is the saddest job one could ever have.”

“I have been in so many situations with my loved one that have helped me learn what to do. I can write it down but no one bothers to read it. We need to be able to give staff training and knowledge of caregiving. There also needs to be a willingness to receive the information.”

“The fact that somebody actually took time, because I was not the patient, made me feel valued. It made me feel like all of a sudden someone saw me and my struggle.”

“I felt very upset, shocked and angry to be forced to drive nine hours for a 20-minute meeting [at which] I was not listened to regarding my mom's care.”

Communication between caregivers and system providers

Communication between family caregivers and providers across health care settings was a major and overlapping theme. From a caregiver's perspective, serious challenges included the lack of information about the patient's health condition and poor communication about navigating a large and multi-faceted health system.

First, there is often a lack of communication with caregivers about what to expect regarding the patient's condition, its anticipated trajectory and what to expect in terms of their caregiving role.

Second, there is often an expectation that caregivers will be responsible for cross-provider communications and provide the continuity of information from one health care provider to the next. This is a by-product of a much larger system issue—the inability to easily, consistently and securely share health information between providers, especially if they are from different organizations or parts of the system. Caregivers often say they feel they are ill-equipped to play this role.

In every engagement session, communication ran through discussions and various reflections as a common thread. It was identified by participants as an area for immediate action.

The voices of caregivers on communication

Caregivers described feeling left out, shocked, angry, feeling small, anxious, rushed and excluded by health specialists when their family member was referred to them. On the flip side, the times when caregivers were acknowledged, included and even embraced by health care providers stood out as great experiences for caregivers and patients.

It was clear that system challenges and navigating through Ontario's complex health care system added to caregiver frustration and distress, and often manifested as communication issues.

Many caregivers talked about “falling into the role” and having to “push” and “take charge” in order to advocate for their family member. They described the constant need to “fight” to get the services they were entitled to, especially for home care and publicly funded respite care.

We also heard a constant refrain about the large variation in care provided by different personal support workers (PSWs) and different agencies—and the lack of communications between them. Caregivers found it stressful to have so many different people through the house to provide care. This was heightened for caregivers who were providing care to frail/elderly care receivers. Those who could afford it hired private care specifically because of the inconsistency and unpredictability of home care services.

In their own words

“I feel like I am always talking to the wrong person.”

“While I was trying to get my wife diagnosed, I felt like I was the Lone Ranger. I felt that I wasn't being heard, that I wasn't being understood, and that if there had been some kind of available treatment, or medication at the very early stages, we didn't know about it or have access to it, because she wasn't diagnosed right away.”

“Our wait was eased somewhat [made more enjoyable] when an emergency volunteer came by to chat, see if we needed anything, and he got us coffee, etc. He got my loved one a warm blanket. It didn't shorten the wait, but it filled in some time. The bright spot in an otherwise tedious afternoon.”

“When dad went into the hospital recently, the communication was excellent. Doctor told us what time he would be there everyday and if we missed him he emailed us with daily updates. Choice is the most important thing today—people make educated choices regarding their care.”

Communication between caregivers and system providers

“I remember talking to one nurse. She listened to what I was describing. She asked appropriate and thoughtful questions. She left me feeling confident that she understood what was happening with my loved one. The nurse asked questions that did not lead me to wonder if she were judging me, rather they were specific to symptoms of mental illness. That nurse left me feeling like she believed that my loved one would return to having a better quality of life.”

“I had a specialist sit us down and honestly tell us he could not predict where the client would be in five years. He advised of ongoing medical developments that could help the client regain some of what we had lost. He provided the name of a further specialist whose specialties were more in line with my loved one’s deficiencies. He spoke calmly, confidently and compassionately. We left feeling empowered and ready to move forward wherever that journey may take us.”

“Many health care professionals expect me to be the expert or go-to resource in his care. I am not a health care expert.”

“I’m very forceful about getting what I think is needed done, I try and do it in a very nice way. I’ve never had anybody get upset with me. But I think it’s very important that you have to take charge of your own lives, and your loved one’s treatments.”

“In my experience with the Canadian health care system, I know that you’ve got to push just enough, you need to be quietly assertive and sound intelligent enough so that people take you seriously, but you don’t want to be so pushy that you sound like you’re becoming unhinged. My mindset [throughout caring] was to be very quietly, pleasantly assertive, to make sure my mom got best access to care possible.”

“Although I am not afraid to talk, it is very stressful/uncomfortable for me to talk about my needs. I am very private. I am greatly saddened that I had to place him in long-term care rather than keeping him at home. Rather than me asking for things, I would like people to offer me help, tell me they care, offer me information on my loved one. I hate asking how he is doing, although I am dying to know. The long-term care home says call anytime [but] they are always so busy. I hate to disturb. But I need the information as he is the love of my life and I need to know he is okay.”



Family caregiver assessment and identification of caregiver needs

Once the caregiving role begins, there is little assessment of what families are able to do and what they might need help with. Moreover, there often aren't any ongoing check-ins to see how the caregiver is doing. This is of particular concern for long-term situations where the patient's condition deteriorates and the intensity of the caregiving role increases.

As one caregiver explained, "Too many times health care professionals take it for granted that caregivers can just take on the responsibility of caregiving. They don't ask if we are capable and if there are other challenges you are living with that are increasing your stress levels."

A caregiver's time, energy and resources are not endless.³ In fact, if a caregiver's well-being isn't considered early on and in a proactive way, caregiver burnout and distress is inevitable.

Identifying the main family caregiver for a patient can sometimes be challenging. In times of illness many family and friends rally to the patient's side, but identifying who will be the primary support is not always easy. Once that person is identified, there is seldom much opportunity to sit down and assess what the caregiver will need to fulfil their new role. Providers pointed to this challenge repeatedly in our engagement with them. For family caregivers, this lack of identification and assessment meant they constantly had to stake a claim for information and other needs.

The voices of caregivers on assessment

As participants shared their stories throughout The Caring Experience, it became clear that many of the issues mentioned coalesced around the need for formal assessment to address caregiver abilities, knowledge, and preparedness to take on their role.

There's no question that caregiving has health implications, both physical and emotional, for many caregivers. The financial impact for caregivers is also very real and can be profound. For some, it's the added costs of medications, equipment, and specialized treatment including supplementing what the public system offers with additional therapies from private, out-of-pocket providers. For others, the financial stress was more fundamental than that, it was about just trying to make ends meet.

Because caregiving transcends everything caregivers do, it is incredibly hard to find any balance in life because it's hard to reconcile the needs of the caregiver and the needs of the patient. Many expressed their inability to maintain a sense of self due to the intensity of caring. Others explained that the impact of caregiving came out at unrelated times, such as during their daily commute, because it was the only period in the day that they have time to themselves.⁴

The scheduling and timing of appointments, both doctor's appointments and home care visits, can cause massive amounts of stress for a caregiver. Caregivers often get used to shifting their personal priorities to accommodate the schedule of others.⁵

^{3, 4, 5}Overlap Associates report for The Change Foundation

CAREGIVER PROFILE

Meet Marilyn, former caregiver to her husband Jim. She is a powerful example of how empowering and training family members can improve the health and quality of life of a patient with Chronic Obstructive Pulmonary Disease (COPD) and other chronic illnesses.
<https://www.youtube.com/watch?v=8FoeBOI9y9E>



Family caregiver assessment and identification of caregiver needs

In their own words

“My husband refuses care. He says, ‘you can’t send me to respite. I have rights’. But from the caregiver perspective, if that’s making me sicker, where are my rights?”

“It seems as if [providers] don’t realize that it is often the caregiver that is the one that needs the help. The caregiver is the one putting all of the time and energy into keeping their dependent stay healthy and comfortable. Most health care providers seem to look at only the dependent. If the dependent is healthy, it is because their caregiver has kept them that way.”

“She is getting care, but nobody cares for me.”

“Just because someone appears able and competent doesn’t mean they don’t need help. Once I started having melt downs, services started taking our needs more seriously. It should not have to get to that point.”

“I’ve tried so many different jobs revolving around my loved one’s needs. When I have a job, it’s better for me. When I don’t, it’s better for the family.”

“Why is it so expensive to get equipment? Why is the profit margin so huge to providers of this equipment? Why are aids for daily living so expensive? If we are caring for our loved ones outside of the nursing home or hospital settings, why are we not entitled to the equipment and products patients get in those settings?”

“Why is it so difficult for caregivers to get the help they need when they are on the cusp of burning out? Why do health care professionals not ask me how I’m coping with the situation?”

“I go to food banks. Some home care workers are so kind they bring me extra Depends from supplies people donate to them. I use mash potatoes to thicken soups and carefully monitor my loved one’s intake till I can afford store bought thickener to add to drinks. Right now I cannot afford fruits, whole wheat breads and sugar free canned food! I’m relying on food banks and doing my best to go without for myself so my loved one can get more to eat.”

“Lifting my husband can be strenuous on my body due to our size difference, but the hardest part of my role is the coming to terms with the guilt I feel. I have a tendency to treat the caregiving role as a job and early in the morning/late in the evening is ‘my time’. When this is intruded upon I have to swallow my anger and then of course I feel guilty.”

“I felt like I was being punished for keeping my loved one healthy, and it made me extremely disappointed in the whole health care system. They were only looking at my loved one, and not seeming to understand that it was me that needed that help in order to keep my loved one healthy.”



Support, training and education for caregivers

Beyond recognition of the family caregiver role, caregivers clearly stated that they want and need support and training to help them in their role.

Simply needing “a break” was top of mind for many family caregivers. Respite is imperative and should start early. However, caregivers want respite beyond time to do chores, go to their own appointments, or buy groceries. They also need time to themselves, to do what they want and need to do.

For caregivers who arranged respite, however, they sometimes found themselves unable to comfortably take time away from their loved one. This was due to the fact that a new support worker, unfamiliar with the patient’s specific case or health history, might need time for instruction and training from the caregiver. As a result, caregivers might feel it easier to maintain the status-quo with their regular support team than try to seek new support and make additional time for themselves.

In this case, caregivers are looking for more flexibility from the system to make their own arrangements with the professionals of their choice. They may have had time to develop a closer relationship and familiarity with certain individuals, establishing a better rapport and elevated level of trust.

As well, caregivers want caregiver skills training because they are being asked to do personal care and medical care for which they have had no training. Caregivers reported feeling that they were putting themselves and their family members in an unsafe position or at risk.

They also want help advocating for the patient and navigating the system and they want support managing their own mental and physical health.

The voices of caregivers on support and education

The need to be and feel supported was a very consistent comment from caregivers. We heard this over and over, and in some cases, we heard the level of desperation they have about needing support.

When caregivers were asked what helped them get through their time as a caregiver, or what supports they found helpful, many answered that it was connecting with other caregivers in similar situations. Unfortunately, many caregivers said that they had lost friends who were not in the same situation, or had never provided care like they did.

Caregivers need education and training. They aren’t given the tools or formal training needed to care for their family member with the confidence and tools they want and need.

In their own words

“My work schedule is 168 hours a week, of which you send someone to help for nine and a half hours. I want to keep myself and my husband safe and home, where he belongs, as long as possible. I need you and the help you can provide to help this happen.”

“When I connected with another caregiver, that was the first time I thought I wasn’t crazy.”

“There is nothing better than interaction with another mother of a brain injured child.”

“The problem with caregiving is that we always assume we aren’t doing a great job. We haven’t been trained or given the tools.”

“You have been trained in the health and safety of how to move a patient, change an incontinent product, use the myriad of equipment we now have in our home. I have not. Please teach me. My health and safety counts too.”



The ideal future: What do caregivers want and need?

A key component of our caregiver workshops was an opportunity for caregivers to describe the ideal future state for caregivers. They were asked to fast forward 10 years, and write a postcard to themselves to describe this ideal future. Quotes and passages that illuminate their wishes and expectations have been included in this section.

Often times, caregivers' needs are quite simple. Of course, they would all like a more coordinated system, and one that is easier to navigate. They want health care providers to speak to each other, and share information seamlessly. But aside from the wider system issues, their needs are quite straightforward, and in many cases, these needs can be met with little or no additional resources.

A big step forward would be to change the organizational mindset about caregivers, and build a caregiver-friendly culture. Small gestures of support go a long way for many caregivers.

Fundamentally, caregivers just want to be informed about what is going on, and to be acknowledged. When that happens, they feel more confident and able to care.

Consistency in care providers was also a constant refrain among caregivers.

“What I needed would have been one person coming to take care of my wife. It would have been somebody that came in every single day, knew her and did something for her. But that didn't happen. Instead there was a different person every time.”

“We need a single case worker for patients who also deals with social and financial issues as well as home care.”

“I feel elated when we do have a PSW who is consistent and communicates with the rest of the team.”

When caregivers were asked to describe the ideal state for caregivers, they didn't hold back.

“What a great doctor visit! The doctor came to my mom's room, mid-morning. He commented on her art and complimented her. This encouraged her to open up and talk about what she was doing. She got up to show him her art on display in her bedroom. The doctor was able to assess her mobility, notice any change in fine or gross motor skills. By engaging her in conversation he was able to assess her cognitive abilities as well as her memory. He casually inquired about her sleeping habits and, noticing the bathroom handrails, he inquired about falls. On returning to the living room, he took her blood pressure and gave her the flu shot. He then thanked her for the visit. She smiled and said goodbye. I left with the doctor and shared my concerns.”

“I am so confident being a caregiver because I have medical support when I need it at home. I have enough people helping me in the house with shopping, cleaning, and personal support.”

“In a perfect world there will be a coordinated approach between doctors and the health care system to support and educate caregivers throughout the journey. Clients will be cared for in the home for as long as possible and then helped to transition to a beautiful facility with lots of support and care for families of the client. More outreach; satellite facilities in large and small communities.”



The ideal future: What do caregivers want and need?

“In the future, the following might characterize a health care system:

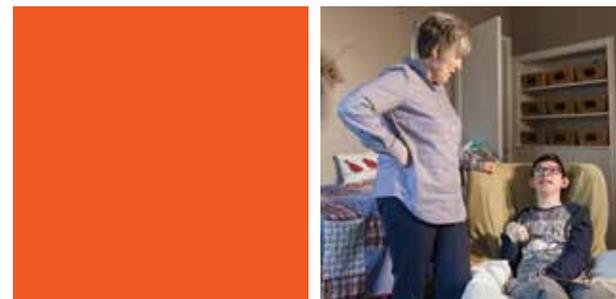
- It is focused on health care not sickness care.
- The caregiver is as valued as the care recipient.
- There is a coordinated information management system, where the caregiver is not repeatedly asked the same information and the client not discharged and reactivated for each health decline or manifestation.
- Respite care is a reality not just a concept.
- There is a 24-7 helpline for caregivers.”

“For me, the ideal caregiving situation would be to have someone explain to me what is going on. I would want someone to be there to listen to me about my fears and anxiety. This needs to happen immediately. How can I be expected to take care of my loved one if I can't take care of myself? Guide me through what to expect from my loved one's conditions and help me to help him.”

“One person should be assigned as the 'specialist' who will know my loved one the best and is a go-to person for any issues with my loved one, or who I can go to to ensure things are logged on the chart or communicated.”

“A full team in place when entering hospital. Everyone is awesome with all the information and support we are getting. We have a doctor that really listens. The stigma of mental health no longer exists. We even got a package of information to take home with support in place even for us caregivers. We as caregivers have a say when our loved ones can't, and we actually get results.”

“I would have liked a road map of what needs to be done and when, from the doctor on diagnosis. Not a folder with pocket inserts, a proper guide book, spiral bound, so it can lay flat with places to make notes. It should all be in on place with an index, a list of abbreviations and their meanings, a list of financial help and where to find it, websites, names and phone numbers. All that and more.”



Speaking from Experience: Meet Hanni



Age: 70

Caregiving since: 2010

Person she cares for: Her husband Laurie, who suffers from early-onset dementia

Husband's age: since he was 62 (now 68)

At left, Hanni video chatting with her husband Laurie.

About Hanni: Hanni is the primary caregiver for her husband who was diagnosed with early onset dementia in 2012, following two years of trying to get an accurate diagnosis. At first, Laurie lived at home, and she could maintain her part-time job. They received some home care services, and he attended a day program at the Alzheimer's Society. Within 18-months of being diagnosed Laurie was suddenly admitted to a psychiatric ward. Knowing it wasn't the right place for him, but having no other options, Hanni's role had to change from caregiver to advocate. After a number of months he was moved to a long-term care home, which was not successful. Ultimately he was admitted to a specialized senior inpatient facility in Kingston where he is still awaiting a long-term care bed.

Here is Hanni's story, in her own words.

"My error, due to exhaustion, was waiting so long before acting. I don't blame myself but do feel badly that my husband had to struggle through a medication-induced stupor, messed up sleep cycles and bed restraints at night for three months while I put out fires all along the way and regained some energy."

"When he was in the psych ward, it was like being at war. I was strategizing every second. I was trying to protect him and trying to figure out a way for him to have some quality of life."

"You have to pick your battles. And you learn that along the way. Also you don't know who your allies are early on."

"Six months ago we started to FaceTime. It's made such a difference to him and to me. Every facility should offer this. It's reassuring for him, especially when I'm away and can't physically visit him. The only downside is that he needs to have a staff person with him for this as he can't manage that on his own, so it requires resources."

"When Laurie went to the facility he is now for the first time, I was told there was to be a Meet and Greet for 15 minutes. I was skeptical. Another meeting? The 15-minute meeting was an hour! All 10 staff wanted to know about Laurie, and they asked intelligent questions. It was excellent. They were interested in who he is."

"There was one nurse who was amazing. I knew when I was talking to her, she was giving me her full attention and was thinking about what she could do to help. It's so simple, really."

"I wanted to take a course in Gentle Persuasive Approach¹ (GPA) and was told it is not available to lay people. Hello? How can the system say they want people to stay in their homes as long as possible, say they are concerned about caregiver burnout and then turn around and deny them the tools with which to facilitate dementia people staying in the home longer?"

"The thing that irks me the most is when health care staff talk to me about Laurie, and he's right there, but they don't acknowledge him. They talk as though he is not there. They call me Mrs., and they call him by his first name, like I am his mom."

Advice to caregivers to those with dementia:

"Alzheimer's Society is the place to go. But what most people don't seem realize when they get this diagnosis is that, your first line of defence is CCAC. If you don't think you need CCAC, you are doing yourself and your loved one a disservice. It's the only way to get your name on a list for a long-term care facility, which can be a very long wait."

¹GPA is a training program to teach people an approach to managing behavioural issues in dementia.

Unique caregiving profiles

Young carers

Although caregivers are a heterogeneous group, one category of caregivers is often forgotten or not considered—young carers. Young carers are children, youth and young adults, who are in a caregiving role for a family member who needs assistance with their daily lived experience due to illness or disability.⁶

They face the same challenges as other caregivers, but their issues are amplified. They are most often not recognized or even acknowledged by health care professionals, and due to their age, their viewpoint can often be dismissed or ignored. Most of all, too early in life they are “parentized” (in a role reversal, they assume a parental role towards their family member), and rarely have time to “just be a kid”. In light of that, their feedback and reflections were especially poignant. This is what they wrote down, when they were asked what they wished for:

- **I would wish for financial stability for my family.**
- **I wish that there were more hospitals and institutions nearer to my home that provide the care we need.**
- **I wish that there was less medication to keep track of and more results.**
- **I wish my sister didn't have autism.**
- **I wish people were more understanding.**
- **I wish for my mom to play with me.**
- **I wish I could be able to spend more time with my family.**
- **I wish my sister could talk and being a carer wasn't stressful.**

⁶For more information, please visit: www.powerhouseproject.ca/about/.

To see videos created by Powerhouse Project youth, please visit: www.changefoundation.ca/ontario-young-carers

Indigenous caregivers

The experiences of caregivers in the Indigenous community were starkly different from those of other caregivers, as were their needs. In one case, a caregiver explained that there simply is no access to services. “You are talking about a system. There is no system for us. You are talking about apples, and I’m dealing with oranges.”

One Indigenous caregiver expressed her need for the health care system to listen to her brother who is an herbalist and holistic healer. As she described it, “he gets dismissed by health care providers.”

Another caregiver described her challenge: “CCAC, both on and off the reserve, do not really listen to what the true needs are.” She went on to explain that, just because her mom can stand at the sink briefly, they were denied someone coming to help her bathe.”

Another caregiver said that his wife, who is the main caregiver, needs someone to talk to, as she gets frustrated. He said his wife is occasionally able to speak to a social worker at a hospital, but that she needs such help to be more regularly available.

One caregiver, who provided care to his father, expressed his difficulty in “adjusting to the role reversal that takes place between child and parent when they get older.” He added that what is needed is “culturally appropriate programming” to address the loneliness for seniors. Although he said that such programming is more available now, it didn’t exist when his dad needed it.



Conclusion

Listening to, and learning from, so many caregivers across Ontario impressed upon us the many types of challenges and experiences that occur each day in our health and community care systems. Not only were stories extremely varied in terms of subject matter, some caregiving experiences spanned months while others had been going on for years. Although it was clear before the start of The Caring Experience, the reality that caregiving cannot be considered a uniform experience was staring us plainly in the face.

Despite this, it was these same stories told at workshops, through journaling, or in interviews, that stitched together common themes to be addressed in our future work: Recognizing the caregiver and their role; communicating and exchanging information clearly; assessing caregiver abilities and knowledge; and providing the right kinds of support and education at the right time. These all emerged as pathways that could lead to improved experiences for family caregivers.

We believe that, by addressing these themes in partnership with both Ontario health providers and family caregivers, it is possible to transform the health and community care sectors in meaningful ways that benefit everyone.

Part of the next step is to encourage ongoing caregiver engagement, and ensure caregiver voices—with their concerns, ideas and expertise—are amplified across the province.

We plan to do just that.

Appendix: Engagement Activity Summary



Appendix: Engagement Activity Summary

Each of our formal caregiver engagement activities are described below.

Province-Wide Town Halls: November 24, 2015

On November 24th, 2015, The Caring Experience project hosted two, 60-minute “Open Lines” town hall events. These province-wide, telephone-based town halls served two primary purposes: to disseminate project information to the Ontario population, and to drive recruitment for further project engagement activities.

A total of 114 people attended the Town Halls. Seventy-three people joined the afternoon session, and 41 joined the evening session. The Town Halls were hosted by the moderator, Denise Harrington, who gave an overview of The Caring Experience project, and outlined the opportunities to get involved. A main feature of the Town Halls was live interviews with two caregivers, Donna Thomson and Maciek Karpinski, both from Ottawa. Donna shared her story and experience as the mother and primary caregiver to her son, Nicholas, who was born in 1988 with severe disabilities. Maciek’s caregiving experience involved providing support and care to his mother, who has a chronic condition, and at the same time, supporting his brother who had an unexpected health crisis at the height of his caregiving duties with his mother.

Throughout the sessions, poll questions were asked of the audience. Their responses were fed back into the live facilitated discussion. In addition, callers were invited to ask questions about The Caring Experience, or to share their own caregiving experiences.

Caregiver workshops

In January and February of 2016, we held nine Caregiver Workshops across Ontario with local caregivers in the following locations.

- January 11, 2016 – London
- January 13, 2016 – Hamilton
- January 18, 2016 – Sudbury
- January 19, 2016 – Thunder Bay
- January 20, 2016 – Kingston
- January 21, 2016 – Ottawa (French language)
- January 25, 2016 – Lindsay
- February 2, 2016 – Toronto
- February 25, 2016 – Toronto (Indigenous)⁷

The caregiver engagement workshops were designed to provide insight and understanding about the role and experience of family caregivers, with a specific focus on their interaction and experience with the Ontario health and community care systems.

In partnership with the Ontario Caregiver Coalition (OCC), we promoted the workshops locally using a first-come, first-serve registration model. More than 140 caregivers registered to participate in the workshops, and in the end, each session had between five and 21 participants.

Overlap Associates facilitated each session, and one representative from The Change Foundation attended each session.

⁷Short Interviews at 2016 Chiefs of Ontario Health Forum



Appendix: Engagement Activity Summary

The two-hour workshops included three activities: an individual empathy mapping exercise, a collaborative threads and themes activity, and an individual visioning exercise.

Individual Empathy maps: The purpose of this activity was to ground each participant in their personal caregiving experience. Participants were asked to think about an aspect of their life as a caregiver, and fill out a sensory wheel with description of what they were hearing, seeing, feeling, saying, thinking and doing during that experience. This step helped participants recall and reflect on the details of that experience. The sensory prompts garnered a holistic view of the example being thought of, and encouraged participants to examine the experience through different lenses, prompting new insights.

Next, participants were asked what they were trying to achieve during the chosen experience; what they had to do to achieve it; what made it difficult to achieve; and, crucially, what single change would make the biggest impact to improve the experience. This section of the empathy map helped identify participants' needs in that moment, the obstacles they perceived and the opportunities for change.

To wrap-up this activity, a few participants shared something they had written with the group.

Collaborative Activity: Threads & Themes. In this part of the workshop, participants were guided through a collaborative activity to contribute their experiences to a larger discussion. Participants were given a few minutes to individually write down experiences related to interactions with the health care system, each with an associated feeling. Associating experiences with feelings provided a useful way to organize and interpret the events.

Participants were then brought together in small groups and asked to share what they had written. They were encouraged to build on each other's experiences by sharing related stories written on sticky notes. This activity was meant to generate conversation amongst participants. Hearing the experiences and feelings of others often prompted participants to recall and add an event beyond those they had originally written down. As themes of feelings and/or experiences began to emerge, groups were asked to cluster those ideas.

Time was given for groups to share learnings, surprises and/or insights with the larger group.

Visioning Activity: Postcards from the Future. To conclude each workshop, caregivers participated in an individual "Postcards from the Future" activity. Everyone was given one postcard and asked to envision themselves in an imaginary future, one in which they are living out an ideal caregiving experience.

They were asked to write a postcard to themselves describing what they felt like in this ideal situation. Half of the participants were asked to write postcards specific to health care interactions, while the other half were asked to speak to the caregiving experience in general. This activity helped identify the elements of a better caregiving experience.

The ninth and final caregiver workshop was reconfigured to engage the Indigenous community. We attended the 2016 Chiefs of Ontario Health Forum, and spoke with 20 attendees through short, conversational interviews, and asked them to share their experiences of providing care. It's important to note that although many family caregivers don't identify as such, this is especially true within the Indigenous communities. In speaking with Indigenous people, there was a widespread sentiment that caregiving was simply doing what should be done to support others in their community.

Appendix: Engagement Activity Summary

Journey mapping

From January to early March 2016, the project team at Overlap Associates coordinated and completed journey mapping activities with 18 participants across Ontario.

The purpose of the journey mapping process was to gain a deeper understanding of the lives of a cross-section of family caregivers. Twenty people were selected from a list of 35 people who had put their name forward to participate. Selection was based on a matrix of participant characteristics developed by the Foundation and the OCC in collaboration with Overlap Associates to ensure diversity in age, gender, geography, health challenges and length of caregiver experience. Due to the nature and challenges associated with caregiving, two of the 20 participants made the decision to withdraw from journey mapping at various points throughout the engagement.

All of the caregivers who were not asked to participate in Journey Mapping were offered the opportunity to contribute to The Caring Experience in other ways, including Caregiver Workshops in their local areas, mini online pulse check surveys, or one-on-one caregiver interviews (done over the phone).

It is a challenge to represent the diversity of caregivers across Ontario through a limited engagement process. However, the caregivers who engaged directly in journey mapping represented the following characteristics:

- **Geographic dispersion throughout Ontario**
- **Rural and urban**
- **Male and female; aged 35 to 69**
- **Indigenous peoples**
- **Francophone**
- **Multi-lingual**
- **LGBTQ**
- **New Canadian and other diverse groups**
- **Full-time and part-time caregiving roles**
- **Varied employment status: full-time par time, self-employed, unemployed and retired**
- **Interactions with a wide range of services and organizations**
- **A variety of diagnoses and caregiving needs or responsibilities⁸**

⁸Journey mapping included caregivers to people with: Achalasia, acquired brain injury (ABI), issues related to aging, Alzheimer's disease, amyotrophic lateral sclerosis (ALS), aphasia, autistic spectrum disorder (ASD), cerebral palsy, congestive heart failure, dementia, diabetic ketoacidosis, early onset Alzheimer's, fetal alcohol spectrum disorder (FASD), gigantism, lymphoma, mental health concerns, mild intellectual delay, mood disorder, multiple sclerosis (MS), paralysis, Parkinson's disease (PD), schizoaffective disorder, reactive attachment disorder (RAD), sleep apnea, and medically fragile/technology dependent people.



Appendix: Engagement Activity Summary

Journey mapping activities

Journey mapping is traditionally a “real-time” activity used to document the steps in a person’s experience. Due to the nature of caregiving, this exercise was adapted to make it easier and more flexible for caregivers to participate. The Caring Experience Journey Mapping process took place over five non-consecutive days in which participants agreed to share and record the details of their day-to-day life and experience as a caregiver in-the-moment, with a specific focus on their interactions with the health and community care systems in Ontario. The stories reflected a mixture of current and past caregiving experiences.

Participants were invited to share and record their experiences in whichever ways they felt comfortable. These included:

- **Empathy map and journey map worksheets (hand-written or typed) to explore particular events or processes from a highly personal perspective;**
- **Journals (handwritten, typed or photographed, or video journals) to understand caregiver tasks, skills and resources;**
- **Typed responses to structured, qualitative question sets; and**
- **Scheduled check-ins (email or phone) to elaborate on details of specific experiences both past and present.**

At the end of the five days, a 30-minute debrief phone interview was completed with each participant.

A small honorarium in the form of a gift card valued at \$200 was given to each journey mapping participant, due to the time and intensity of participating in Journey Mapping exercise. To determine the honorarium, The Change Foundation used our own compensation framework, *Should Money Come Into It?*

Online pulse check surveys

Three online ‘Pulse Check’ surveys documented input from approximately 120 respondents (some caregivers responded to all three surveys). These online surveys were sent out by email to gather more information about the experience and demographics of who Ontario family caregivers are, and to learn more about the contributing factors to their positive and negative caregiver experiences.

This is a snapshot of the caregivers who responded to the pulse surveys:

- **On average they were providing 52 hours of caregiving per week**
- **88 per cent felt (or sometimes felt) included as a member of the care team**
- **75 per cent have NOT had any training regarding the specific health needs of the person(s) receiving care**
- **Only 37 per cent have been offered education about the health issues of the person(s) that receives care**
- **63 per cent did not receive any help navigating the health and community care system**



63% did not receive any help navigating the health and community care system

Appendix: Engagement Activity Summary

Organization-specific caregiver focus groups

To achieve our interest in reaching as many diverse caregivers as possible, The Change Foundation also participated in a number of caregiver focus groups. Through partnerships with a variety of organizations, we took advantage of any opportunity to meet with caregivers. In some cases, we joined existing gatherings of caregivers, and in other cases, organizations asked us to meet specifically with their group, as they knew the caregivers in their group brought a unique perspective that the Foundation would be interested in hearing. In other cases, we made a concerted effort to reach out to under-represented and/or marginalized communities that were unlikely to attend our more formal engagement formats.

Yee Hong Centre for Geriatric Care

In the fall of 2015, The Change Foundation was invited to participate in a series of family and caregiver focus group sessions at the Yee Hong Centre for Geriatric Care that were designed to help inform their new strategic plan. Four sessions were held onsite at three of their long-term care facilities: Finch (Scarborough), Markham, and Mississauga.

A total of 45 caregivers participated at all three events and the focus groups were conducted in Cantonese and/or English.

Reflections coming from the Yee Hong Centre engagement work were as follows:

The family caregivers of residents in the long-term care homes and in the Community Programs, mostly “Baby Boomers”, unanimously want electronic information exchange, a common place for the care recipient’s life and health story to reside, and the use of Internet for caregiver education and communication with providers.

They appreciated the uniqueness of Yee Hong’s commitment to Chinese languages and culture, but they noted that they do not necessarily want that for themselves. They don’t necessarily want Chinese exclusivity for themselves as they move into community programs, retirement and assisted living.

Hospice Care Ottawa

The Change Foundation met with the Executive Director and several staff members from Hospice Care Ottawa (HCO) to learn about their approaches to caregiver support and engagement and to discuss and learn from the results of recent caregiver interviews that HCO had conducted.

At HCO, when a patient is admitted, their caregiver is also seen as a client. Caregivers are asked if they want to also be admitted and if they do, HCO staff uses a network of volunteers to check in and see what caregiver needs can be met.

However, challenges also exist. For Registered Nurses (RNs) doing largely task-oriented home visits, it can be difficult to take time to ask caregivers if they need anything.



Appendix: Engagement Activity Summary

Gilda's Club Greater Toronto

The Change Foundation met with eight caregivers from Gilda's Club Greater Toronto to discuss their caregiving experience. Each of the caregivers in the group was caring for an immediate family member with a significant cancer diagnosis. The comments and stories heard in this session were similar to what we heard through other groups, however they were more intense due to the acuity of the situations these caregivers were dealing with. Although those we met with were receiving great support from Gilda's Club, they told us that they experienced critical gaps in other services and resources especially during times of transition, calling into question the perception that resources for cancer patients and caregivers are highly organized.

The Young Carers Initiative: Powerhouse Project

The Change Foundation facilitated two engagement sessions with The Powerhouse Project Young Carer's Initiative in both Hagersville and St. Catharines. These sessions were held with young carers between the ages of 10 and 17 who are providing support or care to a family member.

The activities asked the young people how they felt about their role, what advice they would give to another young caregiver, and what wishes they have for their role as a caregiver. There were several common themes that emerged from these activities, including feelings of frustration, anger, pride, happiness, and embarrassment.

Mirroring the advice of many adult caregivers, these young carers offered words of strength, patience, and perseverance. Interestingly, young carers in the St. Catharines group said they felt that they were treated and included as a member of a care team, whereas those in the Hagersville group did not feel like part of the care team.

Sessions with parents of the young carers were held separately but concurrently. Key issues and themes that emerged included: frustration with the health care system and exclusion as a member of the care team, the lack of consistency of care and care providers, financial hardships and employment issues, and overwhelming stress. As well, many parents of children with developmental disabilities noted substantial problems with the education system. Consistent issues with access to appropriate care, as well as recognition of the parent's caregiving role and expertise were also noted. Many parents expressed that the young carers are often "parentized" early in life and as a result absorbed a lot of responsibility and stress from caregiving.

Both parents and young carers identified the crucial role that The Powerhouse Project plays in teaching children and teenagers coping skills and stress management techniques, in addition to giving them an invaluable opportunity to interact and socialize with others in similar caregiving roles.



Appendix: Engagement Activity Summary

Caregiver interviews

Interview Participants: By the Numbers

Caregiver Locations

1 Bancroft	1 North Bay
1 Burlington	2 Ottawa
1 Cambridge	1 Renfrew
8 Coburg	1 Strathroy
1 Grand Bend	1 Sudbury
1 Huntsville	1 Thunder Bay
1 London	7 Toronto
1 Newmarket	1 Whitby

Care receivers

Dementia: 6	Alzheimer's: 3
Cancer: 5	Parkinson's: 2
FASD: 4	Ageing: 1
Stroke: 3	Renal/heart failure: 2
Medically complex children: 3	Mental illness: 1

To contribute to our understanding of the vast array of caregivers in Ontario, The Change Foundation completed 30 open-ended telephone interviews with family caregivers about their experiences, particularly their interactions with health care providers. The interviews, approximately an hour long, were done over the phone between September 2015 and March 2016. Family caregivers were recruited through The Change Foundation's PANORAMA panel and PATH project as well as system partners (e.g., the University Health Network (UHN) Toronto and the Hamilton Niagara Haldimand Brant LHIN). Caregiver interviewees were also drawn from among caregivers who were interested in participating in a workshop with The Caring Experience project but were unable to attend, or who were not selected to participate in Journey Mapping. The analysis of interviews contributed to the themes outlined in this report.

“Many family caregivers said they were looking for basic kindness, respect and acknowledgement from the health providers looking after their family member. Family caregivers want to be seen as a valuable member of the care team, able to offer vital information for care planning.”





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