

THE WAY FORWARD

Care & Work: A Balancing Act

Experiences from Health Care Employers and Their Employee Caregivers

Developed by



Advancing Excellence in Home Care

BACKGROUND

Each day, caregivers step forward to provide support for someone in their life in need of care, due to a life-limiting illness. Many view caregivers' efforts as an act of love or simply a personal choice; their support easily taken for granted. The stark reality is that many caregivers sacrifice their own health, psychosocial and financial well-being to provide the necessary care that enables an individual to die at home surrounded by friends, family and loved ones. Family caregivers are an essential part of an integrated palliative approach to care.

Across Canada, more than 8 million individuals are caring for someone in their life with a diminishing physical ability, a debilitating cognitive condition, or a chronic life-limiting illness. Of this group, three-quarters or 6.1 million Canadians are in the paid workforce, balancing their work responsibilities with caregiving duties and personal life. Most employed family caregivers are mid-life baby boomers whom are at their peak earning years and starting to consider plans for retirement. As caregiving can be a full time job in itself, many of these individuals find themselves restricting their paid work in various ways to fulfill the care requirements and needs of their loved ones. When family caregivers are unable to perform this balancing act they experience lost wages, diminished retirement income and sacrifice their extended health benefits. Not only do family caregivers and care recipients experience negative impacts, an enormous impact is also felt by Canadian employers and the economy. The Conference Board of Canada estimated the cost to employers in lost productivity due to their employee caregivers is \$1.28 billion per year.

In 2012, 13 percent of Canadians (3.7 million) aged 15 and older reported providing end-of-life or palliative care to a family member or friend at some point in their lives.ⁱ Caregiving for a loved one at end-of-life, although a rewarding experience, often comes with many challenges:

- Family caregivers identified a lack of necessary resources or abilities to provide end-of-life care in their own home. Specifically, home care services, financial assistance, paid time off from work and home modifications were among the supports listed by the one in six family caregivers who would have preferred providing palliative care to their loved one in their own home.
- Family caregivers often face difficulties getting information from health care professionals, finding local support services and navigating the health care systemⁱⁱ.

As the number of older Canadian rises, so will the number of individuals who rely of family caregivers to support them when they choose to die at home. Recognizing the urgent need for immediate actions, the Canadian Home Care Association – in partnership with The Way Forward – felt it was critical to gain a better understanding of the impact of family caregiving on Canadians' work and life balance. Specifically, the focus concentrated on the home care sector, as family caregivers are a critical part of all home care services and are often the difference between an individual dying at home or in hospital. For home care service providers, challenge of helping employees to achieve balance between their family caregiving responsibilities and work will only increase over time. To identify strategies and approaches that support working caregivers, the CHCA recognized the need to consult caregiver-friendly organizations and understand their journey in providing a supportive workplace environment for their own employees.

METHODOLOGY

The Canadian Home Care Association, as a secretariat for the Canadian Caregiver Coalition, reached out to coalition partners and home care stakeholders to identify health care organizations that provide supportive workplace environments for their employees who are balancing care and work. An e-mail invitation was then sent, requesting a scheduled time to undertake the following activities:

1. 20 minute interview with a representative from the leadership team (preferably, an HR perspective) to discuss the organization's experience and strategies to support their employees who are family caregivers.
2. Identify 5 employees who would be willing to share their family caregiving experiences and how their employer supports them in their role as double duty caregivers (health care providers who are also family caregivers) (approximately 15 minutes/interview)

A total of 8 corporate leaders and 24 employee caregivers participated in the interviews. All interviews were qualitative to allow rich and detailed information sharing about individual experiences and the challenges and rewards they face as family caregivers. The format of the interviews were semi-structured. A standardized, scheduled interview with set questions were arranged with all respondents. However, the interviews were conducted as fluid conversations to allow interviewees to focus on what they think is most relevant to the question and providing the broadest set of perspectives. Therefore, the interviewer frequently had to formulate impromptu questions in order to follow up unique conversation areas that emerged during the interview. The interviews were conducted face-to-face at the employer's location. Questionnaires were shared with the participants prior to the interview. All interviews were tape-recorded to minimize loss of information and allow the interviewer to fully engage with the participant during the session.

Organizational Leadership team members were asked the following questions:

1. How does your organization support employees who are caregivers?
2. What motivated your organization to adopt these practices?
3. What advice do they have for other organizations who want to create a more supportive workplace environment?
4. What are your organization's future plans to support working caregivers?

Frontline employee caregivers shared their experiences in the following areas:

1. How has your caregiving experience impacted your personal and work life?
2. What are some of the challenges you have faced? Sources of frustration?
3. How have you found the strength to keep going?
4. Where do you find support and how do you care for yourself?
5. How has being a caregiver blessed your life?

WHAT WE HEARD: THE EMPLOYERS' PERSPECTIVES

EXPERIENCE IN CREATING SUPPORTIVE WORKPLACE ENVIRONMENT

To understand the experience of employers in providing supportive workplace environments for their employee caregivers, two main questions were asked and common themes were identified to characterize their experiences.

- **What motivated your organization to become more caregiver friendly?**

- Values and culture of the organization

"It speaks volumes about us as an organization and it speaks a lot about our culture when we want to find better ways to support them [employee caregivers]."

"It has been our culture and been happening within the organization for as long as we have been an organization. We have a caring culture."

"We ask whether we operate according to our values."

- Operating within "the business of caring" enables organizations to witness the impact of caregiving for each other

"Looking after people is something we do every day. We see the impact of caring for somebody, we see the work that caregivers do. If this is what's happening at the front line, it is happening in our organization too"

"Working in the home health care business, the one thing that we recognize is the incredible value of caregivers. We get to see what some of the caregivers' burdens are like and also the incredible joy that it can bring in supporting families as they deal with challenging issues."

"We are already in the caregiving business. That is something that is real and relevant to us because this is the nature of what we do"

- Need to address the reality of our demographics: increasing aging population and the number of people who are in the sandwich generation, caring for children and parents.

"We see now more than ever before the need to support our employee caregivers."

"The reality of understanding that our employees who work for us are going to be involved with aging parents or loved ones that choose to die at home and need care and support. It is an aging demographic and an issue that as an employer, we need to provide content in - we just have to address it."

"It is not going to go away with the demographic shift. There is no sense to put your head in the sand when the problem is already here and it is only going to amplify"

- **Seeing employee caregivers as individuals with unique needs**

“We recognize that all our staff are complete people that have lives outside their regular job.”

“Our employees are whole people. They have multiple dimensions of their life. Work is one of those dimensions but there are other dimensions in their life that we need to acknowledge, be sensitive to, that we need to support.”

“I just think that we see this as the right thing to do”

“You want to be there for your employees. They show up for work every single day, you want to give something back.”

“Most people want to do good, want to do well”

- **Supporting employee caregivers is an investment in the organization**

“If we are working together with our employees to understand what their needs are, inside and outside of work, we will build a different level of engagement with our staff when we accommodate the whole person, accommodate all their needs, and acknowledge all the dimensions of their life.”

“It is an investment in your employee and you get that back in spades.”

“If you don’t have satisfied and healthy employees, they can’t give their all to our clients. From a motivational point, that to me is common sense that we need to ensure that they [employee caregivers] are able to do their job and focus on their job.”

- **What are the benefits of supporting employee caregivers?**

- **Increased engagement and enhanced performance**

“If you allow people the opportunity to step away whether it is a day or 6 months wherever it may be, the ability to reintegrate them into the workplace and into their team is much easier. When you support them, they come back quickly, their teammates are supportive, and they integrate much more easily. They become more like a team.”

“Staff is more engaged when they know the organization sees them as people, rather than just an employee”

“The creativity that comes from employees is enhanced, their desire to still achieve all the things they are supposed to achieve is heightened, their relationship to their colleagues is improved, and their advocacy for the company is stronger.

“We experience higher retention, increased loyalty and increased commitment. People become more engaged.”

“As an employer, I also find that when you are willing to give as much as you possible can, you will get back 10 fold.”

“When employees see that we are trying to find ways to support them, they recognize and appreciate that.”

STRATEGIES TO CREATE SUPPORTIVE WORKPLACE ENVIRONMENTS

We asked employers, “How does your organization support your employee caregivers?” and “How do you let your employee caregivers know that they can come to you for support?” All employers indicated that flexible workplace arrangements are very important. This includes flexibility in scheduling or work hours, flexible work locations, job sharing, and telework/telecommuting. Concrete programs that employers offer include the Employment Assistance Program and a variety of leave provisions (i.e. emergency leave or extended leave of absence). In creating their initiatives to become a supportive organization, below are the common strategies that are practiced by the organizations:

- **Building Relationships**

“It is about creating relationships, caring about your employees, understanding what is important to them and what is going on with them”

“It is not good enough if the leadership is the only one that is supportive. It has to be colleague to colleague as well. So it is ensuring that everyone understand that we need look after each other.”

“We have been training our supervisor to focus on what matters most to staff, to create that space to talk about the challenge and jointly arrive at solutions. We have been spending a lot of time encouraging and providing simple tools to help supervisors in their dialogue with staff about what matters most to them”

“My goal in HR is really trying to improve the quality of that connection and relationship. So if there is something that needs to be worked out, that there is a place to go.”

- **Flexibility**

“Because the caregiving experience is so individualized, you need to tailor your solutions - whatever accommodation that works for one person might be different for another person”

“You have to deal with each individualized situation, because first and foremost, everyone deals with stress differently. Everyone sees their role as a caregiver differently.”

- **Ask and Listen**

“We make sure that we connect with our staff so they know that if they need help, they can reach out to us.”

“It is about creating relationships, caring about your employees, understanding what is important to them and what is going on with them”

“If you don’t engage in the dialogue, you are really losing out on the opportunity to develop a solution that works beneficially for both employers and employees.”

“Often what we think people need is not really what people need at all.”

ADVICE FOR CREATING SUPPORTIVE WORKPLACE ENVIRONMENT

The discussions identified many common themes and provided numerous practical solutions in creating a supportive workplace environment. Key themes from the interviews are:

1. Start small. Often, organizations are too quick to assume that caregivers will ask for something big that the organization cannot afford. The reality is, people ask for very small things. Create a caring culture.
2. Have the conversation and start creating awareness. Learn what your employees need and what would be helpful for them. This should be an evolving and reoccurring process.
3. Really Listen. Don’t make assumptions on what would be helpful for them. Create a forum and opportunities for staff to raise issues.
4. Look at other organizations. There are a lot of best practices out there that can be adopted.
5. Trust. Know that most people want to do good things and that together, organizations can create processes and structures that are beneficial to both parties. Don’t plan programs or approaches around the few “bad eggs” that may be there.

WHAT WE HEARD: THE CAREGIVERS' PERSPECTIVES

Although each caring situation is unique, all family caregivers have been in some way filling the gaps in our system to ensure their loved ones choose to die at home in a safe and comfortable environment. They provide a variety of supports, including coordinating and facilitating appointments, managing household duties, helping with the management of pain, providing emotional supportive care and delivering personal care. By observing the nature of caregiving roles, it is easy to say that caregiving is not without a cost. Caregiving can be taxing on the individual's physical, social, financial, and psychological well-being.

The questions answered by employee caregivers offered us the opportunity to understand some of the work and home challenges and experience the lives of 'double-duty caregivers' (health care providers who are also family caregivers).

EXPERIENCE IN BALANCING CARE AND WORK

Below are the common themes that characterize the experience of informants. We asked:

- **How has being a family caregiver blessed your life?**

- **Recognizing the value of health**

"I learn how to value my health, my body. It changed my lifestyle"

"Caregiving has brought into focus how precious health is. It is the one thing that you really only recognize [the value of being healthy] after you have lost it. It is the realization – hey, you gotta take care of yourself too because there are all these people that need you, but you also need you."

- **Building a stronger relationship**

"We talk more than before. It is interesting – we can understand each other more than before."

"Number one and foremost, caregiving has brought me that much closer to my dad. I am starting to see that other side of my dad's life. It is very rewarding and I get a sense of how he lived, some of the decisions he made that have impacted him his entire life."

- **Becoming a stronger person**

"Caregiving has given me lots of strengths – to be able to look at a situation and say 'ok, I have been there' and know that it will pass."

"It makes me want to be a better person."

- **Advance care planning**

“We are starting to form values and have discussions with our children about our future. It helps us make sure that we also take the time to plan ourselves – Retirement planning and long term care planning”

“On day to day basis, you are just living you don’t think about eighteen months down the road. When your husband is really sick, you think about the next eighteen months. In fact, you think about the next month. But then you think longer term.”

- **Appreciation of their employers who are supportive**

“Support of [my] manager – more than anything is helpful. I know that I have the full confidence and support in my boss and my direct manager. And the know that as soon as I can, I will go back to juggle all the balls I have for work, for life”

“It removes another layer of responsibility and another layer of worry and stress for me in an already full stressful environment.”

“It was amazing that I could focus on my mom and not being pulled in fifteen thousand directions. That’s something that I will forever be grateful for - not everyone is blessed in working in the same circumstances”

“My work has been great because they provide flexible scheduling for me to reduce that stress”

- **What are some of the challenges you have faced?**

- **Caregiving is a 24/7 job**

“I feel that caring for a family member is very hard. At work, you care for your clients for a few hours. But with family, it is different – it is 24 hours. You are always thinking and worrying about the person. It is a full time job.”

“I know I have to care for myself. But I don’t have the time - between work, going home and looking after my sister”

- **Caregiving impacts every elements of the person’s life**

“The balancing act really comes with respect to reduced social interaction, reduced family vacation, outings, and holidays.”

“You can’t balance a full time job. Obviously with that, you don’t have pension, benefit and things that you would get with a full time job”

“Sometimes you feel like you are a disappointment to the team because you are not available.”

“It was totally something I didn’t expect. You go through all this turmoil in your life. I am having to give up an amazing job here.”

- **Lack of resources**

“I have always wanted to look after my mom by myself. But, it is hard to care for somebody at home especially when you don’t have the resources. Financially, I couldn’t. I needed to work.”

STRATEGIES IN BALANCING CARE AND WORK

We asked the employee caregivers where they find the support and strength to continue caring not only for the person they care for, but also for themselves. Family caregivers articulated their reasons in a variety of ways. Essentially all their answers really come down to love and investment in his or her family. Many of the family caregivers stated “*You do what you have to do – you don’t think about it*”. Below are the responses that interviewees have shared:

- **Ensuring the care recipient’s quality of life**

“And most important to me, I was able to take care of him, allowed him to die with dignity beside me”

“In the end, I know I have done everything possible to make sure that my mom gets the best quality of care and quality of life. That she gets to stay at her home and doesn’t have to go to long term care.”

- **Investment in family**

“Regarding my job as a PSW, I could still earn it when I’m back for work. But my brother - once he’s gone, that’s it and he will never come back anymore.”

“I take pride in my work but I also look after my family. Family is number one”

“It is a privilege to have the ability to give back. I am honoured of holding both their hands”

“They take care of us all these years. Now, it is our turn”

- **Valuable lessons**

“My children are learning about compassion, empathy and care. They are learning the importance of family and values and you simply don’t abandon those who are sick and can’t take care of themselves.”

- **Self Care**

“When I get up early in the morning, I always have my little five minutes of what you call mindfulness. I have my coffee and read the paper. Then I do my five or ten minutes of exercise. Then I am ready”

“I try to find time go to yoga, stay active, I volunteer in the community, and do things for myself to help me cope”

“We all have demanding careers and a heavy workload, you have to carve out time just for you. That’s how I recharge. It’s hard to recharge fully, but it can help you the most in finding some energy.”

ADVICE FOR BALANCING CARE AND WORK

We also asked the caregivers to share tips and advice for other caregivers. Here are some of their suggestions:

1. Plan ahead.
2. Connect with all the resources you can.
3. Try to take care of yourself.
4. Have an open communication with your family and your supervisor at work.
5. Create a routine.
6. Keep a journal and have all your information together. This can help with information overload (i.e. medical conditions, doctor appointments, important phone numbers).

ⁱ Statistics Canada, Study: End-of-life care, 2012. October 2014.

ⁱⁱ The Way Forward. (2014) The Caregiver Voice: Consultations with Family Caregivers. Accessed from <http://www.hpcintegration.ca/resources/family-caregivers.aspx>