

ALLER DE
L'AVANT

DES SOINS QUI INTÈGENT
L'APPROCHE PALLIATIVE



THE WAY
FORWARD

AN INTEGRATED PALLIATIVE
APPROACH TO CARE

THE CAREGIVER VOICE

Consultations with Family Caregivers



Executive Summary



In today's environment of medical innovation and discovery, the aged and individuals with chronic and life-limiting illnesses are living longer and with improved quality of life. As a result, family members and friends are taking on the caregiver role in ways they had never envisioned. The Canadian Caregiver Coalition (CCC) defines a caregiver as someone who provides care and assistance for spouses, children, parents and other extended family members who are in need of support because of age, debilitating medical conditions, chronic injury, long term illness or disability. Of the estimated 8.1 million caregivers in Canada, one out of thirteen is providing care to someone who is dying.¹

In partnership with *The Way Forward: An Integrated Palliative Approach to Care*, the Canadian Home Care Association (CHCA) reached out to caregivers of individuals with life-limiting illnesses. Specifically, the CHCA wanted to consult with caregivers across the country to uncover what caregiver supports would be needed to implement an integrated palliative approach to care. The CHCA also sought caregiver feedback on the effectiveness of current supports. The widespread dissemination and uptake of *The Way Forward* can only be accomplished by recognizing and understanding caregiver needs. If the goal is to continue to provide quality integrated palliative care in the places where patients choose to live, for as long as possible and with as much quality as possible, then the needs of their family caregivers must be addressed.

The needs of caregivers were solicited through a variety of dynamic caregiver engagement platforms, including round table discussions, a public survey and one-on-one caregiver interviews. Three common themes of caregiver needs emerged across all consultations and discussions: communication and information needs; workplace needs; and client care needs. Within each of these categories, caregivers were able to identify both the gaps and highlights of care supports, along with their specific needs.

Communication and information needs are those supports that allow caregivers to understand, plan, provide and advocate for their loved one's care, as well as communicate with the allied teams and individuals involved. Workplace needs are employer-provided supports, tools and mechanisms that enable individuals to function in both their caregiver and workplace roles. Client care support needs specifically refer to the care provided by physicians, case managers and nurses, support workers and the allied health team. The following tables summarize the identified caregiver needs within each theme.



ABOUT THE CANADIAN HOME CARE ASSOCIATION

The Canadian Home Care Association (CHCA) is a not-for-profit membership association dedicated to ensuring the availability of accessible, responsive home care and community supports to enable people to stay in their homes with safety, dignity and quality of life. Members of the Association include organizations and individuals from publicly funded home care programs, not-for-profit and proprietary service agencies, consumers, researchers, educators and others with an interest in home care. Through the support of the Association members who share a commitment to excellence, knowledge transfer and continuous improvement, CHCA serves as the national voice of home care and the access point for information and knowledge for home care across Canada.

For more information, visit our website at www.cdnhomecare.ca

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COMMUNICATION AND INFORMATION NEEDS:

- Access to support groups (either virtual or actual) that allow caregivers to liaise with other caregivers who may or may not share a common disease or experience, share knowledge and reduce the sense of isolation (experiential or geographical);
- Access to mental health professionals to help address the burnout, stress and emotional distress experienced by caregivers;
- Access to social workers to help caregivers navigate the social and financial support services available to them;
- Understandable and in-depth disclosure of their loved one's health condition and trajectory of illness;
- Single point of communication and unified health care record for the client/patient; and
- Improved system navigation facilitated by one key, informed appointed individual.

WORKPLACE NEEDS:

- Equitable access to the Compassionate Care Benefit across Canada, with all provincial labour code ensuring equal provision of benefits;
- Increased length of leave (greater than the currently provided eight weeks, only six of which are funded);
- Increased employer understanding of the needs of caregivers; and
- Increased awareness by employers of the supports available to employee caregivers.

CLIENT CARE NEEDS:

- A primary nurse/primary team involved in care;
- An overlap in care at times of transition between services or providers;
- Front-line staff who are comfortable and knowledgeable in the care they provide and who use best practice guidelines;
- Flexibility of services and the patient and caregiver having more involvement in determining what services are provided and when services are put into place; and
- Continuing true client and family centred care beyond the death of the patient to include bereavement support for the caregiver.

Engaging caregivers as part of The Way Forward initiative allowed the CHCA to gain valuable insight into the support needs of caregivers. Despite differences in experiences, diagnoses and geography, caregivers articulated a number of shared needs. In order for The Way Forward to have a far-reaching impact and sustainability, all suggestions and options must be considered. Central to the provision of care in the home and community is recognizing the needs of those who will provide the greatest proportion of care—the family caregiver.

The face of the Canadian caregiver is changing rapidly. As medical innovations are enabling the aged and those with chronic and life-limiting illnesses to live longer and with improved quality of life, we are witnessing an increasing number of Canadians taking on the caregiver role.

The Canadian Caregiver Coalition (CCC) defines a caregiver as someone who provides care and assistance for spouses, children, parents and other extended family members who are in need of support because of age, debilitating

medical conditions, chronic injury, long term illness or disability. In this respect, spouses, siblings, children, grandchildren, relatives and friends are stepping in to the caregiver role in ways they had never envisioned. An estimated 8.1 million Canadians are currently providing care to a loved one or friend who is chronically ill, disabled or aging.¹ One in thirteen caregivers is providing care to someone who is dying.²

As part of our commitment to The Way Forward: An Integrated Palliative Approach to Care, the Canadian Home Care Association (CHCA) engaged in a dialogue with caregivers across Canada providing care in the home to individuals with life-limiting illnesses. The aim was to connect with caregivers to gain insight into their needs. Specifically, the CHCA wanted to speak directly to caregivers to learn what supports they need to help implement an integrated palliative approach to care, which supports currently in place have a positive impact on their caregiving role and what changes caregivers would make to existing supports.

“Providing my mother's care is something I do gladly and willingly. It is something I want to do when she needs care the most. When you ask me if something could be done to make that job easier, the answer is yes! There is plenty of opportunity to make things better for caregivers, and not all of them big things.”

- Round table participant, caregiver

Engagement methods and process

Caregivers from across Canada, including Nova Scotia, Quebec, Ontario, Saskatchewan, Alberta and British Columbia, participated in this project. Given that a caregiver's free time is not only limited, but tremendously valuable, the CHCA used several unique and innovative ways to connect with caregivers, including:

- administering a public survey;
- conducting teleconferences and virtual meetings over the Internet between caregivers and a key interviewer; and
- hosting a round table discussion with caregivers.

While planning and organizing the engagement sessions, several important factors became readily apparent. A caregiver's day has no beginning and no end; they are "on the clock 24/7." Many caregivers have limited ability to plan for a telephone interview, a virtual meeting or a round table meeting since they do not know when a break in their day may come. The coordination of meetings depended on when respite was available or when a service provider was available to provide care. Caregivers also experience unpredictable disruptions to their routine. On more than one occasion,

an engagement session was postponed due to an unforeseen change in a loved one's health or care needs. The CHCA needed to be flexible, and appointments were rescheduled at a moment's notice to adapt to the changing needs of both the caregiver and the care recipient. Finally, we learned that caregiver stories and experiences are often deeply rooted in emotion. For the caregivers, this was their story, their life, their everyday journey. We often needed to pause an interview to allow a caregiver time to regain composure or to vent frustration over their situation.

BROAD CAREGIVER ENGAGEMENT

To engage caregivers across the country, the CHCA and the CCC leveraged their relationship to encourage members and the general public to access a survey link that was posted to the Home page of the CCC website (www.ccc-ccan.ca). In addition, the CHCA placed a two-page

feature detailing information about The Way Forward and a call to action (by means of survey participation) in caregiver publications. Respondents were directed to the CCC's website where they were asked to complete a brief ten-question survey that focused on the themes of

caregiver supports, palliative care and Advanced Care Planning (ACP).

The survey was conducted with two streams: (1) individuals currently providing care to a loved one; and (2) individuals for whom the person they were providing care had died. To provide context for the survey answers, individuals were asked to indicate how long they had been providing care to a loved one and how many hours of their day (either retrospectively or currently) were

committed to caregiving responsibilities. Respondents were asked to evaluate the importance of a variety of supports, ranging from informational, respite and financial, to in-home nursing and equipment in the home. Caregivers were also asked to assess palliative care supports and the timing of services offered. Similarly, caregivers were asked about their knowledge of ACP and related activities.

ONE-ON-ONE CAREGIVER INTERVIEWS

A series of caregiver interviews were conducted via telephone or virtually over the Internet using the Adobe Connect platform. Caregivers were solicited through organizations associated with the CCC, as well as those obtained through the CHCA relationships with caregiver support organizations. Key individuals within the organizations were contacted via email with details about The Way Forward and the purpose of the caregiver consultations. The organizations were in turn asked to disseminate the information about The Way Forward and the consultations to their membership, and interested individuals were asked to contact the key interviewer. Interviews were arranged at a time convenient to the caregiver when they could commit an hour of their time. The sessions began

with a presentation of The Way Forward framework to the individual, followed by a structured conversation between the caregiver and interviewer focusing on three key questions:

1. As you provide care to your loved one, what can the healthcare system do to improve the quality of life for you and your loved one?
2. Would you have liked to receive supports earlier than you did? When would that have been? What supports were missing or were needed earlier?
3. As a caregiver, what supports have worked well for you and your loved one? What supports would you like to see changed and how could they be improved?



“We may talk a different language or use different words, but it all boils down to the same thing: That everyone deserves dignity, everyone deserves to be in their own bed at home with someone that loves them. You know, that’s the best place to be when you’re not feeling well.”

-Barbara, caregiver

FACILITATED CAREGIVER ROUND TABLES

As a third method of caregiver engagement, the CHCA asked caregivers to participate in round table discussions. Once again, the CHCA affiliation with the CCC was leveraged to gain access to caregiving organizations or those with a caregiving component or support group. The round table discussion consisted of a two hour session that included a presentation on The Way Forward framework, followed by a facilitated

conversation focused on the needs of caregivers and an integrated palliative approach to care. The questions forming the basis of the discussion were the same as those used in the teleconference and virtual meeting sessions. Those attending a round table discussion were provided with refreshments and a package of information on The Way Forward and Advance Care Planning.

The Caregiver Voice – What we Heard

After having listened to caregivers across Canada, it is clear that each story is unique and personal; no two caregivers share the same experience, regardless of diagnosis, and the approach to care needs to be as individualized as possible. However, three common categories of needs and themes emerged across all conversations: communication and information needs; workplace needs; and client care needs. Interestingly, caregivers identified both the highlights of care supports and areas where change is needed in each of the three general categories.



COMMUNICATION AND INFORMATION NEEDS

When we asked caregivers what supports were missing from their complement of care services, all caregivers responded that they need more information. Caregivers identified information gaps in:

- knowledge about the details, extent and prognosis of their loved one’s illness, specifically information about what to expect about their loved one’s health and how to prepare and plan for the future; and
- services and supports available to both the caregiver and their loved one.

Caregivers reported that it was difficult to find “up front” and clear information regarding the health and prognosis of their loved one. Caregivers often felt that the information given to them was guardedly optimistic, unclear or provided in overly medicalized terms. Many reported having to seek information from several different sources or specialists involved in their loved one’s care and by uncovering the information through their own research on the Internet or through disease-specific support groups.

Caregivers stated that it was difficult not knowing what to expect as their loved one’s health declined, and all individuals involved in the consultations expressed a desire to have the “full picture” disclosed early on in the trajectory of illness. For many, this clear and understandable information would have helped them plan for their loved one’s future care needs and for their own caregiving needs (with respect to respite and both physical and social/emotional supports).

Caregivers also reported that they lack information about the services and supports available to them, and this information is often not readily available, depending on where the caregiver lives. Some caregivers were provided with all the information they require, while others were left to source the majority of the information on their own using the Internet or personal connections, or by chance in the form of pamphlets and brochures available in pharmacies, medical waiting rooms, etc.

Caregivers reported needing both psychosocial and physical supports. The caregivers defined psychosocial supports as those supports that contribute to a caregiver’s mental and emotional well-being, including access to mental health professionals, social workers, virtual actual support groups and volunteers. Caregivers identified physical supports as those that help in the physical daily care of their loved one, including equipment for use in the home as well as nursing and personal support staff.

Caregivers reported that information regarding these supports needs to be readily available and the provision of information standardized so that all caregivers, regardless



“My city has given out this booklet with all sorts of activities and I did notice that there were support groups for all sorts – but no support groups for caregivers of any shape or form.”

-Hélène, caregiver

of where they live in Canada, have equal access to and knowledge of the existence of these types of supports.

Caregivers reported that having access to these types of supports improves their quality of life in the following ways:

- Support groups (either virtual or actual) allow them to liaise with other caregivers who may or may not share a common disease or experience, helping to share knowledge and reduce the sense of isolation (experiential or geographical).
- Mental health professionals help address the burnout, stress and emotional distress that caregivers experience.
- Social workers help caregivers navigate the social and financial support services available to them.

Caregivers identified communication supports as those tools and systems that would facilitate a centralized (all information about a patient kept in one location/source), open and unrestricted dialogue and access to all members involved in the “circle of care.” This would include all involved physicians, primary

nurses, case managers, personal support, allied health care providers (such as physiotherapists, dieticians or respiratory therapists) and all loved ones identified by the client/patient as involved in their care.

Caregivers often have to contact many different people to obtain only partial information about their loved one. This proves to be especially problematic for those caregivers who live a distance away from their loved ones, and for those whose loved ones have memory or cognitive impairment and cannot pass along information. The recommendation was a centralized source with all care notes, laboratory and diagnostic test results, medications and assessments. There was unanimous support for a unified health record.

Caregivers at all levels also indicated that language barriers are a communication challenge. If more information was communicated in writing, it would help caregivers not only overcome challenges presented by language, but would also encourage the sharing of information with all carers.

The information and communication supports needed by caregivers can be summarized in the following points:

- Provide understandable and in-depth disclosure of their loved one's health condition and trajectory of illness.
- Ensure a single point of communication and unified health care record for the client/patient.
- Improve system navigation facilitated by one key, informed appointed individual.



Imagine a new reality, where hospice palliative care is available to Canadians when and where they need it; where living well until death is the goal of care.

Now, imagine a plan to get there. That's The Way Forward: an integrated palliative approach to care across settings.

"A caregiver cannot be worried about losing their home while caring for a loved one who's dying"

-Tracey, caregiver



WORKPLACE NEEDS

Just fewer than half of the caregivers identified supports in the workplace as a need. Data from Statistics Canada indicate that 60 percent of caregivers contend with the demands of their unpaid caregiving and that of paid work.³ According to the same report, 43 percent of employed caregivers reported workplace disruptions, including absenteeism, late arrival and early dismissal, in order to meet the care needs of a loved one. This figure rises as the amount of care hours provided by the caregiver increases.⁴



Caregivers reported a range of workplace supports available to them. Some caregivers reported significant workplace support and flexibility, while others reported unsympathetic and non-accommodating employers. Provincial variations in the Compassionate Care Benefit (CCB), including variation in eligibility criteria, splitting leave time and definition of the care recipient, contribute to caregiver frustration.

A caregiver related the story of reporting to her employer's human resource department seeking information on caregiver supports, Employee Assistance Program help and information specific to her workplace on leave related to spousal care. As retold by the caregiver, not only did the employer not have the necessary information, they also did not know how to address her concerns. This same caregiver was also told, "It's not like it is your child. You can't replace your child, but we will all lose spouses."

Another caregiver was forced to choose between providing care for a loved one

and maintaining full-time employment. The employer would not consider part-time employment, and the end result was the loss of employment for the caregiver.

Yet another caregiver spoke about the added stress of the financial burden that comes with reduced income when taking a leave of absence from work or accessing the CCB, in addition to the stress associated with

caring for a dying family member. Many caregivers reported that the unpredictable nature of their loved one's illness made scheduling or planning time away from work difficult. In many cases, the end-of-life phase was longer than expected and the leave time provided by the CCB was insufficient. Some caregivers indicated that the introduction of the CCB came too late. Despite the CCB being legislated in 2004, Alberta became the last province to enact the CCB benefit in February 2014.

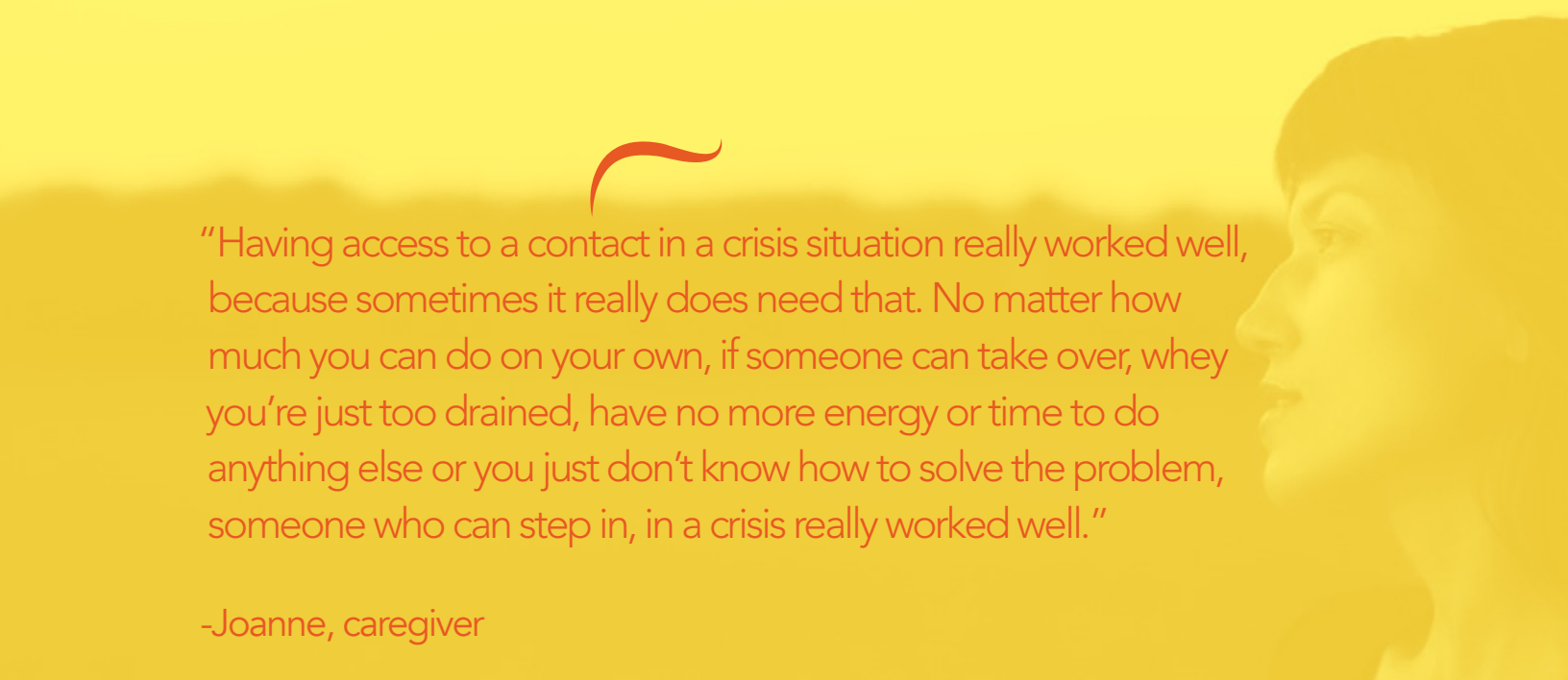
The clear message delivered by caregivers about workplace supports can be summarized as follows:

- Ensure equitable access to and provision of the CCB to caregivers in Canada.
- Increase the length of leave (greater than the currently provided eight weeks, only six of which are funded).
- Increase employer understanding of the needs of caregivers.
- Increase awareness by employers of the supports available to employee caregivers.



CLIENT CARE SUPPORTS

Consultations with caregivers revealed several common themes that we have collectively identified as client care supports. Client care supports refer specifically to the provision of care by nurses, physicians, allied health members or personal support staff. All caregivers recognized that everyone, including themselves, play a vital role in the delivery of care to their loved one. However, how that care is delivered has a significant impact on quality of life for both the caregiver and loved one.



“Having access to a contact in a crisis situation really worked well, because sometimes it really does need that. No matter how much you can do on your own, if someone can take over, when you’re just too drained, have no more energy or time to do anything else or you just don’t know how to solve the problem, someone who can step in, in a crisis really worked well.”

-Joanne, caregiver

A recurrent theme among all interviewed caregivers was the importance of the provision of care by a primary nurse or team. Having a consistent nurse or team of providers, rather than a number of different or random nurses or care providers, is essential. Caregivers reported frustration with frequently having new individuals involved in their loved one’s care, including:

- the need to retell their stories or provide the specific details about their loved one’s health and care;
- the need to supervise new providers until all parties (caregiver, loved one and provider) have established a trust in the care being provided; and
- the embarrassment and awkwardness involved in the provision of personal care by new and strange individuals.

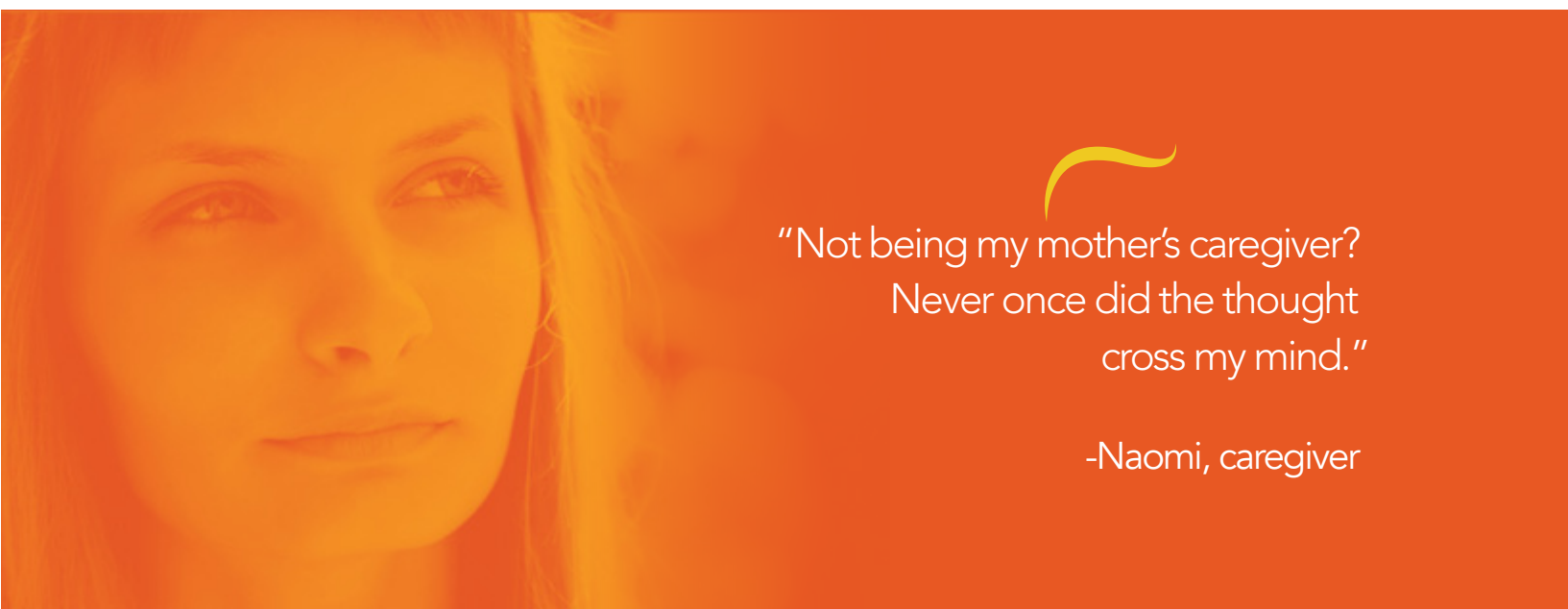
These frustrations all lead to a lower quality of life for the caregiver’s loved one, which translates into a poorer quality of life for the caregiver. Caregivers viewed minimizing the number of individuals involved in a person’s care, whenever possible, as a positive support. In addition, at times of transition, caregivers reported that disruption is minimized when there is a period of overlap between the services or staff involved. When change in services or care needs are anticipated or are made, all caregivers agreed that changes need to be phased in (when possible) to minimize interruption and disturbance.

Caregivers also reported that front-line staff need to be knowledgeable and competent in the care they provide. Caregivers commonly reported that they experience stress and decreased satisfaction with care when they have to instruct care providers about the care practice, or feel the provider is inexperienced or has limited experience in providing specialized care. Caregivers identified that the establishment of and adherence to best practice guidelines would greatly improve their quality of life and that of their loved one.

Caregivers recognized that providing care for their loved one in the home and community would not be possible without the support of front-line staff. However, the sentiment repeated across many consultations was that more flexibility in the provision of these services is needed. Caregivers would like to be more involved in the allocation of services to their loved one. Many said that although there are care responsibilities that they can perform themselves, they have to have an outside care provider perform them to ensure that they qualify for certain other services that they are unable to provide. For example, one caregiver reported being capable of bathing and shaving her loved one, but if she performed that care activity, she did not qualify for other care services that provided respite. Another caregiver related the scenario of needing nursing support during the day that would also provide respite, however support was in place during times when respite was not especially needed or useful.

Finally, many caregivers identified the need for involvement of the care team after the loved one’s death. For many caregivers, once the loved one has died all involvement with the care team ends. Without a patient to provide care to, home care organizations are no longer paid for visits. Caregivers expressed a need to have closure with the team and have an opportunity to say goodbye. Many caregivers felt that this would also be an opportunity to ensure that they are receiving the grief and bereavement support that they may require. Caregiver needs regarding client care supports can be summarized as follows:

- Have a primary nurse/primary team involved in client/patient care.
- Provide overlap in care at times of transition between services or providers.
- Ensure front-line staff are comfortable and knowledgeable in the care they provide; using best practice guidelines is key.
- Allow flexibility of services and allow the patient and caregiver to have more involvement in determining what services are provided and when services are put into place.
- Provide bereavement support for the caregiver to ensure true client and family centred care beyond the death of the patient.



“Not being my mother’s caregiver?
Never once did the thought
cross my mind.”

-Naomi, caregiver

THE WAY FORWARD – MEETING THE NEEDS OF FAMILY CAREGIVERS

The opportunity to engage caregivers as part of The Way Forward initiative provided an opportunity to gain valuable insight into the support needs of carers. In order for The Way Forward to have a far-reaching impact and sustainability, all suggestions and options must be considered. Central to the provision of care in the home and community is recognizing the needs of those who will provide the greatest proportion of care—the family caregiver.



Caregivers identified many supports as invaluable, particularly the support of volunteers. Volunteers provide assistance in many forms and capacities, and fill the gaps in care. Many caregivers also remarked that localized initiatives often work well, such as the *Centres locaux de services communautaires (CLSC)* in Quebec, specifically the home care and caregiver support divisions. In Ontario, the 2-1-1 service was recognized as being helpful. In remote areas of the country, online support groups and forums were beneficial, and in some cases were the only way of connecting with other caregivers, researching information or sourcing supplies or services.

The needs of caregivers can be summarized as follows.

1. Access to the following information and communication supports are essential to the well-being of caregivers:
 - access to support groups (either virtual or actual) that allow caregivers to liaise with other caregivers who may or may not share a common disease or experience, share knowledge and reduce the sense of isolation (experiential or geographical);
 - access to mental health professionals to help address the burnout, stress and emotional distress experienced by caregivers;
 - access to social workers to help caregivers navigate the available social and financial support services available to them;
 - understandable and in-depth disclosure of their loved one's health condition and trajectory of illness;
 - single point of communication and unified health care record for the client/patient; and
 - improved system navigation facilitated by one key, informed appointed individual.



2. The following workplace supports are essential to the well-being of caregivers:
 - equitable access to the Compassionate Care Benefit across Canada, with all provincial labour codes ensuring equal provision of benefits;
 - increased length of leave (greater than the currently provided eight weeks, only six of which are funded);
 - increased employer understanding of the needs of caregivers; and
 - increased awareness by employers of the supports available to employee caregivers.
3. The following client care supports are essential to the well-being of caregivers:
 - a primary nurse/primary team involved in care;
 - an overlap in care at times of transition between services or providers;
 - front-line staff who are comfortable and knowledgeable in the care they provide and who use best practice guidelines;
 - flexibility of services and the patient and caregiver having more involvement in determining what services are provided and when services are put into place; and
 - continuing true client and family centred care beyond the death of the patient to include bereavement support for the caregiver.

¹ Statistics Canada. (2013). *Spotlight on Canadians: Results from the General Social Survey. Portrait of Caregivers, 2012*. (Catalogue number 89652X — No. 001 ISBN 978-1-100-22502-9)

² Ibid.

³ Ibid.

⁴ Ibid.



The Canadian Home Care Association would like to acknowledge and thank all of the individuals who participated in the caregiver engagement sessions. Your thoughts, your shared stories and your time were greatly appreciated.

For more information about The Way Forward:
www.hpcintegration.ca

