Unsung Heroes:

The Hidden Strength Behind Cancer Care

A National Survey Report on the Experiences, Challenges and Needs of Cancer Caregivers

CANADIAN CANCER SURVIVOR NETWORK RÉSEAU CANADIEN DES SURVIVANTS DU CANCER

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Science meets Strategy

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Executive Summary

The Impact of Being a Caregiver

- Caregivers are an essential part of the support system for patients with cancer, often dedicating an average of 21 hours per week to caregiving responsibilities.
    - This commitment can significantly disrupt their daily routines, alter their lifestyle and limit social engagement.
    - Beyond the time investment, caregiving can lead to emotional and physical exhaustion, as well as financial strain — factors that collectively take a toll on both physical and mental well-being.

Support Systems and Services for Caregivers

- Caregivers identified that the top 3 support systems and services they use are those for emotional support, practical support and respite care.
- Factors that caregivers took into consideration when looking for support in caring for patients varied greatly, with the most common ones being accessibility (including location/proximity, convenience), emotional support and financial impact.
- Accessibility of existing services and government programs were identified as areas in need of improvement.
    - *Accessibility of services:* 21% of caregivers reported difficulties in accessing support services, and only 32% believed that the currently available support services for caregivers of patients with cancer are easily accessible.
    - *Government programs:* Some caregivers have applied for government programs for caregivers, but no single program stood out as particularly effective.

Caregiver Recommendations

- Caregiving takes a toll on caregivers' overall and mental health. As a result, caregivers should seek support from family and friends, use professional caregiving services and join support groups.
    - Caregivers should prioritize self-care and mental health by taking breaks, engaging in self-care activities and connecting with support networks.
- Caregivers should advocate for, and ask about, support services. Only 32% of caregivers had heard about these services through healthcare practitioners (HCPs), and the majority found them through their own internet searches or community centres.
- Caregivers identified they would benefit from improved support systems and resources such as better access to services, financial assistance and more in-home support.

Survey Objectives and Key Topics

Objectives

CCSN commissioned Leger to conduct a survey to identify and understand the experiences, challenges and support needs of caregivers (N=1000) for patients with cancer in Canada, with the goal of helping CCSN develop better support systems and resources for cancer caregivers.

Key Topics Addressed by the Survey

- Primary reasons patients with cancer need help from caregivers.
- Duration and extent of caregiving responsibilities.
- Help received from others, including family, friends and social services.
- Impact of caregiving on physical and mental health of caregivers.
- How caregiving affects caregivers’ daily routine, lifestyle and social activities.
- Challenges faced and strategies to overcome challenges.
- Support services utilized by caregivers, and effectiveness and accessibility of services.
- Gaps in existing support services and what additional support is needed.

Overview of Patients & Caregivers Included in the Study

Patients Being Cared for

4 out of 5

patients being cared for were

RELATIVES

(mainly a parent or spouse/partner) of the caregiver

>4 in 5

patients receiving care were diagnosed within the past

5 years

and spanned a variety of cancer types, including:

Breast **Lung** **Prostate** **Colorectal**

3 in 10

patients receiving care had

STAGE 4 or METASTATIC CANCER

> **In this type of situation, you also become more aware of just how lucky you are. I tend to count my blessings more often. Being able to help support someone means a lot of responsibility and that in itself is important.**

Caregiver from British Columbia

- Patients being cared for by the caregivers had various cancer types, the top 4 including breast cancer (22%), lung cancer (16%), prostate cancer (11%) and colorectal cancer (10%).
    - The stage of cancer varied, with the majority having stage 1 (18%), 2 (22%) or 3 (15%) cancer; 29% had stage 4 or metastatic cancer.
        - 6% of caregivers indicated the patients they cared for were in remission and 10% noted they were unsure of the patient’s cancer stage.
    - The recency of diagnosis of the patients being cared for ranged from less than 6 months ago to more than 10 years ago. Half the patients being cared for were diagnosed 2-5 years ago.
    - Overall, 94% of patients being cared for received treatment, with the majority receiving chemotherapy (57%), followed by surgery (46%) and radiation therapy (40%).

Characterizing the Caregivers

Caregivers spend

~21 HOURS

per week providing care for their patient(s)

Most common care provided by caregivers was support with

DAILY LIVING ACTIVITIES

Including:

- Driving to and from appointments and tests
- Grocery shopping
- Household chores
- Keeping track of doctor’s appointments and tests

7 in 10

caregivers have

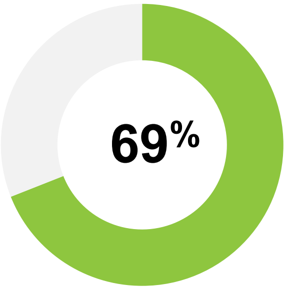
ADDITIONAL SUPPORT

to help with their caregiving duties

> **I am my own person with my own ambitions, goals, hopes and dreams. But as a caregiver, my role has been delegated to “support” staff. I am no longer my own person since I spend a lot of time taking care of someone else.**

Caregiver from British Columbia

- The majority of caregivers (69%) had others supporting them to care for their patients. The most common additional support persons were:
    - Other family members of the patient (45%)
    - The patient’s child(ren) (45%)
    - The patient’s partner (39%)
    - Professional caregiver (21%)
- In cases where the primary caregiver was unavailable, the most common persons to take the role of caring were:
    - Other family members (35%)
    - The patient’s child(ren) (35%)
    - The patient’s partner (28%)



of caregivers had **ADDITIONAL SUPPORT** to care for patients

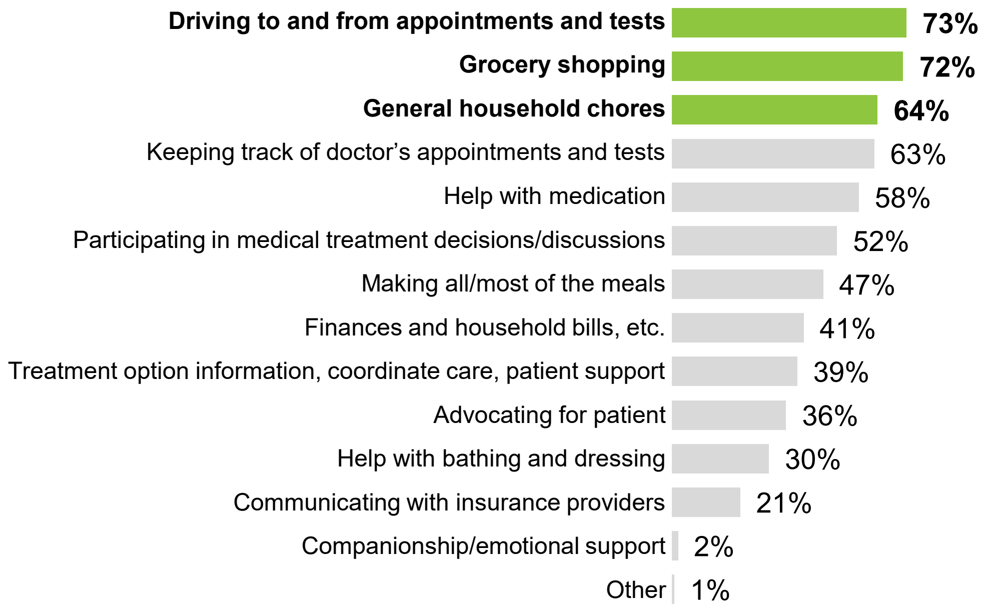
Services Provided and Time Spent on Caregiving

Services Provided

- Caregivers identified the top three services they provide to patients as:
    - Driving to and from appointments and tests
    - Grocery shopping
    - Household chores
- Additionally, 40% of caregivers indicated they have had to take over the finances for the patient or their family.

2 in 5 caregivers have had to take over the **FINANCES** for their patient or family

Services Provided by Caregivers (N=1000)



Time spent on caregiving

- On average, caregivers spend 21 hours per week providing care for patients, which amounts to approximately one-quarter of their waking hours. Despite this, more than half of caregivers reported having time to attend events or socialize, with 64% of those being retired.
- The caregivers believed that others caring for the patient(s) spend an average of 24 hours per week providing additional care. However, 34% of caregivers were unsure about the number of hours others spend caring for their patients.

Challenges of Being a Caregiver

9 in 10

caregivers report having experienced

CHALLENGES

with caregiving, which most often include

EMOTIONAL STRESS & LACK OF TIME

Among those who have experienced challenges,

THREE-QUARTERS

have taken action to overcome challenges, including:

- Taking time for self-care
- Seeking support from family and friends

2 in 5

caregivers have either **REDUCED WORK HOURS, STARTED A NEW JOB OR FULLY STOPPED WORKING** as a result of caregiving

> **As a mom of 3 little kids, working more than part-time and having a home to look after, I have to logistically plan pick-ups and drop-offs of 3 kids plus cross cancer appointments for my dad. It's hard to juggle all the balls without dropping one.**

Caregiver from Alberta

Challenges Experienced by Caregivers

- Overall, 91% of caregivers indicated they experienced challenges, which included: emotional stress (71%), lack of time (49%), physical strain (36%) and financial burden (24%). The top 3 issues stemming from these challenges were time management (21%), emotional toll (21%) and anxiety/stress (13%).
    - Other issues that caregivers encountered included physical demands, lack of support, coping with patient's emotions, sense of loss, financial burden, burnout/tiredness/exhaustion, navigating the healthcare system.
        - It was identified that women mention almost all issues at a higher rate than men, significantly so for anxiety/stress, physical demands, lack of support and navigating the healthcare system.
- Of the caregivers who experienced challenges, nearly half have taken the time for self-care (46%) or sought support from family and friends (46%).
    - Others used professional caregiving services (16%) or joined support groups (10%).
    - Of those who have experienced challenges, 24% of caregivers noted they have not taken any action to overcome the challenges.

>

Women experienced almost all issues at a higher rate than men

- Caregivers described the challenges of caregiving in more detail:
    - **Emotional and psychological challenges**

> **Feeling helpless, not being able to provide the relief from pain that was necessary. Mental health was lacking due to not having time for self-care, not having the ability to perform healthcare duties and not knowing how or who to go to learn these things.**

Caregiver from Ontario

- Caregivers expressed deep emotional pain from witnessing their loved ones deteriorate daily, knowing the outcome was inevitable.
- After the patient's death, caregivers often felt guilt, questioning whether they had done enough.
- Many wished they could do more, describing the experience as emotionally exhausting.
- Lack of time for self-care and emotional support led to deteriorating mental health.
- One caregiver noted feeling unseen and alone, especially when others focused solely on the patient's suffering.
- Caregivers found it hard to maintain positivity and avoid empty reassurances during difficult moments.

- **Time and life disruption**

> **I was studying nursing (technical) and I had to put my studies on hold because I couldn't do everything.**

Caregiver from Québec

- Caregivers had to pause studies or reduce work hours to provide care.
- The role consumed all available time, leaving no room for rest or enjoyment.
- Managing caregiving alongside parenting, work and household duties created overwhelming pressure.

- **Finance and workplace strain**

> **Empathy, wishing I could do more, it's very difficult to watch them struggle everyday. Wage issues, I am in financial hardship due to cutting back time at my full-time job to help support.**

Caregiver from British Columbia

- Cutting back on work hours led to financial hardship.
- Caregivers felt unsupported by workplaces that didn't recognize the stress and demands of caregiving.

- **Healthcare system frustrations**

> **The biggest challenge I currently have is getting timely communication with any and all health devices such as doctors and specialists. I'm always having to leave messages and waiting for return calls…**
>
> ***Caregiver from British Columbia***

  - Difficulty reaching doctors and specialists added stress and uncertainty.
  - Caregivers struggled with performing healthcare duties without proper guidance or resources.

- **Physical demands**

> **A lot of physical effort to take care of all the outdoor work in the fall where usually it is my spouse who does the work that requires more arms/strength.**
>
> ***Caregiver from Québec***

  - Described as a full-time job in itself.
  - Physical tasks like outdoor work became burdensome when the patient could no longer help.

Impact of Being a Caregiver

Impact of Being a Caregiver on Overall Health

- Caregiving has a significant impact on both the overall and mental health of caregivers. While some caregivers experienced positive effects, many faced challenges that negatively affected their well-being.
- Despite the challenges and changes to their routines, half of the caregivers felt a sense of purpose, and nearly half reported better self-care.
  - However, many reported getting less sleep and experiencing worse mental health compared to before they began caregiving.
  - Caregivers had mixed feelings about how caregiving affected their personal time and organizational involvement.

Overall Health Impact

- Positive impact: 27% of caregivers reported a positive impact on their overall health. The contributing factors included:
  - Improved self-care (31%)
  - Improved perspective (20%)
  - Sense of purpose (16%)
  - Heightened health awareness/lifestyle (11%)

> **… it was a stark reminder of how fragile life is and how easily it all goes away. How little time one has to waste on things/people/stresses that frankly aren't important.**
>
> ***Caregiver from Manitoba***

- Caregivers provided additional insights into the positive impact caregiving has on their overall health:
    - Caregiving fosters a deeper appreciation for life, relationships and everyday experiences. It encourages caregivers to be more present and intentional in how they spend their time.
    - Exposure to illness and loss through caregiving often prompts caregivers to adopt healthier habits, including regular screenings, improved diet and physical activity. It can also lead to meaningful lifestyle changes inspired by the memory of loved ones.
    - Caregiving can instill a strong sense of meaning and direction, helping individuals feel more connected to their values and goals.
- Negative impact: 35% of caregivers reported a negative impact on their overall health. The contributing factors included:
    - Increased stress/anxiety (33%)
    - Increased physical strain (17%)
    - Emotional toll (15%)
    - Disrupted routines and loss of self-care (15%)
    - Disrupted sleep patterns (8%)
    - Decreased physical activity (7%)
    - Burnout/tired/exhausted (6%)
    - Time management (5%)

> **I take care of my health needs much less now that I am providing care for someone else. I have skipped my own doctor's appointments mainly due to time constraints.**
>
> ***Caregiver from Ontario***

- Caregivers provided additional insights into the negative impact caregiving has on their overall health:
    - Caregivers often deprioritize their own health due to time constraints and competing responsibilities, leading to missed medical appointments, poor nutrition and lack of physical activity.
    - The emotional toll of caregiving is significant, especially during end-of-life stages. Caregivers often suppress their own emotions to protect the patient, leading to internalized stress and isolation.
    - Caregiving can lead to a diminished sense of self, where personal goals and identity are overshadowed by the caregiving role. This can result in feelings of resentment, guilt and emotional conflict.

Mental Health Impact

- Positive impact: 23% of caregivers indicated a positive impact on their mental health. The contributing factors included:
    - Sense of purpose (36%)
    - Improved perspective (14%)
    - Maintaining positivity (7%)
    - Increased stress/anxiety (7%)
    - Taught me to be resilient/strong (5%)
    - Emotional toll (5%)

> **Learned how to deal with strife in a more positive manner and to keep a healthier perspective on life.**
>
> ***Caregiver from PEI***

- Caregivers provided additional insights into the positive impact caregiving has on their mental health:
  - Caregiving provides a strong sense of meaning, responsibility and emotional satisfaction. Feeling needed and useful contributes positively to mental well-being.
  - The challenges of caregiving can foster emotional growth, resilience and a more grateful outlook on life. Caregivers often develop healthier coping mechanisms and a deeper appreciation for their circumstances.
  - Caregiving strengthens emotional bonds and provides reassurance through presence and positivity. Seeing the impact of their support on the patient's emotional state reinforces the caregiver's own mental health.
- Negative impact: 51% of caregivers noted a negative impact on their mental health. The contributing factors included:
  - Emotional toll (30%)
  - Increased stress/anxiety (27%)
  - Decline in mental health/neglecting own mental health and well-being (8%)
  - Time management/balancing caregiving with other responsibilities (6%)
  - Lack of support (6%)
  - Sense of loss (5%)

> **I sometimes feel trapped because I can't do many things I did before. I have to be home a lot more.**
>
> ***Caregiver from Nova Scotia***

- Caregivers provided additional insights into the negative impact caregiving has on their mental health:
  - Witnessing a loved one's physical and emotional decline is deeply distressing. Caregivers often experience anticipatory grief, helplessness and emotional pain as they support someone through serious illness or end-of-life stages.
  - The ongoing nature of caregiving, compounded by systemic challenges and lack of support, contributes to chronic stress and emotional exhaustion. Caregivers often feel overwhelmed by the constant demands and unpredictability.
  - Many caregivers feel isolated and unsupported, especially when professional care is inconsistent or impersonal. This lack of continuity and understanding can intensify feelings of loneliness and emotional burden.
  - Caregiving often restricts personal freedom and requires emotional labour that can be draining. Caregivers may feel confined by their responsibilities and unable to express their own vulnerabilities.

- Caregivers indicated they support their overall and mental health by maintaining a balanced diet and regularly seeking emotional support, with most eating nutritious meals several times per week and more than half connecting with friends, family or a support network when needed.
- Factors that contributed to reduced overall and mental health included:
  - Most caregivers experienced stress or anxiety at least once or twice a week. Additionally, over half of them reported feelings of depression or sadness with the same frequency. Many caregivers also mentioned that they engage in self-care activities only once or twice a week, or even less frequently.
  - More than half of the caregivers consumed foods high in sugar, fats or processed ingredients at least once or twice a week, with about one-third consuming these foods 3 or more days per week. Sleep is another area of concern, as over half of the caregivers reported getting a full night's sleep only once or twice a week, or less.
  - Physical activity was limited for many caregivers, with more than half indicating they engage in it only once or twice a week, or less. Lastly, over half of the caregivers reported they only take time off work or responsibilities to relax and recharge less than once a week or not at all.

Occupational Impact

- 40% of caregivers reported their occupational status/job has changed (reduced hours, fully stopped working, started a new job with more flexibility/fewer hours) since starting caregiving.

Caregiver Support Services

Accessing Caregiver Support Services

- Overall, half the caregivers rated their current level of support as neutral, with less than one-quarter feeling well- or very well-supported.
- Over half (51%) of caregivers reported using caregiver support services including emotional support, practical support (meal preparation, etc.), equipment, respite, breaks or time off, money management, housing, advocacy support and emergency planning.
- Of the caregiving support services, they ranked the following as the top 3:
  - Emotional support
  - Practical support
  - Respite, breaks or time off
    - While most caregivers had accessed or used caregiver support services, 42% rated the support as average, 23% rated them as good or very good and 35% rated them as fair or very poor.
- Caregivers primarily learned about these support services through HCPs (e.g. family doctor, nurse, nurse practitioner, other HCPs). However, other ways of learning about these services included word of mouth, internet searches and community centres.
- Only 32% of caregivers thought currently available support services for caregivers of patients with cancer are easily accessible, and 21% had issues accessing support services.
- Some caregivers have applied for government programs for caregivers but none of the programs stood out over others.
  - Among the most applied to government programs for caregivers were home and community care services, Canada Pension Plan (CPP) disability benefits and Disability Tax Credit (DTC).

Considerations for Seeking Caregiver Support

> **Would the individual be caring and sensitive, honest and reliable…**
>
> ***Caregiver from Ontario***

- Factors that caregivers took into consideration when looking for support in caring for patients varied greatly, with the most common ones being accessibility (including location/proximity, convenience, hours of operation), emotional support and financial impact.
    - Other key considerations for caregiving support included financial assistance for caregiving expenses, more/better in-home services, emotional/mental health support and respite care.
- Caregivers described the considerations in more detail:
    - Caregivers prioritized trustworthiness, honesty and professional reputation when selecting support services or individuals.
        - Concerns about fraud and unreliability were prominent.
    - Emotional sensitivity and respect for the patient's dignity and preferences were identified as essential.
        - Compassionate interactions and personalized attention were seen as valuable.
    - Timely access to HCPs and logistical support (e.g. transportation, appointment assistance) were critical needs, as gaps in service availability can significantly impact caregiving.
    - Caregivers struggled to locate reliable resources and support systems. There is a clear need for better guidance and centralized information.

The Evolution of Caregiving Services

- Several caregivers (97 total) have been caring for patients for more than 5 years and reported on the changes before and after the COVID-19 pandemic.
    - Caregivers indicated there are a variety of actions they can do now that they could not do during the peak of the pandemic, including:
        - Attend appointments and treatments with patients
        - Spend extra time with the patient
        - Take notes during appointments for record-keeping or to report back to the patient's family
        - Participate in medical decisions
- The support services used by caregivers prior to the pandemic remain the same after the pandemic, with the top ones including emotional support, respite/breaks/time off and practical support.
    - 44% of the caregivers noted the level of support is the same now as it was before the pandemic, while 14% indicated support is better now and 9% said support is worse now.
- Taking into account all caregivers, more than half believe the level of support is the same as when they initially started caregiving, while 13% believe it is better now and 8% believe it is worse now.