ÉQUIPE SANTÉ ONTARIO
NIAGARA
ONTARIO HEALTH TEAM

Caregiver Experience in Niagara

Executive Summary • March 2026

What We Heard. What It Means. What Comes Next.

Executive Summary

Caregiving is a critical and often invisible part of the health system in Niagara. Based on the experiences of 360 caregivers, this report highlights a consistent reality: caregivers are essential, but too often feel unprepared, unsupported, and left to navigate a fragmented system alone.

- 82% did not fully understand what to expect at the start of caregiving
- 70% experienced difficulty accessing services when needed
- 61% reported impacts on work or education
- 43% felt overwhelmed or unsupported

These findings reflect not isolated issues, but a pattern. Caregiving is intensive, continuous, and layered onto everyday life.

To Caregivers Who Shared Their Stories

Thank you. Your experiences form the foundation of this report and are shaping change across Niagara.

“My family all relied on each other because we found navigating the system both confusing and disheartening.”

“I begged for more PSW help... They never showed up.”

Understanding Caregiving in Niagara

Caregiving includes physical, emotional, financial, and social impacts that accumulate over time. It is a central and consuming role that shapes daily life.

Caregiving is most often provided in the home and frequently reflects the equivalent of a full-time role or more:

- 44% provide more than 40 hours of care per week
- 16% provide 20–39 hours per week
- 84% provide care primarily in the home
- 80% provide care for more than six months

“Caregiving cannot be ‘left at the end of the day.’ It is a role that does not turn off.”

SYSTEM CHALLENGES: INFORMATION, ACCESS AND NAVIGATION

> **“The challenge was not only whether services existed, but whether people could find them, understand them, and access them in time.”**

Caregivers consistently described a system that is difficult to understand and navigate, particularly at the beginning of their journey.

- Only 18% fully understood what to expect at the start
- 70% experienced inconsistent access to services
- Only 30% could always access services when needed
- 15.5% reported significant difficulty accessing services

Caregivers need early information, clear navigation pathways, inclusion in care decisions, and support before reaching crisis. A coordinated and responsive system is essential.

What Helped Caregivers

Caregivers identified both formal and informal supports as critical.

- 32% identified family and friends as most helpful
- 30% identified healthcare providers
- 18% identified information and education
- 11% identified hospice services

EQUITY, REPRESENTATION AND ONGOING ENGAGEMENT

Not all caregiver voices are equally represented in this report. Indigenous, Francophone, newcomer, diverse and equity deserving communities require ongoing, intentional engagement to ensure their experiences are understood and reflected in system planning.

- 2% identified as First Nations, Inuit or Métis
- 4% identified as Francophone
- 15% identified as newcomers to Canada
- Younger caregivers likely underrepresented

“Even when support exists, it does not always meet linguistic and cultural needs.”

Impact on Work, Finances and Daily Life

- 62% reported impact on work or education
- 46% experienced financial strain at least some of the time
- 7% experienced consistent financial strain

Caregiving often results in reduced income alongside increased costs, creating economic vulnerability.

Conclusion: What This Means

Caregivers are central to the health system. Supporting caregivers requires early information, coordinated services, and recognition of their role. This report provides a clear foundation for system change across Niagara.

The Niagara Ontario Health Team-Équipe Santé Ontario Niagara is a steadily growing network of 50 health care providers, social service agencies, educational institutions, and patient/client and family/caregiver representatives. We are committed to working as one coordinated team to provide exceptional service, support, and care to you, no matter when or where you need it, now and for our future generations.

The survey was developed by the NOHT-ÉSON's Palliative Care Working Group in collaboration with network partners.

This report was authored by Carol Nagy, Co-Lead of the Working Group and Executive Director of Hospice Niagara, and edited by Ron Laroche, Manager of Communications and Engagement at the NOHT-ÉSON.

Stay Connected!

www.noht-eson.ca

info@noht-eson.ca