



"I'm honoured to care for my mom, but I'm tired and overwhelmed. I don't know where to find the information I need."

Time to Talk

Being a caregiver often means you have less time to care for your own needs. If you're overwhelmed or need support, speak to a member of your healthcare team. We want to help.

CHANGING
CARE
CONNECTING THE DOTS
FOR CAREGIVERS

ABOUT CONNECTING THE DOTS FOR CAREGIVERS

Being a caregiver can be rewarding and fulfilling. It can also be challenging and cause frustration, stress and anxiety.

Connecting the Dots for Caregivers brings together six local healthcare organizations and caregivers to create tools and resources that will help caregivers feel more supported, valued and engaged in their important role.

The work focuses on three key themes:

-  Awareness and Recognition
-  Communication and Information
-  Education, Training and Supports



As a first step, the first co-design team created this awareness campaign to help healthcare providers understand the challenges of being a caregiver and help caregivers feel more comfortable discussing their needs with healthcare providers. Future co-design teams will build on this work and create tools to support the themes of communication and information and education, training and supports. Over the next two years, these tools and resources will be spread to partner organizations and then more broadly among healthcare providers in Huron Perth.



"Not everyone is willing to go on that journey with you. No one asks how I'm doing"

CAREGIVER



Most Ontarians have been or will be someone's caregiver at some point in their lives. Twenty-nine percent of the provincial population – or 3.3 million people – provide some form of support, assistance, care or enrichment to a family member or friend.

But who is caring for caregivers?



ARE YOU A CAREGIVER?

Caregivers are defined as a family member, friend, or neighbour who provides personal, social, psychological and physical support, assistance and care, for family members and friends in need. This support can be provided for any period of time.

The reality is that caregivers often don't see themselves as a caregiver. Instead, they see themselves as "just" a spouse, a son, a daughter or a friend – someone who cares about the person and steps in to fill a necessary need.

Caregivers told us they find it hard to ask for help, and in some cases the person they support won't allow them to accept it. They feel overwhelmed in their role, unsure of where to get information and anxious about what the future holds. They are frustrated, worried and feel tremendous guilt. They put themselves last and find it difficult to cope.

Their responsibilities include but are not limited to:

- Bathing, toileting, grooming
- Scheduling appointments
- Shopping
- Laundry, cooking, cleaning
- Taking care of the home (repairs and outdoor maintenance)
- Managing finances
- Planning social activities
- Driving
- Care navigating
- Patient advocating

WHAT ARE THE IMPACTS OF CAREGIVING?

For many caregivers, providing support to a loved one is a rewarding experience. However, there are impacts to the caregiver that can't be ignored. Time spent caregiving takes time away from other family responsibilities, as well as from work. Time is also taken from personal relationships and restricts a caregiver's ability to participate in social activities. This can cause more stress and feelings of isolation.



CAREGIVING HAS AN IMPACT ON:



Time



**Employment and
Work-Life Balance**



Finances



**Health and Wellness:
Mental, Emotional,
Physical and Social**



**Personal
Relationships**

CAREGIVER BURNOUT

Caregivers often feel mentally and physically exhausted. This can eventually leave a caregiver feeling burnt-out or feeling a loss of self. They are no longer able to cope with even simple tasks. Unfortunately, many caregivers don't seek help until they reach this point. In extreme cases, it takes being hospitalized for caregivers to accept support.

There are a number of factors that contribute to caregiver burnout:



Need for perfection

Many caregivers focus on what they need to do to improve rather than focusing on their accomplishments.

Overwhelming list of things to do

The never-ending list of tasks can lead caregivers to feel like they are not completing anything and trying to keep up contributes to exhaustion.

Self-sacrifice

Many caregivers agree to take on the role but may not want to, or they may have to give up other activities to be able to support their loved one. This can lead to feelings of resentment.

Unspoken feelings

Unexpressed emotions can manifest in unproductive ways and impact a caregiver's ability to complete tasks or function in relationships.

Not taking time for themselves

Many caregivers put themselves last and find it hard to find time for self-care.

SIGNS YOU MAY BE EXPERIENCING CAREGIVER BURNOUT

If you are experiencing any of the following, you may be showing signs of caregiver burn-out. Please speak to a member of your healthcare team.

- Lack of energy and exhaustion
- Feelings of tremendous guilt
- Frequently sick, feeling unwell, anxious
- Neglect own needs because life is dominated by caregiving
- Difficulty relaxing even when help is available
- Impatience, irritability
- Feeling overwhelmed or helpless, and possibly hopeless
- Changes in sleeping or eating patterns and/or the excessive use of alcohol, cannabis, and/or prescription medications
- Unable or unwilling to ask for help



► WHAT CAN YOU DO?

It's **Time to Talk**. Don't wait until you reach a point where you can no longer cope. If you are a caregiver and feeling overwhelmed in your role, please speak to a member of your healthcare team.



"Friends drift away, they don't know what to say. It surprised me at how quickly it happened...It was like we had the plague and not Alzheimers"

CAREGIVER

CAREGIVER RESOURCES



The following is a list of resources that you might find helpful.

You may find it helpful to contact the HuronPerth Community Support Services Network or Home and Community Care, South West Local Health Integration Network first.

Huron Perth Community Support Services Network

Central Intake service offered by Community Support Providers in Huron and Perth. Service includes, information about existing services, accessing new service, changing or cancelling current service.

1.844.482.7800

Home and Community Care, South West Local Health Integration Network (SWLHIN)

If you, or someone you care about, needs health care services at home, at school or in the community, or if you are considering supported living programs or long-term care options, home and community care at the SWLHIN can help.

1.800.811.5146

www.healthcareathome.ca/southwest/en

Ontario211 (dial 2-1-1)

The helpline and website provide a gateway to community, social, non-clinical health and related government services.

www.211.ontario.ca

Alzheimer Society of Huron County

Provides support, education and information for people with Alzheimer's disease and other dementias, and their caregivers.

519.482.1482

www.alzheimer.ca/en/huroncounty

Alzheimer Society of Perth County

Provides support, education and information for people with Alzheimer's disease and other dementias, and their caregivers.

519.271.1910

www.alzheimer.ca/en/perth

One Care Home and Community Support Services

Supports people to remain independent in their own homes for as long as possible.

1.877.502.8277

www.onecaresupport.ca

Huron Perth Helpline and Crisis Response Team (24 hour)

One number access to service for individuals in emotional distress, or in need of addictions and mental health support.

1.888.829.7484

South West Healthline

Provides information about local health services.

www.southwesthealthline.ca

Telehealth Ontario

Identify yourself as a caregiver in order to be directed to the correct resource. Free, confidential service you can call to get health advice or information. A Registered Nurse will take your call 24 hours a day, seven days a week.

1.866.797.0000

Caregiver Exchange

A blog and website for caregivers. It provides information and encouragement to caregivers, including events, news and community resources.

www.caregiverexchange.ca

The Caregiver Network

Connect with a network of experts and other caregivers online.

www.thecaregivernetwork.ca

The Change Foundation

A healthcare think tank currently focused on improving the caregiver experience. There are a number of resources on their website including Making Privacy and Consent Rules Work for Family Caregivers.

www.changefoundation.ca

The Ontario Caregiver Organization

Provides information and helps to connect caregivers to supports and services.

www.ontariocaregiver.ca

If you are a young carer - a child, youth or young adult that provides physical, medical, emotional or other supports to a parent, grandparent or sibling, please visit www.changefoundation.ca to learn more about provincial resources.

A SPECIAL THANK YOU

The Connecting the Dots for Caregivers team travelled across Huron Perth engaging with caregivers and healthcare providers to better understand the experience of caregivers and identify improvement opportunities. Thirty-six engagement sessions were held and a total of 251 individuals participated, sharing their experience at either a community forum, coffee chat or in a one-on-one interview. A special thank you to these caregivers and healthcare providers who shared their stories and insights.

This pamphlet was created through a co-design process involving equal participation of caregivers and healthcare providers on the Awareness and Recognition team in Huron Perth.

The information provided in this pamphlet has been developed based on work done at The Change Foundation, Caregivers Alberta and with the help of caregivers and healthcare providers in Huron Perth.

PROJECT PARTNERS

Caregivers in Huron Perth
Huron Perth Healthcare Alliance
Alzheimer Society of Perth County
North Perth Family Health Team
One Care Home and Community Support Services
South West Local Health Integration Network
STAR Family Health Team

If you would like to receive our newsletter, please
contact Ashley Bedard at Tel: 519.527.1650 ext. 4219
or ashley.bedard@hpha.ca



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