

A PLANNING FRAMEWORK FOR IMPROVING SUPPORTS TO CAREGIVERS

A DISCUSSION DOCUMENT • MAY 2017



WELCOME

On behalf of our collaborative group of individual caregivers and organizations, I am pleased to share this comprehensive planning framework for improving the ways that we support caregivers.

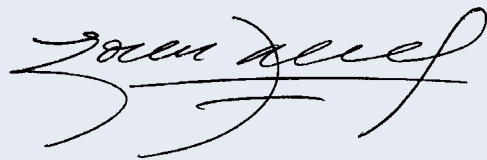
Caregivers play a critical role in providing support to our families, communities and society. The needs of caregivers are often not recognized or understood. Therefore, it is vital that caregivers are identified early in their care journey, to enable timely access to needed education and supports (e.g. education/training, respite, counselling, navigation of health system). When caregivers are adequately supported, their own risks of distress or declining health are reduced.

By creating and publishing this guiding framework, we are demonstrating our continued commitment to envisioning a better system – and planning meaningful changes – that address the needs of caregivers. This Framework introduces a more structured approach to recognizing and supporting caregivers. It is intended to be a “living document” – one which can be adapted based upon further consultation and learning from the experiences of implementing new approaches and practices.

Now is the time to focus on making the caregiver role more visible. By listening to caregiver experiences, we can change the way we respond and better provide the supports to caregivers of all ages and circumstances.

Please join us in this important work!

Sincerely,



Loren Freid
Executive Lead and
CEO, Alzheimer Society of York Region

ACKNOWLEDGMENTS

This Framework has been collaboratively developed by individuals and organizations, led by the Alzheimer Society of York Region, and with financial support from the Central LHIN.

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This document was created using a set of tools and methods called **Experienced Based Co-Design (EBCD)**. These methods capture the experiences and insights about what really matters to patients, caregivers and staff through discussion, observation and interviews. By enabling patients, caregivers (the service users) and front-line or management staff to share their experiences, feelings and perspectives and use these constructively, EBCD often reveals gaps, unmet needs, opportunities and successful practices for making front-line and system-level changes and improvements.



INTRODUCTION

This Caregiver Support Framework is the result of a creative co-design process involving both caregivers and healthcare and community service providers within the Northern York Region and South Simcoe areas of the of the Central Local Health Integration Network (LHIN). It has been developed under the executive leadership of the Alzheimer Society of York Region (AS York).

The experience-based co-design sessions identified key problems and issues that require change – in order to improve the caregiver experience at home, and when interacting with staff in various healthcare or other organizations. The group envisioned a more supportive system for caregivers, including how they are recognized by formal care providers and society. For more information on the methods of experience-based co-design visit: pointofcarefoundation.org.uk

Many new ideas were generated about specific education and training resources, peer supports, various respite and in-home supportive services. A scan of practices, tools and resources was also undertaken, to gain insight into how other jurisdictions have improved the experience and well-being of caregivers.

Based on this initial co-design work, the group identified three foundational building blocks from a policy perspective:

- Development of a **Caregiver Support Framework** – a common framework to guide the development of new programs and policies, and to identify gaps in policies, programs and services affecting caregivers, and monitor and evaluate the effectiveness of interventions from the caregiver perspective.
- Development of a **Supported Referral and Navigation Model** – a model of early recognition of caregiver needs and linking to appropriate supports to provide timely and relevant supports to foster their self-care and resiliency.
- Development of a **Care Plan for the Caregiver** – a care plan that is specific to the needs of a caregiver, that is separate and aligned to the care plan for the client.

In publishing this planning framework, we are using these three building blocks to lay the groundwork for a more supportive culture for caregivers.

**For more resources and information about this initiative, you can visit:
www.alzheimer.ca/en/york/We-can-help/Support/Caregiver-Framework**

Definition of a caregiver

Family Caregivers are people – family, friends and neighbours – who provide essential and often ongoing personal, financial, social, psychological and physical support, assistance and care, without pay, for family members and friends in need of support due to frailty, illness, degenerative disease, physical/cognitive/mental disability, or end of life. (Source, adapted from: *Change Foundation Report: A Profile of Family Caregivers in Ontario, 2016*).

Definition of a person who receives care

In a healthcare context, the person who receives care is often referred to as a “patient”. Whereas in a social service context, he/she is referred to as a “client”. For the purposes of this document, the terms “client” and “patient” are used interchangeably to ease readability.

“Finally, when my husband was formally diagnosed with Alzheimer’s disease, the **only thing** the doctor provided to us at the time was a prescription and written diagnosis. That was it!”

CAREGIVER,
CO-DESIGN SESSION
SEPTEMBER 2016

Who are Ontario’s caregivers?

In the Profile of Family Caregivers report prepared by the Change Foundation, a snapshot was provided of caregivers in Ontario based on the findings from Statistics Canada General Social Survey (GSS) 2012 data. These statistics illustrate the various circumstances of caregivers (e.g. age, culture, linguistics, living situation and proximity). There are also variations in the types of care they provide.

Some of the key findings from this analysis are:

- An estimated 3.3 million Ontarians, 29% of the provincial population, are family caregivers.
- 53% (1.8 million) of caregivers are women and 47% (1.5 million) are men.
- Family caregivers vary in age – with largest proportion (23%) between 45 and 54 years old. Of the balance, 11% are over the age of 65 and 19% are 55-64 and 17% are 15 to 24 years old.
- The majority of caregivers (65%) are married or living in common law arrangements.
- In terms of proximity to the person being cared for, 30% of caregivers live in the same dwelling, 50% live in a community less than one hour away by car, and 20% live in a community that is one or more hours away by car.
- 21% report that their primary language is not English or French, and approximately 25% were born outside of Canada.
- Almost 29% of caregivers have one or more children under the age of 14 years old.
- Nearly three in 10 caregivers perform medical treatments such as tube feedings, wound care and injections.
- 2.5 million Ontario caregivers are balancing caregiving duties with paid employment and of these caregivers.
- 30% (741,000 people) were late for work or had to leave early to fulfill caregiving duties.
- 29% (735,000 people) missed an average of six days of work because of caregiving duties and 1% (33,000 caregivers) left their employment voluntarily or involuntarily.
- One million caregivers said they felt they had no choice in taking on their caregiving responsibilities.

This planning framework is designed to be flexible enough to allow customization based on consultation input and feedback from a wide range of caregivers.

The nature of caregiving and the caregiver role

The term *caregiver* – as a title or position, is not always recognized or understood. There can be external barriers to recognizing caregivers (e.g. the social stigma of caring for a person with a mental health diagnosis or dementia). Or, sometimes the barrier can be internal to the person (e.g. he/she may identify themselves as a wife or son who is helping their family member, rather than seeing their caregiving as an additional role).

Caregiving is a voluntary and unpaid role, yet not all caregivers feel that they have a choice. As the needs of person being cared for become more significant, the nature of the relationship can change with the caregiving role and responsibilities becoming more prominent.

The caregiving process is dynamic and is affected by both fluctuations in the conditions and circumstances of both the client and caregiver. For example, when

a frail senior is caring for another senior, as their respective health conditions change, it can become more complex to manage for both parties.

Regardless of the type of barrier to role recognition, when the caregiver role is not identified, it can be challenging for the caregiver to become informed and empowered to meet his/her own needs, or become a partner in the care process.

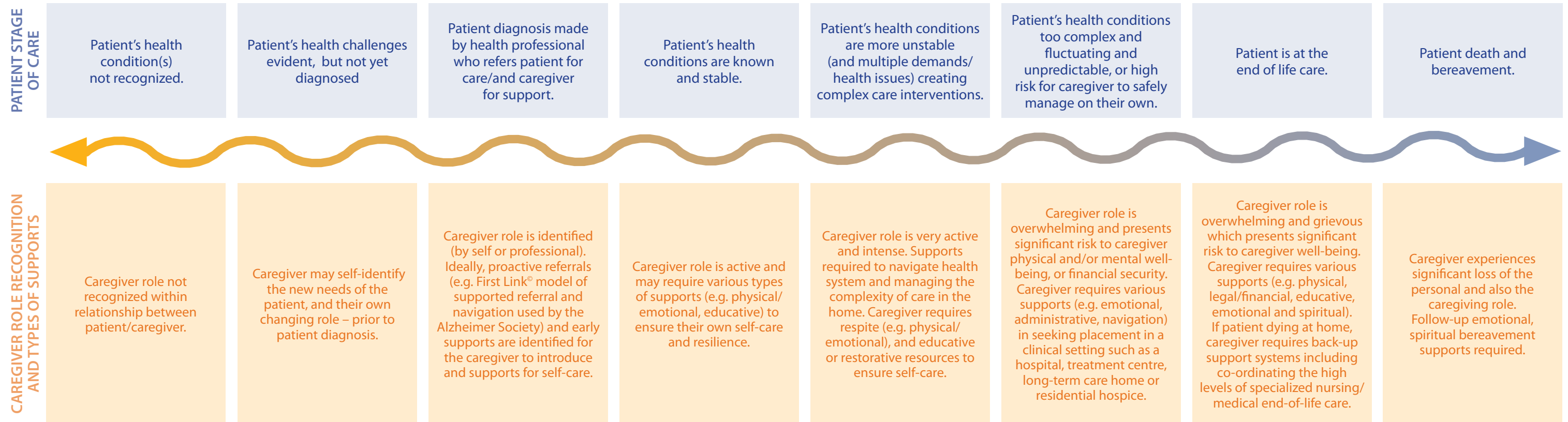
Stages of caregiving

When a patient or client’s condition becomes diagnosed and known, it is often the defining point in the caregiver trajectory. For example, if the client/patient is diagnosed with a chronic or degenerative condition, the caregiver role is more likely to become an ongoing role.

It is at this key point in the care process that clinicians have an opportunity to identify and recognize the role of the caregiver – and the associated demands – and proactively begin the process of seeking out and linking the caregiver to the appropriate supports.



Snapshot of patient and caregiver journey



Respectful and compassionate communication and interactions throughout the care process (amongst healthcare providers, patients and caregivers) are vital to the quality of the patient and caregiver's experiences. With clear communication, this reduces the amount of time and energy caregivers spend on coordinating care.

Caregiving is not a linear path, nor is the patient experience. There can be normal cycles where things are more certain and manageable (or a "steady state"), and times when things are unpredictable and overwhelming, as illustrated above.

From the caregiver perspective, there can be positive emotions associated with caregiving tasks, such as pride, enhanced self-esteem, and mastery. The positive emotions are more prominent when the caregiver feels that they are enhancing the patient/client's quality of life through symptom management, physical and/or emotional supports.

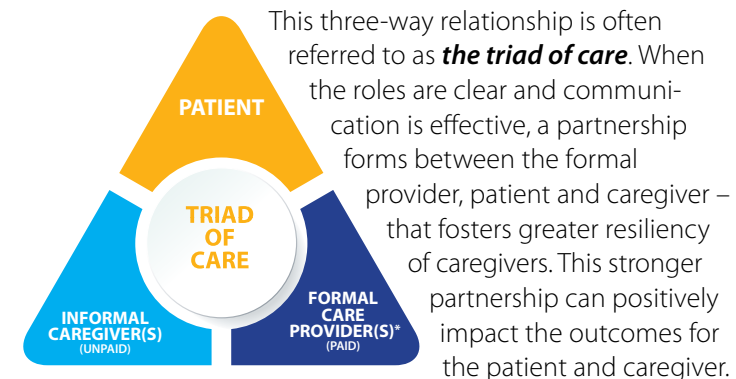
As the patient's needs intensify in complexity and unpredictability, the demands in the amount of time and types of caregiving tasks also increase (over a long duration). These heightened demands, combined with other negative emotions (e.g. feelings of fear, ambiguous loss, grief, depression, social isolation),

can lead to deterioration of the physical health and the emotional health of the caregiver.

When the caregiver's role and needs are not recognized, it also means they do not access resources and supports in a timely and relevant way to ensure their own self-care, and health. Their increased caregiving duties can also lead to depression, physical or emotional burnout, and/or social isolation. **By not accessing supports, caregivers forfeit assessments, care plans or timely referrals to supports to meet their own needs.** The emotional and physical health risks can be very high (to both the patient and caregiver) from the negative chain of events that result from not recognizing the caregiver's role.

And, as the client's health conditions become more complex, more interaction is required with the various healthcare clinicians and settings. Caregivers often report that these interactions with the health system (or at work or school), *can be made worse by poor communication within and across healthcare settings (e.g. hospital to home).*

There is a shared accountability between the client, informal (unpaid) caregivers and the formal (paid) care providers.



This three-way relationship is often referred to as **the triad of care**. When the roles are clear and communication is effective, a partnership forms between the formal provider, patient and caregiver – that fosters greater resiliency of caregivers. This stronger partnership can positively impact the outcomes for the patient and caregiver.

When caregivers are not acknowledged as full partners in care, it can be discouraging. They feel a lack of support and spend more time and energy trying to work with the formal health system to co-ordinate the care of their loved one. This can take away from their ability to manage normal life activities such as work, school, or managing household responsibilities.

Ideally, the goal is to reach caregivers and introduce supports early in their care trajectory. By taking a proactive approach to caregiver education and providing needed physical, psycho-social, and spiritual supports, it is possible to decrease the risks to the caregiver.

* doctors, nurses, healthcare or community organizations, etc.

“I was in the hospital every day for 41 days with my brother, and I don't think anyone knew who I was. I wasn't made to feel like part of the team at the hospital.”

CAREGIVER,
CO-DESIGN SESSION
SEPTEMBER 2016



LOGIC MODEL VIEW – A PLANNING FRAMEWORK FOR STRENGTHENING CAREGIVER SUPPORTS

The co-designed sessions led to the creation of the following guiding principles about how caregivers should be considered and treated. These statements have been used to set the directions for the logic model.

“As a caregiver, I became extremely overwhelmed and anxious with the increasing supports and services my brother needed. I had enormous trouble navigating the healthcare system on my own.”

CAREGIVER,
CO-DESIGN SESSION
OCTOBER 2016

Purpose of the logic model framework

This planning framework is broad in scope, and intended to provide a system-level perspective on improving supports to caregivers. Drawing upon the ideas generated during the co-design sessions held in the Central LHIN, the framework sets out a vision, main components, activities and outcomes to be achieved over a period of time.

The visual representation of the Framework in the Logic Model format provides a roadmap for achieving the outcomes and the desired future state. This format brings together all of the aspects of the framework on one page, to enable stakeholders (caregivers, providers, policy makers, advocacy and community groups) to visualize the key elements of the approach, identify gaps, plan and set priorities for implementing specific activities, and measure progress over a period of time.

Through conversations and consultations on the Framework, and further co-design work, a common perspective can be shaped on the desired culture and practice changes (e.g. supported referrals, care plans for caregivers) that will enable diverse caregivers to be adequately supported via healthcare settings, community networks, neighborhoods, workplaces and schools.

Guiding Principles

1. Caregivers play an integral role in society, and their contributions are recognized and valued.
2. Caregivers experiences and perspectives are vital to informing the design and delivery of care.
3. Caregivers needs and choices are respected in their places of work, education, and in healthcare and community environments.
4. Caregivers have a right to safety, security, respect for their dignity.
5. Caregiver self-care is essential to sustaining well-being, and the continued fulfilment of caregiver role and responsibilities.
6. Caregiving involves people of all ages with diverse cultural and religious backgrounds.
7. Caregivers are a vital part and equal partners in the healthcare team.
8. Caregivers are entitled to compassionate person-centred care that supports their independence.
9. Caregivers need flexible and individualized supports due to the multiple and competing demands of caregiving.
10. Caregivers deserve supportive environments (e.g. workplaces, schools, cultural/religious organizations) in carrying out their roles/responsibilities.

• VISION

To improve the recognition, resiliency and supportive resources for informal caregivers, in collaboration with health and community care providers and other organizations.

In creating the vision statement during a co-design session, participants identified the following statements about the desired caregiver experience:

- Caregivers feel less fear, anxiety, guilt and stress and thereby reduce the possibility of becoming overwhelmed by the caregiver role.
- Caregivers will have more peace of mind and less uncertainty about who can help them and more navigational support – including from other caregivers who are “walking the path”.
- Caregivers are more equipped and supported for resiliency – empowered with more options for self-care to maintain personal life balance along with their caregiving responsibilities.
- Caregivers will receive a (“live”) human response through the referral process (e.g. for example First

Link® which involves dementia caregivers and the person diagnosed at the time of diagnosis – via an “in reach” type of process for supporting engagement).

- Caregivers of individuals with dementia and/or complex needs feel that their voices have been heard, and their own unique needs for support will be addressed.
- Caregivers feel more supported by a co-ordinated team – this team could be other caregivers (peers), their support networks, and clinicians working in different healthcare and community settings are communicating on their behalf.

• MAIN COMPONENTS

The five main components of the Caregiver Support Framework identify the main activities along with the supportive activities to achieve the implementation objectives for each key area. The five key elements are:

- **Inform and Recognize** – This element is about increasing the public awareness and recognition of the value and contributions of caregivers. Through a better public understanding of this role, caregivers can more easily self-identify themselves, or professionals can be more skilled at identification of caregivers.
- **Referral and Navigation** – This element is about increasing the tools, processes and coaches that help caregivers link with the right resources to access the right type of help in a timely and supportive way.
- **Caregiver Assessment and Care Planning** – This element is about healthcare and community organizations increasing their caregiver assessment and care planning skills and tools, to create and update a unique care plan for the caregiver, when this is needed.
- **Caregiver Education and Supports** – This element is about expanding the delivery of caregiver education and training resources, workshops, and programs (including counselling, respite, peer supports) that support caregivers and increase their skills, confidence and resiliency.
- **Monitor and Re-evaluate Caregiver Care Plans** – This element is about monitoring the impacts of specific caregiver education and support activities, hearing the stories, testimonials and feedback of caregivers, including care plan fulfilment, to identify the barriers and success factors that contribute to effectively supporting caregivers.

“I was my parents’ principal caregiver for ten years. Looking back, it was especially challenging when I felt isolated, alone and overwhelmed. This planning framework will help to ensure that caregivers have their own care plans for arranging needed respite and supports, be more educated, feel less alone and isolated – by establishing connections with peers and professionals that can provide needed help and advice.”

CAREGIVER

• TARGET GROUPS

There are three main audiences or groups that are involved in implementing this framework:

- Caregivers of all ages and circumstances caring for someone that is aging, and/or has a chronic illness or disability (physical, mental health, addiction, etc.)
- Care Providers and Organizations (healthcare, education and social services) that can support caregivers.
- General Public (including organizations and employers).

• ACTIVITIES

The specific activities contained in each the five components of the logic model are intended as illustrations. They are not presented in a specific order. Once more dialogue and consultations have taken place, the designs and plans for specific activities can be refined.

Some generic examples of activities (e.g. tools, processes, training content and delivery) that can be implemented within the five logic model elements are:

- Self-identification tools (for caregivers)
- Communication tools (for providers and caregivers)
- Self-screening/self-referral tools (patient and caregiver)
- Health Self-Management education and tools (patient and caregiver)
- Professional referral tools and processes (e.g. First Link ©supported referral model) (for providers)
- Caregiver Training and education tools (for caregivers)
- Provider Skills Training (for providers)
- Public Education materials (for public, workplaces, schools and community groups)
- Caregiver Assessment Tools (for providers)
- Caregiver Care Plan Tool (for providers and caregivers) to address caregiver needs as the situation changes
- Communication tools/processes are developed that ensure smooth patient transitions (e.g. coming out of hospital, placement into a LTC or residential hospice) in care settings and support caregivers

• LONG TERM OUTCOMES

There are two broad categories of outcomes to achieve this Vision:

1. Early Caregiver Recognition with Proactive Referral and Access to Supports for Caregivers

- Heightened public awareness and understanding of the caregiving role and responsibilities.
- Caregivers identified and supported earlier in the disease or care trajectory of the client/patient.
- Health and service providers are competent in recognizing and communicating with caregivers.
- Simplified and effective system of access to supports for caregivers.
- Caregivers are equal partners early in the patient care process.

2. Caregiver Assessment, Care Planning and Co-ordination of Supportive Resources and Services

- Service providers are competent in assessing, care planning, and supporting caregivers as full partners in the care process.

- Reduced caregiver uncertainty and stress due to lack of information or poor quality communication between healthcare providers, particularly at transition points between settings/providers.
- Caregivers receive timely and relevant supportive resources/services enabled by assessments and care plan.
- Reduced caregiver burden based on service provision and mitigating socio-economic risk factors (such as health conditions, single parent, frail elderly, language barrier, low income level, etc.).
- Caregiver’s are satisfied with their experiences with self-care, receiving supports, and providing care for others.

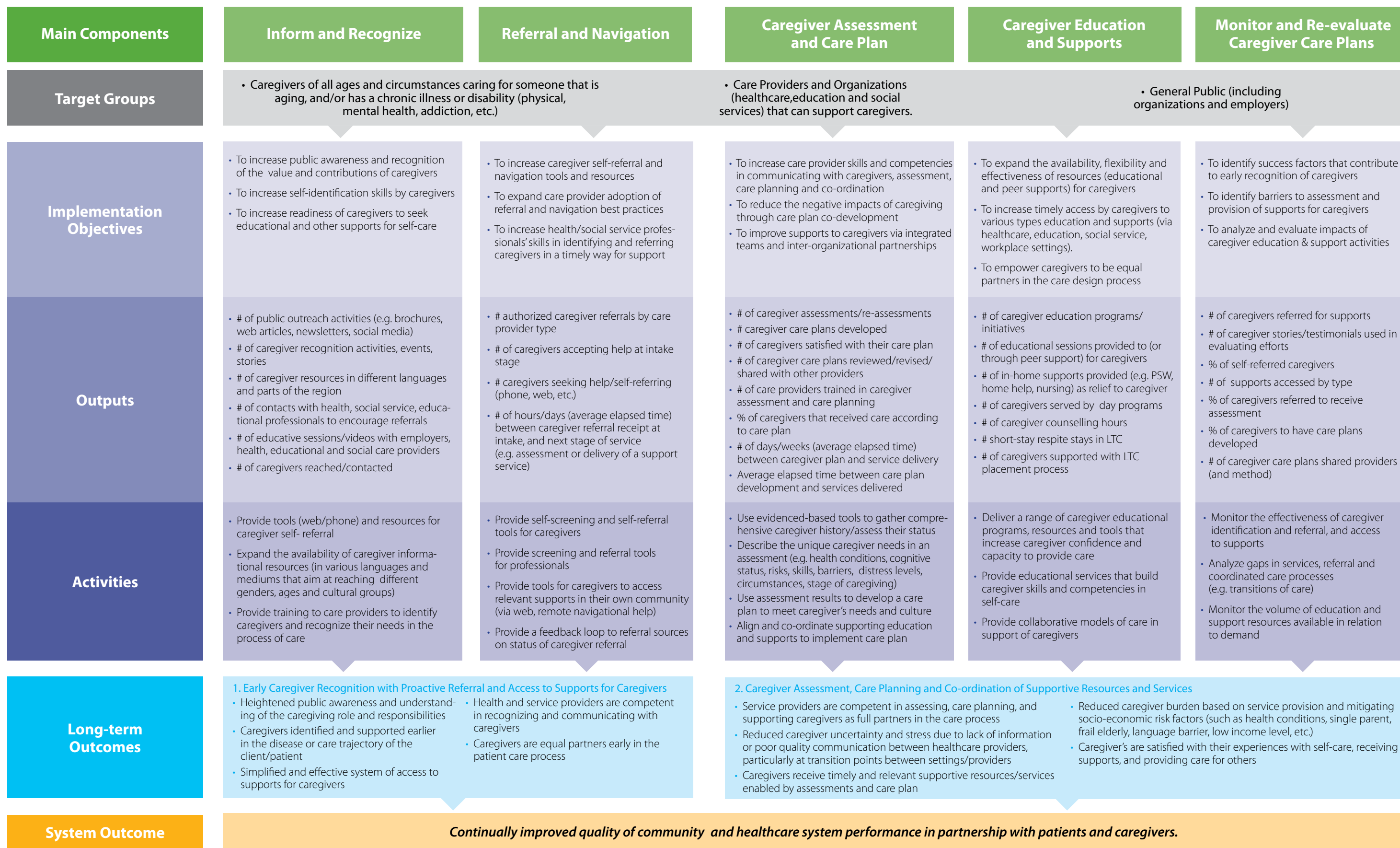
• SYSTEM OUTCOME

Continually improved quality of community and healthcare system performance in partnership with patients and caregivers.

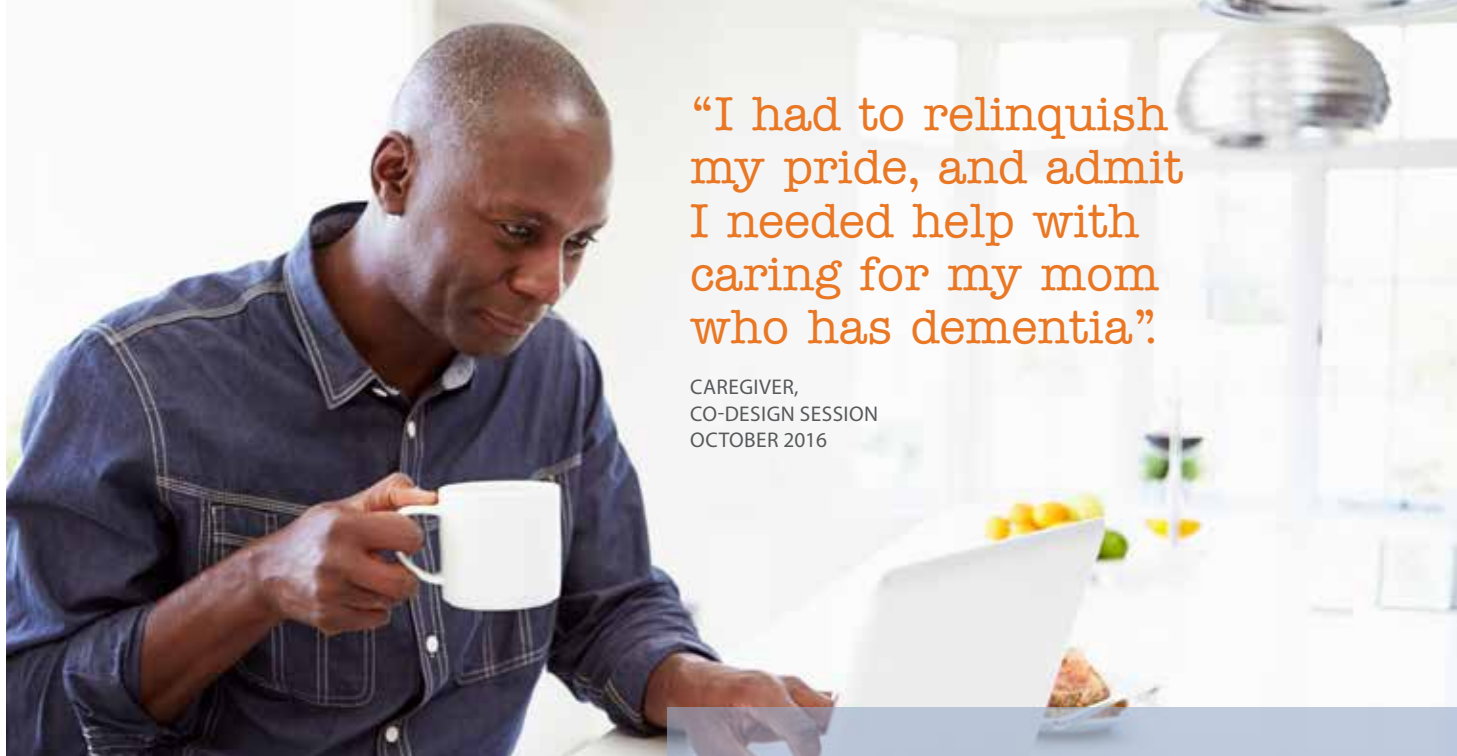


A PLANNING FRAMEWORK FOR STRENGTHENING CAREGIVER SUPPORT – LOGIC MODEL VIEW

VISION: To improve the recognition, resiliency and supportive resources for informal caregivers, in collaboration with health and community care providers and other organizations.



CAREGIVER DEFINITION: A Caregiver is an unpaid/informal caregiver (often family, partner, close friend), who is caring for an individual with a chronic illness, disability or is aging.



“I had to relinquish my pride, and admit I needed help with caring for my mom who has dementia.”

CAREGIVER,
CO-DESIGN SESSION
OCTOBER 2016

SUMMARY AND NEXT STEPS

Consultation Phase and Framework Adoption

This planning framework is intended to foster further discussions and consultation about the “how” to improve the supports to caregivers. The Logic Model format of the framework can be used as a starting point for conversations about the unique barriers and challenges that caregivers face, and innovative ways of addressing these challenges by strengthening the supports to caregivers.

The consultation phase must involve the input and hearing the experiences of caregivers from various:

- age ranges
- economic situations
- cultural and linguistic backgrounds
- rural and remote locations
- settings – such as neighborhoods, community/ cultural networks, healthcare environments, schools and workplaces. It will be important to find ways that connect caregivers who can be particularly isolated – including those who may live in cities.

Based on discussions during the consultation phase, new ideas and partnerships will emerge for offering education and training, peer supports, communication methods, and adapting care processes within

and across health and community care sectors (e.g. primary care, hospital and home and community service and health service provider organizations). It is also anticipated that consultation discussions will yield ideas about options for implementing a caregiver care plan and more supported referral systems for caregivers.

The framework can also be used to guide organizational and cross-sector quality improvement planning. And more broadly speaking, the framework can inform planning efforts related to implementing the changes related to the Ontario’s Patient’s First Act, 2016, and the organizational planning for the sub-regional models in the LHINs.

With input from a wider range of caregivers and staff from various healthcare and community service organizations, the logic model can be refined, and action plans developed for implementing improvements.

By disseminating and consulting on this collaboratively developed framework, we can envision and plan meaningful changes to address the gaps and urgent need to improve supports to caregivers.

Regardless of the type of barrier to role recognition, when the caregiver role is not identified – it can be challenging for the caregiver to become informed and empowered to meet his/her own needs, or become a partner in the care process.

For more information about this initiative, or to participate in the consultations, you can visit:

www.alzheimer.ca/en/york/We-can-help/Support/Caregiver-Framework

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“Ultimately, caregivers need to be a strong and steady support, and an advocate for the continually changing needs of their loved one”

- CAREGIVER, CO-DESIGN SESSION, SEPTEMBER 2016