UHN Research

October 29th, 2026

Neurotrauma Care Pathways

Can Caregiving get E.A.S.I.E.R? Recommendations from a Review of Caregiver Outcomes and Interventions

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Funded by:

CIHR IRSC

Learning Objectives

Neurotrauma Care Pathways

1. **Understand** the current state of evidence regarding the impact of caregiving on the quality of life, mental health, and brain health of caregivers of individuals with brain injury.
2. **Identify** key factors contributing to caregiver burden and examine evidence-based interventions that can improve caregiver health and well-being.
3. **Describe** key policy recommendations aimed at addressing the unmet needs of brain injury caregivers and strengthening available supports and services.
4. **Apply** a proposed framework to guide healthcare providers in identifying, assessing, and addressing the needs of brain injury caregivers



Neurotrauma Care Pathways

"I have an overload of work 7 days a week, 12-14 hours per day, no weekends off and no holidays; burnout, lack of sleep and minimal meals 3 times a day, much like serving a sentence awaiting release day"

'Afterthought'

'Invisible'

"Nobody asks 'How are you doing?' I'd like to say I'm at the end of my rope; I don't know how much more I can take. But nobody ever asks that question"

'Hidden'

'Crisis'

"For me, the gap really is right at the beginning. I should have been able to walk out of that hospital with my spouse and known who to see for support…"

Synthesizing Knowledge on Caregiver Outcomes and Interventions

Neurotrauma Care Pathways

The Neurotrauma Care Pathways Initiative received funding from CIHR to answer the following questions:

- What is the **impact of caregiving** on the life and health of the caregiver?
- What factors drive caregiver **burden**?
- What **interventions and strategies** are effective at mitigating caregiver challenges?
- What **changes need to be made at a system/policy level** to improve the current state of caregiver support?

The Project Team and Discussion Panel

Neurotrauma Care Pathways



Judy Gargaro



Arman Ali



Jackie Quemby



Ruth Wilcock

Jackie’s Caregiving Story



Neurotrauma
Care Pathways

Our Approach

Neurotrauma Care Pathways

Literature Reviews



Worked with a librarian to complete 3 related literature searches:

- Umbrella Review on caregiver outcomes (n=51)
- Scoping review on caregiver interventions (n=64)
- Rapid review on brain health and aging of caregivers (n =41)



Focus Groups

- Recruitment through community-based organizations
- 3 groups were established with 20 participants: parent (n = 11), spouse (n=6), sibling (n=3)
- Discussed impact of caregiving and experiences with interventions/the healthcare system over 9 total meetings
- Prioritized challenges and co-developed recommendations for decision makers

Caregiver Experience Surveys

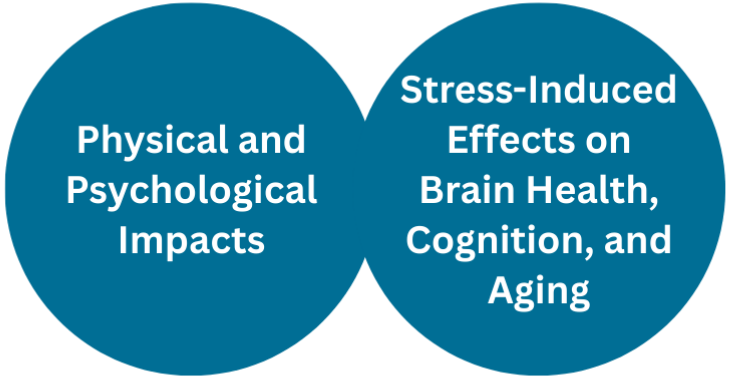


- 42 questions consisting of general details about caregiver and recipient, impact of caregiving on daily life and aging, and factors that may influence caregiving experience
- Completed by 18 caregivers of people with brain injury

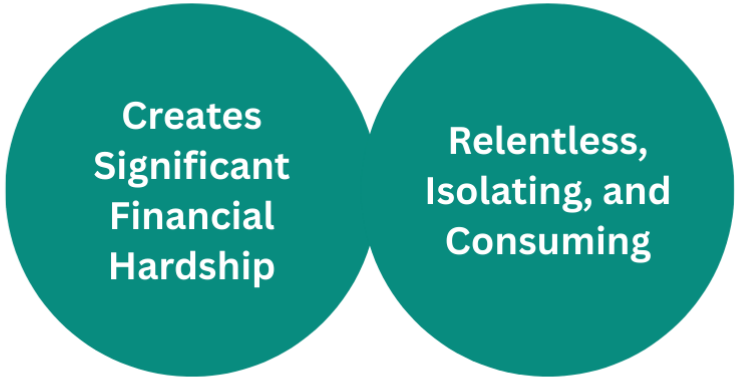
Results Summary

Neurotrauma Care Pathways

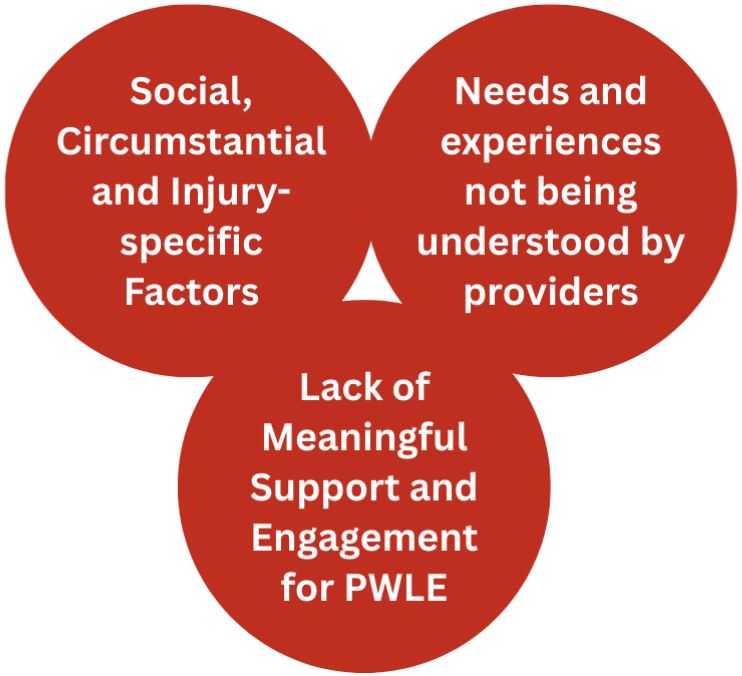
Health Impacts



Socioeconomic Impacts



Drivers of Stress/Burden



Effective Interventions



Challenges and lessons learned

- Lack of quality literature
- Need to capture more diversity in the caregiver experience
- Involve caregivers at each stage

Neurotrauma Care Pathways

The Health Impacts of Caregiving

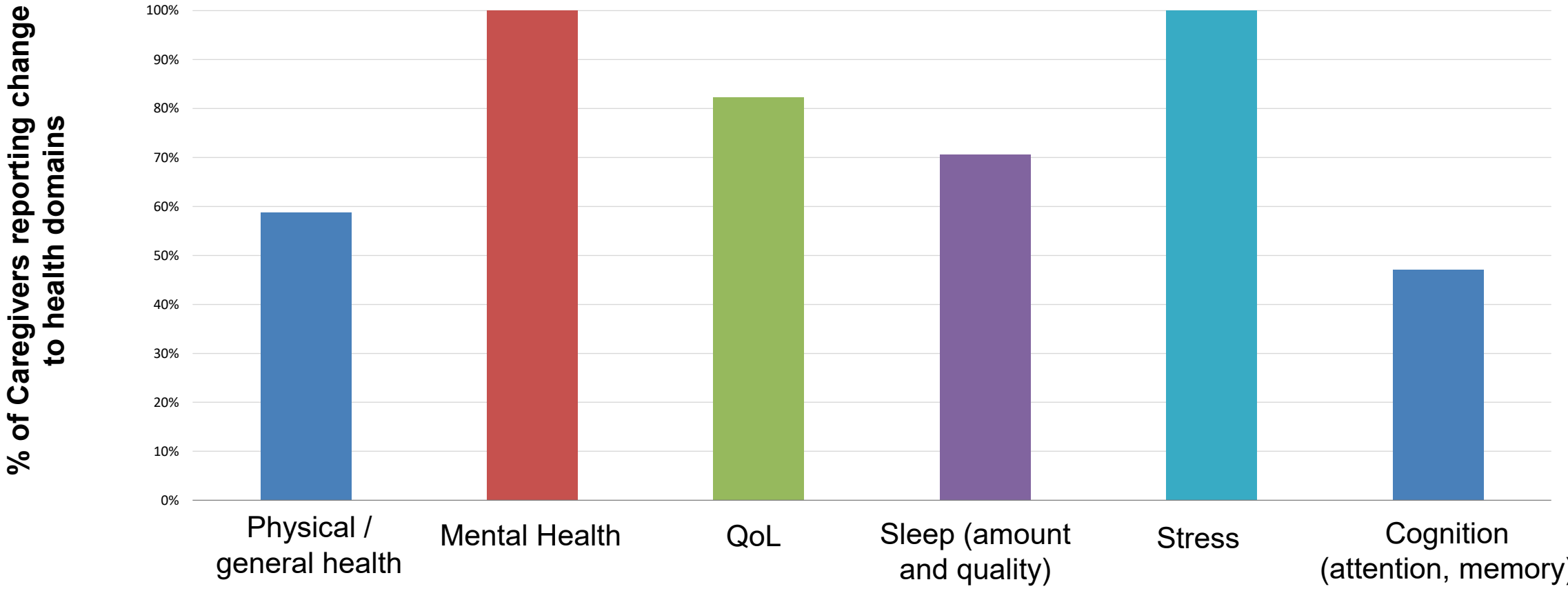
1. **Brain Injury Caregivers Experience Physical, Psychological, and Quality of Life Impacts**
   - Across all sources of evidence, there was acknowledgement of pervasive caregiver burden, poor overall health/wellbeing, and low quality of life
   - 100% of survey respondents indicated that their **stress levels and mental health** were impacted by caregiving



2. **Caregiving-Induced Stress Affects Brain Health, Cognition, and the Aging Process**
   - Chronic exposure to stress experienced by caregivers can affect cognitive function and accelerate aging
   - Over 85% of research papers included in our brain health rapid review reported negative effects related to brain health, cognition, or aging in the caregiver



Impact of Caregiving on Health Domains



The Socioeconomic Impacts of Caregiving





1. **Caregiving Creates Significant Financial Hardship**
   - Caregivers collectively ranked financial burden as the highest priority gap that should be addressed in the short-term
   - Sources of financial stress: loss of job/inability to resume full-time work, loss of income from care recipient + Insufficient disability support, medical/care expenses
2. **Caregiving is Relentless, Isolating and Consuming**
   - Social isolation driven by the intense demands of caregiving was a recurring theme across all sources of evidence

Drivers of Burden (1)

- **Caregiver Burden, Stress and Emotional Load are Created by a Variety of Social, Circumstantial, and Injury-driven Factors:**
  - Severity of the care recipient's injury and intensity or duration of caregiving
  - Sociodemographic factors (age, sex, gender, race/ethnicity, location, income)
  - Family dynamics and relationship types (e.g., relational dynamics, household composition)
  - Presence of social support or lack thereof (i.e., social isolation)
  - Types of coping mechanisms used (e.g., attitudes about hope and recovery)
- Survey respondents indicated the following had the greatest impact:
  - severity of injury (88%)
  - presence of emotional (82%), cognitive (76%), or behavioural symptoms (76%)

Drivers of Burden (2)

- **The Needs and Experiences of Persons with Brain Injury and their Caregivers are Often Not Understood by General Providers**
  - Awareness, management and aftercare of the brain injury itself, but also lack of communication, system navigation support, and connection to services.



- **There is a Lack of Meaningful Support and Community Engagement for People with Brain Injury**
  - The insufficient services for people with brain injury, and the impact this has on caregiver burden was a recurring theme in Focus Groups
  - **Quote:** *"Support for the individual, for the person that has received the brain injury [is the biggest challenge]. There are nowhere near enough services…"*

Survey Data: Factors that Impact Burden

Care Recipient-Related Factor	n (%)
Severity of injury	15 (88.24)
Emotional symptoms	14 (82.35)
Cognitive symptoms	13 (76.47)
Behavioural symptoms	13 (76.47)
Physical symptoms	12 (70.59)
Ability to access rehab and support	11 (64.71)
Age	10 (58.82)

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Informing Services and Interventions

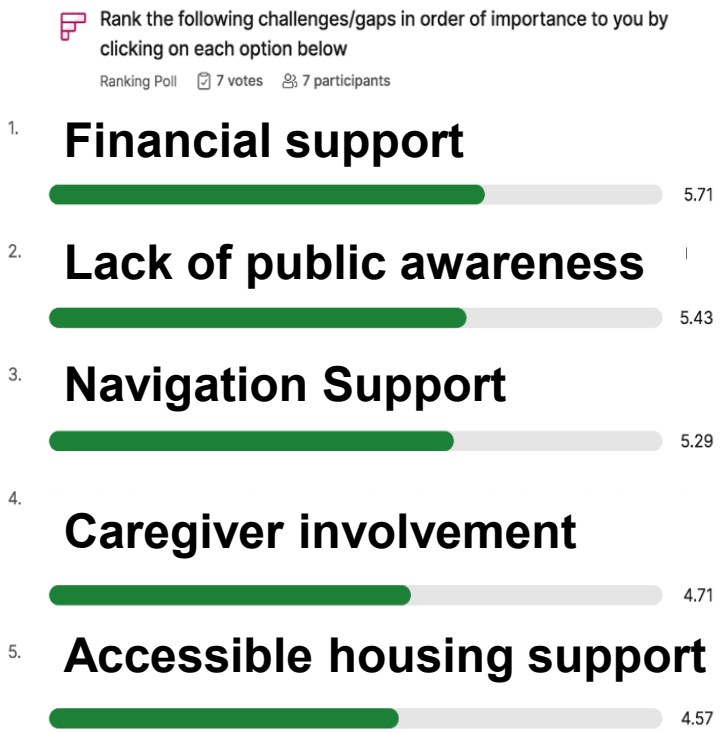
- **Psychosocial Interventions and Social Prescribing are Effective at Improving Caregiver Outcomes**
  - Particularly effective: Interventions based on psychoeducation, resiliency-building, problem-solving, life change adaptation, or peer and community-support approaches

- **Information to address Overwhelming Anxiety About what the Future Holds Given the Intersection Among Stressors, Aging, and Lack of Housing**
  - Support to plan for the future to ease worry
  - Build a backup plan

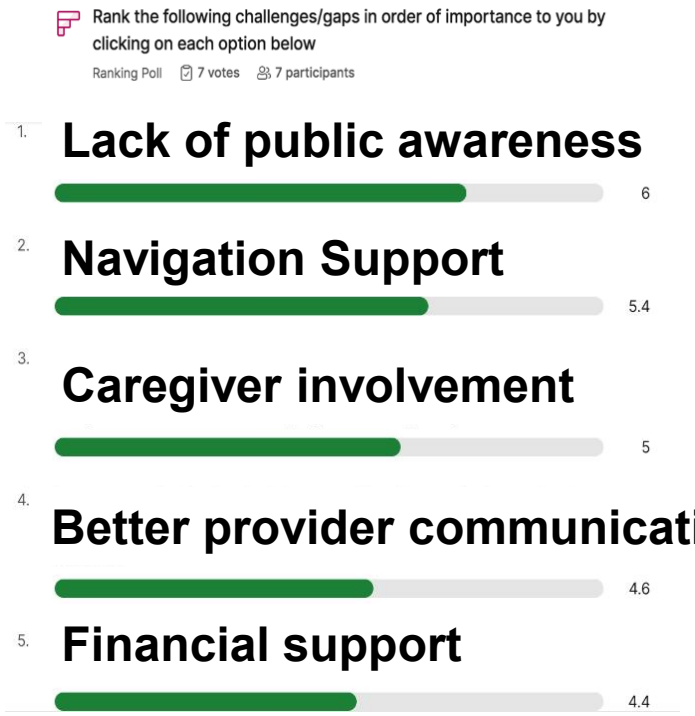
Ranking Priorities: FG Exercise

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Parent Group



Spouse Group



Gap	Parent Rank	Spouse Rank
Financial Support	1	5
Lack of specialized knowledge, awareness, understanding, and training specific to BI	2	1
Navigation support	3	2
Caregiver involvement and empowerment	4	3
Need for safe and accessible housing and support options	5	NA
Better communication from providers	NA	4

Policy Recommendations

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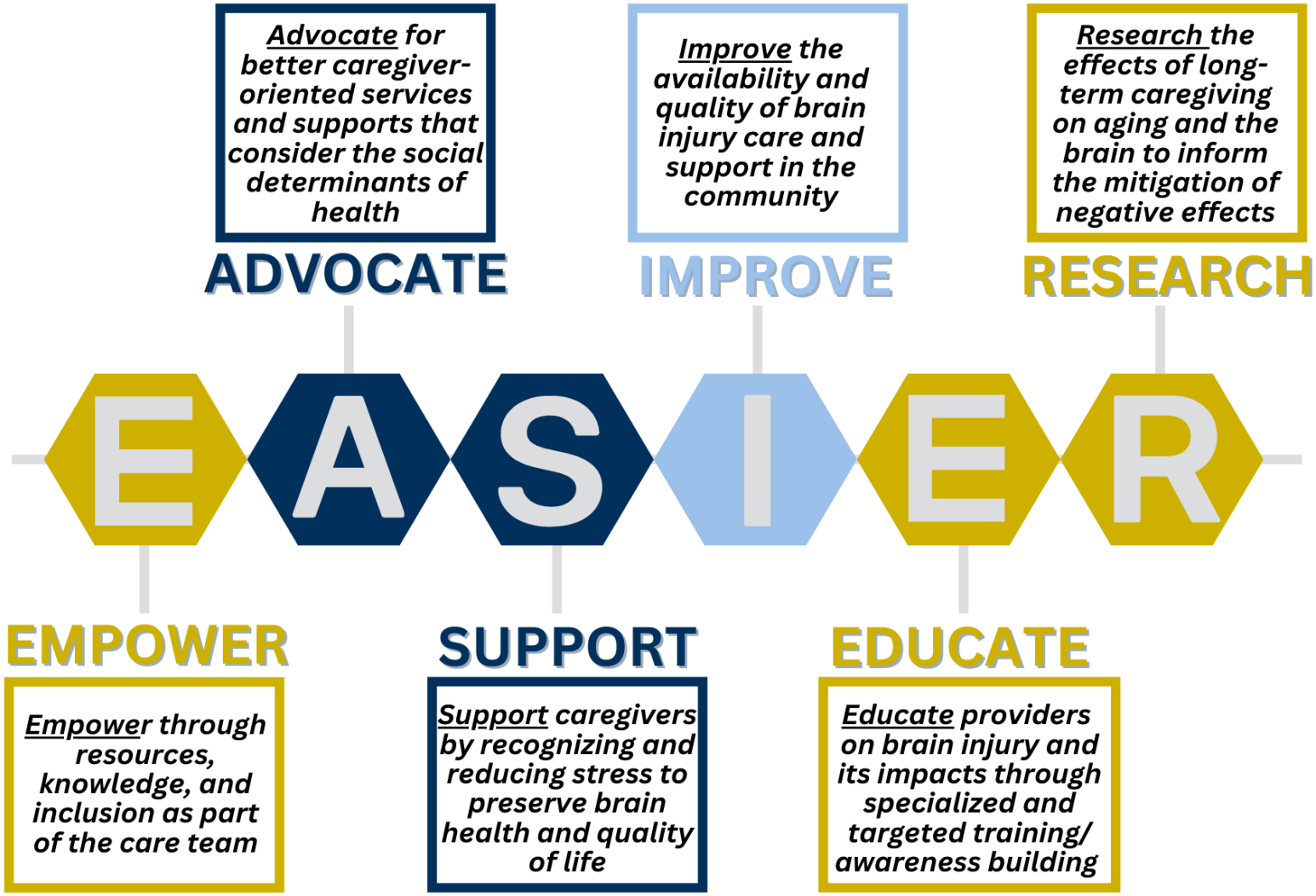


Who Needs to Act on These Recommendations?

Regional Health Authorities | Regional Government | Clinicians and Researchers

The E.A.S.I.E.R Framework

Neurotrauma Care Pathways



- Applicable to different conditions and jurisdictions
- Co-developed with caregivers
- Maps onto policy recommendations
- Aligned with Canadian Caregiving Centre of Excellence (CCCE) National Caregiving Strategy

Key Takeaways

- There is a clear impact of caregiving on health (including mental health, cognitive function, and aging) and quality of life
- Social determinants of health influence the caregiving experience
- Need to develop inclusive policies and healthcare initiatives that consider caregiver needs and circumstances as part of patient-centered care
- **Caregivers must be recognized** as essential contributors to the Care Pathways for not only brain injuries but all chronic conditions

Facilitated Discussion

1. How can we proactively recognize and respond to the needs of caregivers throughout the ABI journey?
2. What are some actionable approaches to improving the awareness among general healthcare providers?
3. We have identified some areas where change is needed. Where do you see the greatest opportunity to make a meaningful difference, and what would it take to get there?
4. What is the one thing you want to challenge everyone in this room to do starting tomorrow?

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Thank you !

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Read our Graphical Policy Brief

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