



ENDING HALLWAY MEDICINE THROUGH NEUROTRAUMA CARE PATHWAYS

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Ending Hallway Medicine through Neurotrauma Care Pathways

Neurotrauma (spinal cord and acquired brain injury) is a complex chronic condition that impacts over half a million people in Ontario and costs the province \$3 billion annually. Ontarians living with a neurotrauma injury face a myriad of hurdles, not the least of which is gaining access to community care and supports. While our trauma system in Ontario provides excellent and immediate emergency care and our provincial rehab centers have specialized programs for in-patients, when patients transition into the community care systems, they find essential support to be inadequate, ineffective or, depending on the type of injury and where the patient lives in the province, unavailable.

Ontarians injured in a car crash or at work have access to private funding through insurance. Those who sustain injuries from other causes must rely on publicly funded services to meet their complex needs. There is little communication or co-operation between the different access routes for private and/or publicly funded health care, with no mechanism to ensure optimal and effective use of resources. This disjointed approach puts a greater burden on publicly funded health care, creating inequitable access to care across the province, extended wait times and over-reliance on hospital services. Hospital emergency departments that exist to provide trauma care often become the community care provider for ongoing health needs for this population that has nowhere else to go.

To maximize neurotrauma recovery and reduce the burden of health care costs from a fragmented and complex system, Ontario requires a Neurotrauma Care Pathway similar to the best practice pathways implemented by Cancer Care Ontario and the Ontario Stroke Network. This new approach to neurotrauma care would integrate health care for those sustaining a spinal cord or acquired brain injury - no matter what the cause or where the patient lives - and ensure that care is based on evidence-based strategies that will improve treatment outcomes. The 2018 Ontario Budget provided support for this activity to be undertaken by the Ontario Neurotrauma Foundation in partnership with Spinal Cord Injury Ontario and the Ontario Brain Injury Association. The budget provided for an investment of \$2 million per year for three years, an amount that would make positive and substantial inroads toward the annual \$3 billion cost burden.

The benefits of implementing this recommendation in the 2019 Ontario Budget include:

- Reduction of the overdependence on Emergency Department use for ongoing care
- Reduction in over hospitalization to manage preventable secondary complications
- Improvements in access to primary and community care
- Elimination of costly uncoordinated and disjointed care
- Elimination of unjustifiable regional variations in standards of care and practice

In short, an investment in a clear, effective and integrated Neurotrauma Care Pathway, overseen by agencies with expertise in this complex field, will ensure Ontarians gain access to vital health care when they need it and where they need it, at a cost that is sustainable to the province.

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Appendix A – 3-Year Plan and Budget



Ontario Neurotrauma Foundation

Fondation ontarienne de neurotraumatologie

Neurotrauma Care Pathways

November 2018

Kent Bassett-Spiers
Chief Executive Officer
Ontario Neurotrauma Foundation

Executive Summary

Neurotrauma costs the economy of Ontario \$ 2 – 3 billion annually. Moreover, neurotrauma injuries impact over half a million Ontarians and their families in every community in Ontario. Ontarians are left sorting their way through a complex maze of care trajectories that are neither effective nor supportive of their needs.

ONF in partnership with Spinal Cord Injury Ontario and the Ontario Brain Injury Association has been identified by all stakeholders to begin a process to develop Neurotrauma Care Pathways that identifies the appropriate care trajectory over the lifespan of the individual, the gaps in health care delivery across the private and publicly funded systems and, through evidence informed implementation strategies, working with all stakeholders to begin the change process that will improve outcomes and reduce costs.

ONF has a rich twenty-year history as the only provincially funded organization in this area. ONF has a reputation as the “go to” organization working provincially, nationally and internationally. Our guidelines, standards, implementation and research networks position us as the best organization to take on this activity as supported by the community.

Our proposed work aligns with the government’s intent on improving healthcare and eliminating hallway medicine in one of the areas that uses the most healthcare resources. The commitment to this work has been recognized by government staff in both the Ministries of Finance and Health and Long Term Care, and has been identified in the most recent budget through a three year allocated funding envelope.

The investment required to undertake this work is modest when compared to the burden of the injuries sustained. The investment is leveraged against the work that the Foundation is already undertaking in the areas of spinal cord and acquired brain injury. ONF is the only organization that has the partnerships with the community and the expertise to initiate and complete this work in a timely fashion within the funding identified in the budget.

The Foundation and its partners are organized to move this forward and make the impact necessary to organize the system of care to improve outcomes and reduce costs.

Introduction

Neurotrauma represents a significant burden for patients, their families, and the health care system. It is estimated that over 500,000 Ontarians are living with this catastrophic injury with greater incidence trending in older populations via elderly falls, and motor vehicle crashes between the ages of 24-45. Neurotrauma is classified as either a spinal cord injury (SCI) or acquired brain injury (ABI), or both. Neurotrauma occurs when communication to the brain is disrupted, causing a sudden loss in brain function, and/or paralysis, and/or loss of bodily abilities such as bowel, bladder or other autonomic functions.

There is no cure for neurotrauma. Neurotrauma injuries result in a chronic condition that persists over the life span of the individual. The burden of neurotrauma financially is in the order of \$2-3 billion annually, but takes a significant toll on the individuals living with these injuries, their families, their communities and the province. Our health system funded either through public or private resources is uncoordinated and unresponsive to this health burden.

The 2018 Budget addressed the need to develop Neurotrauma Care Pathways with a commitment to support and invest \$ 6 million over three years in the Ontario Neurotrauma Foundation in partnership with SCI Ontario and the Ontario Brain Injury Association. Specifically, the Budget indicated:

THE GOVERNMENT REMAINS COMMITTED TO TRANSFORMING THE AUTO INSURANCE SYSTEM TO PRIORITIZE CARE FOR ACCIDENT VICTIMS. INITIAL STEPS TAKEN BY THE GOVERNMENT INCLUDE IMPLEMENTING STANDARD TREATMENT PLANS FOR THE MOST COMMON AUTO COLLISION INJURIES AND REDUCING DISPUTES THAT CAN ULTIMATELY HURT VICTIMS INSTEAD OF HELPING THEM. AS A NEXT STEP THE GOVERNMENT WILL BE INVESTING IN THE DEVELOPMENT OF PATHWAYS OF CARE THAT WILL SUPPORT CATASTROPHICALLY INJURED PERSONS THROUGH THE ONTARIO NEUROTRAUMA FOUNDATION (ONF). THE ONF, IN PARTNERSHIP WITH SPINAL CORD INJURY ONTARIO WILL WORK WITH INSURERS, LEGAL PROFESSIONALS, AND PEOPLE WITH LIVED EXPERIENCE TO DEVELOP STANDARDS OF CARE THAT REFLECT SCIENTIFIC EVIDENCE, EXISTING RESEARCH AND BEST PRACTICES, TO SUPPORT THE GOVERNMENT'S GOAL OF AN OVERARCHING SYSTEM OF CARE THAT SUPPORTS ALL PEOPLE INJURED IN AUTO COLLISIONS.

Why ONF?

ONF has successfully supported research and implementation in neurotrauma creating Ontario's capacity to lead nationally and internationally. The Foundation has built mechanisms and platforms that engage all stakeholders, including Ontarians living with neurotrauma in our collective effort to reduce the burden of neurotrauma injuries.

The focus of our work moving forward is to leverage this investment to continue to build our networks within the publicly funded health system and extend this effort to the privately funded system as well. At this time the privately funded system is **not** engaged with us in the same manner as the public system, creating inequities for Ontarians living with a neurotrauma injury. The source of funding should not be the determination of care but rather the evidence that supports use.

Policy initiatives to reform the automobile insurance system to make it more affordable to Ontarians creates an opportunity to enhance our work to address the cost of neurotrauma injuries in order to reduce premiums.

Specifically, the investment of \$2 million a year in NT Pathways will achieve the following:

- Identification of best practices and their implementation within the privately funded system to ensure that evidence informed standards of care are applied across all systems.
- A reduction in attendant care costs through improvements in interventions that support Ontarians living with a neurotrauma injury.
- Enhance our concussion care best practices and strategy.
- Improvement in access to primary care across the province for those living with a neurotrauma injury.
- The development of a coordinated and integrated care system for those living with a neurotrauma injury across the province.
- Building best practices in the community to support neurotrauma prevention.
- Equitable care for all independent of the funding system.
- Reduction of Hallway Medicine

Return on Investment in Neurotrauma

In 2014 our Australian partner, the Institute for Safety, Compensation and Recovery Research (ISCRR) at Monash University, conducted an independent review of their Neurotrauma Research Program. Their state auto insurer, the Transport Accident Commission commissioned this independent review utilizing their own data. Based on the review the clear conclusion was that the research program delivered excellent value for the money invested by the Commission.

In particular, a review of six projects totalling an investment of \$4.2 million created expected benefits to the Transport Accident Commission of \$83.4 million.

ONF conducted a similar exercise in 2008 contracting SHI Consulting Services to examine the return on investment of a number of projects. SHI used a Net Present Value methodology to determine a return on investment. The three projects included falls prevention, development of evidence-based guidelines for treatment of persistent symptoms following a concussion/mild traumatic brain injury and the development of a self-management approach for spinal cord injury.

The results indicated that for an investment over 10 years in these three projects the yields predicted savings in health and social costs (attendant care, hospital care, home care, community supports etc.) for a given investment in research would be as follows:

- Falls Prevention – for a \$12.2 million investment the savings generated would be \$232 million.
- Acquired Brain Injury (concussion specifically) – for an \$800,000 investment the savings generated would be \$12.8 million.

- Spinal Cord Injury – for an \$800,000 investment the savings generated would be \$18.6 million.

Return on Investment of Neurotrauma Care Pathways and Reduction in Key Cost Drivers

Ontario does not have a coordinated neurotrauma system. The instant that a person of any age experiences a significant injury to the brain or spinal cord, they face a lifetime of effort to maximize their recovery and carry out activities of daily living such as grooming or eating. Neurotrauma (acquired brain injury (ABI) and spinal cord injury (SCI)) affects almost every physiological system and aspect of human life and requires comprehensive chronic disease management to optimize post-recovery. While significant emphasis within the health care system has been placed on the acute management of ABI and SCI and advances have been made in reducing early onset complications such as secondary injury from persisting compression of nerves and raised intracranial pressure, there has been limited focus on longer-term complications and what burden this brings to the health care system, the individual, and their families.

People with SCI and/or ABI consistently report limited access to effective interventions for long-term management after 3-6 months post injury. A clearly defined best practice approach through implementation science is required to achieve optimal outcomes for families affected by neurotrauma.

The specific investment in Neurotrauma Care Pathways will standardize care across both the private and public systems and reduce the \$ 2-3 billion burden neurotrauma impacts Ontario. Impacts on key cost drivers include:

Impact on Private Health System

Motor vehicle crashes are responsible for 50% of Ontario’s neurotrauma injuries. In 2014 insurers spent \$1 billion on medical and rehabilitation treatments for injuries sustained in motor vehicle crashes and \$315 million on examinations and disputes. Despite massive expenditures, the outcomes of the treatments are largely unknown. The auto insurance industry does not know which treatments are most effective, or whether treatments meet the test of reintegrating injured Ontarians as close as possible to their pre-injury lifestyles.

There is also a complex interplay between public and private funding structures/mechanisms that create inconsistent and inequitable care.

Reduction in Hallway Medicine

Both Premier Ford and Minister Elliott have recognized the need to eradicate hallway medicine:

"One patient treated in a hallway is one patient too many. It's unacceptable that people are still waiting hours before seeing a doctor or are forced to lie on stretchers in hospital hallways when they do finally get care," said Ford. "Patients are frustrated, families are frustrated, and doctors and nurses are frustrated. We told the people of Ontario we'd make our hospitals run better and more efficiently, and we'd get them the care they deserve. Today, we're keeping that promise."

Hallway health care is a multi-faceted problem that will require real and innovative solutions," said Elliott. "Our government will continue to listen to the people who work on the front lines of our health care system as we develop a long-term, transformational strategy to address hallway health care."

Neurotrauma patients are high volume users of the Ontario Health system. Without adequate care provided in the community they seek care in Emergency departments and given the nature of their circumstances are often admitted to acute care beds. Most of this is preventable if appropriate care was provided in the community through primary care and community supports.

Spinal cord injury patients seek medical attention some 20 to 30 times in the first year post discharge. A notable percentage of people with acquired brain injury have behavioural and mental health issues that create crisis requiring ongoing medical management. Without adequate community support these patients either seek care from specialists or more frequently rely on the local emergency department and hospital to provide support.

Attendant Care

Attendant care is arguably the most significant cost driver to those funding the care and support for those living with a neurotrauma injury. Attendant care makes up 55-60% of the life time costs of supporting an individual with a neurotrauma injury. The amount of attendant care is directly related to the level or severity of the injury and the need to compensate for loss of function in performing activities of daily living.

One of the key reasons for investment in a neurotrauma research program by the Transport Accident Commission, the state of Victoria's public auto insurance agency was a recognition that the cost of attendant care was unsustainable.

A report by Krueger et al (2013) estimated that lifetime attendant care costs in Canada for tetraplegia are \$1,021,420 (complete SCI) and \$797,590 (incomplete SCI) and for paraplegia are \$422,548 (complete SCI) and \$294,418 (incomplete SCI).

ONF's research to practice program in spinal cord injury secondary complications and translational research and our work on acquired brain injury interventions across cognitive, functional and physical domains, is to promote greater independence and function and reduce reliance on attendant care.

Identifying successful interventions that promote independence reduces the need for attendant care services and maximizes consumer independence. While some level of attendant care may be necessary reduced dependence creates positive benefits for the individual and the system. A key metric of success is related to this key driver.

Access to Primary and Community Care

Today individuals with a spinal cord injury (SCI) live longer and face new health care challenges reflective of this chronic injury. At this time, neither our community services nor our health system fully reflects these challenges and gaps. The current government's focus on Patient Focused Care and engagement of the people with lived experience to inform care delivery is consistent with our approach to the development of care pathways.

Maintaining health and well-being and managing secondary health complications requires access to timely and accessible primary care. The inability of the health care system to provide services has resulted in increased emergency hospital care, reduced productivity and reduced quality of life, which has been already compromised because of SCI. A study funded by ONF has examined the health system factors which are associated with re-hospitalization. The study found that 27.5% of individuals were re-hospitalized in the first year after sustaining a SCI and this rate has stayed the same over the years. In traumatic brain injury the rate of re-hospitalization is between 15 to 20% for the first five years after injury. This clearly illustrates that the health care needs of individuals with neurotrauma are not being adequately addressed, delivered and utilized.

ONF's proposed primary care research will support self-management including patient education, health behaviour change, and continuity in care transitions from rehabilitation care to community health care.

Three areas of attention are:

1. Access to primary care and related community-based health care services.
2. Active consumer engagement in research, implementation and provision of health care.
3. Equity in public and private health care coverage and payment systems.

Concussion Care

Over 157,000 Ontarians (more than one percent on Ontario's population) were diagnosed with a concussion in 2016. Almost 30% of those patients (about 40,000) were children and youth under the age of 18.

The number of people suffering brain trauma from sports injuries has increased significantly in recent years. Over the past five years the number of emergency department visits for sports related concussion grew 46% in Ontario and Alberta. Brain trauma in kids aged 1 - 9 increased 78% and among 10 – 17-year-olds the increase was 45%.

In most cases, people with concussion will recover within a few weeks or a couple of months. However, 15-20% of patients have longer term, persistent symptoms of dizziness, headaches, fatigue, cognitive impairment and trouble sleeping. These symptoms can greatly interfere with daily life and productivity.

For children and youth, the number is much higher - 30% of concussion patients who are 18 or younger continue to have symptoms longer than one month.

A study by Janessa Graves, assistant professor of nursing at Washington State University noted that traumatic brain injuries in children are costly to individuals and society. She noted in the study that “mild traumatic brain injury cannot be thought of as a low cost or short-term problem. The study demonstrates that concussion costs account for a disproportionate cost burden at a macro level.” Using US data, based on a commercial insurance claims database, the author concluded that concussions in children accounted for nearly 81% of the \$1.59 billion in health care costs for pediatric traumatic brain injuries in the first year.

The Foundation’s work on best practice guidelines for adults and children suffering from a concussion has established the benchmark for standardized care. While this is important it is insufficient in making the changes necessary to improve outcomes and reduce costs. A provincial focus on appropriate pathways of care for people who have sustained a concussion will be able to leverage off the existing best practice work and detail the system pressures and costs associated with greatly variable healthcare across the private and public settings.

Strategy to Move Forward

Neurotrauma Pathways of Care (NT Pathways) is a Project run by the Ontario Neurotrauma Foundation in collaboration with Spinal Cord Injury Ontario (SCIO) and the Ontario Brain Injury Association (OBIA).

The goals established for this work include:

- Develop an Acquired Brain Injury and Spinal Cord injury team comprised of all stakeholders to meet to document the current systems of care over the first 24 months of an acute injury, identify gaps in care and propose an overarching system of care for ABI and SCI
- Undertake a data study within each activity utilizing ICES and other data sources to quantify the scope and nature of the problem
- Validate this system of care with the care communities to ensure completeness in meeting the needs of all Ontarians
- Develop through our existing research and practice activities key performance measures including patient reported outcomes that will guide the evaluation on the success of implementing these pathways

- Develop an Implementation Strategy based on principles of implementation science used by ONF within its SCI Knowledge Mobilization Network and its partnerships with the National Implementation Research Network and the five health science centers
- Develop strategies that will link specific care pathways addressing secondary conditions and lifelong (chronic) care needs resulting from these injuries within these broad-based care pathways
- Develop an Evaluation system to ensure the care pathways remain current based on the best available scientific information

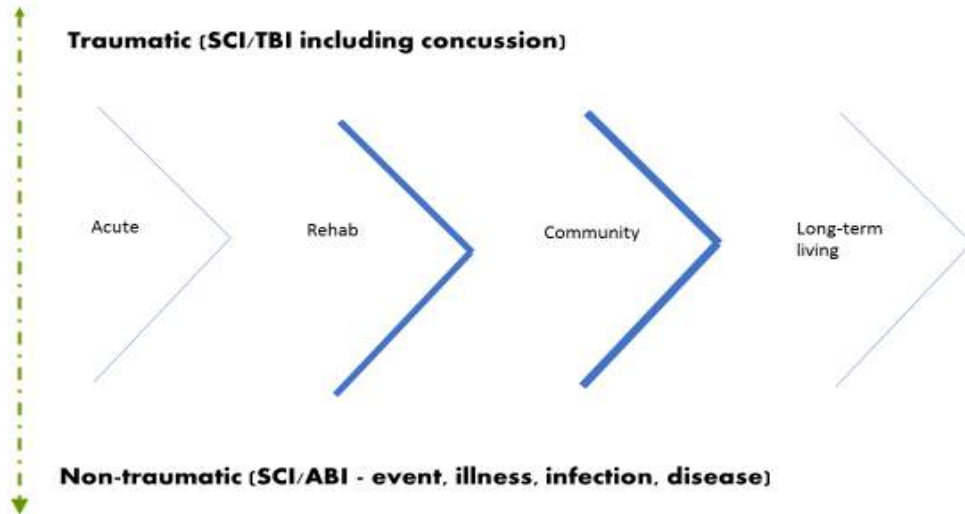
The Project is systemic in nature, and consultative with a broad variety of system experts and people living with Acquired Brain Injury (ABI) and Spinal Cord Injury (SCI) and their families/caregivers. The purpose of NT Pathways is to better understand the health care system in regard to publicly and 3rd party funded care, and to develop an evidence-based optimal pathway that addresses needs regardless of how the individual acquired a NT injury.

Clinical considerations for NT Pathways

Includes non-traumatic SCI and ABI

- The intention is to address all the people who acquire NT, whether by traumatic means or means of disease or infection that render them with consequences of brain injury or paralysis. This excludes stroke and congenital conditions.
- The trajectory into and within the NT pathway will differ between traumatic and non-traumatic injuries and the system group will need to consider and address this. However, once a person has consequences of the brain or spinal cord injury, the system will need to address them in much the same way as someone sustaining a traumatic injury. The needs for the sequelae of NT are the same.

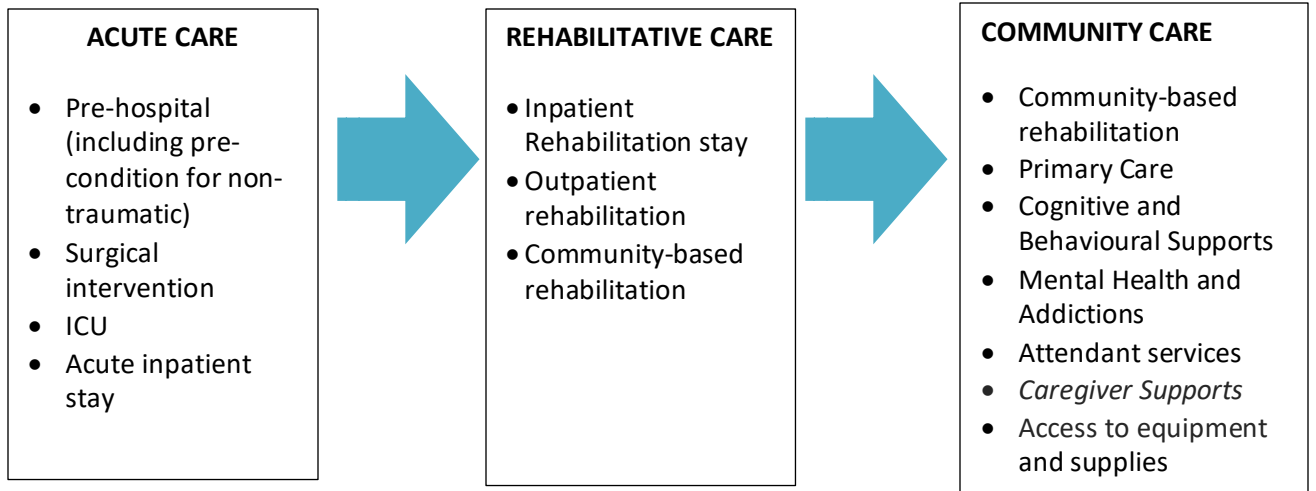
Neurotrauma Pathways of Care



NT Pathways is focused on care and services within the health system. While recognizing the importance of other related issues, NT Pathways does not include:

- Housing accommodation
- Transportation
- Employment
- Social services

The focus of NT Pathways will begin with the Rehabilitation to Community trajectory until 24-months post-injury, then will cycle back and focus on Acute Care trajectories. The purpose of doing this is fourfold; 1) historically the acute care system has received more focus as the purpose is to save lives and stabilize the individual, 2) the acute care system is well organized and regardless of source of payment, people who sustain neurotrauma injuries will receive the same care acutely, 3) people living with neurotrauma will, for the most part, spend the rest of their lives in the Community and 4) the Rehabilitation to Community trajectory have historically not been well addressed and this is where the differences in service access, availability, and equity may well differ.



Oversight and Working Structure

To initiate this activity and to provide appropriate direction, guidance and oversight, the Steering Committee will be established of 8-10 individuals. These individuals will each play a key role in guiding the work of the 4 Sub-Committees and will be responsible for directing the respective Sub-Committee as well as reporting back to the Steering Committee.



Four Sub-Committees will support the work of the Steering Committee and provide the expert guidance necessary to plan for and provide advice towards operationalization of activity. All Committees will need to address the pediatric as well as adult population.

Proposed Budget

Overall Approach to creating Pathways

The creation of neurotrauma system care pathways is based on a consultative process involving key system stakeholders across the care continuum. This effort will be characterized by a robust engagement strategy guided by those with lived experience to ensure all voices are heard.

This engagement strategy will be underpinned by a data and evidence strategy that will support the development of system pathways and identify gaps in care and support throughout the continuum of care and across private and public funders.

Budget

The investment provided for this activity is \$ 6 million over a three-year period. The first year of this activity will require the recruitment of project management staff, establishment of the oversight structure, development of the data and evidence synthesis strategies that will inform this work, the development of an engagement and communication strategy and the establishment of a project plan, milestones and timetable in partnership with the Ministry of Health and Long Term Care that will guide the project through its various phases.

Expenditures	2018/19	2019/20	2020/21
Literature Synthesis and Evidence Development <ul style="list-style-type: none"> • Literature synthesis in systems of care in ABI and SCI • Evidence development and analysis to support Care Pathways • Analysis of existing projects that support care pathways • Information Mapping 	360,000	300,000	300,000
Data Strategy <ul style="list-style-type: none"> • Consultation with ICES • Data Scientist recruitment part time • Data acquisition and analysis • Data collaboration with the Insurance Industry 	400,000	400,000	400,000

Community and System Consultation and Engagement <ul style="list-style-type: none"> Developing engagement and consultation with all stakeholders including, people and families living with neurotrauma, Insurance Industry, Private and Public providers, Legal profession Community and Institutional leaders 	740,000	640,000	400,000
Communication/Knowledge Translation and Mobilization towards Implementation <ul style="list-style-type: none"> Communication Platform Materials/consulting Implementation Exploration and Analysis Framework development, toolkits development Validations Evaluation planning and initiation Develop, initiate and evaluate pilot projects 	200,000	360,000	600,000
Project Management <ul style="list-style-type: none"> Project Leadership Administrative Assistance Project Supports 	300,000	300,000	300,000
Subtotal	2,000,000	2,000,000	2,000,000

In Kind Support

The work being undertaken within Neurotrauma Care Pathways will draw on existing ONF resources including but not limited to:

- INESSS-ONF Guideline
- Concussion Guidelines – Adults and Pediatrics
- Concussion Standards
- Clinical Indicators for Spinal Cord Injury Rehabilitation (SCI HIGH)
- Spinal Cord Injury Research Evidence (SCIRE)
- Evidence Review of Acquired Brain Injury (ERABI)
- System data - concussion, MSTBI, repatriation (TBI)
- Health Economic data (SCI)

The development of NT Pathways will not only be informed by this work but will form a platform for the translation and implementation of this work in practice changes that will improve outcomes and reduce costs.

Conclusion


ONF has been recognized by the Ontario Spinal Cord and Acquired Brain injury community to facilitate, in partnership with them, the development of Neurotrauma Care Pathways. This work has been supported by the Ministry staff in both Finance and Health and Long-Term Care as it supports improvements in health outcomes and costs in both the private and publicly funded health care systems.

ONF is uniquely positioned to undertake this work given its twenty-year history in developing Ontario's capacity in neurotrauma research and for its commitment to move research into practice through its evidence informed implementation strategies.

The development of Neurotrauma Care Pathways is a critical next step in making the improvements in Health Care that is envisioned by the new government. ONF is a leader in the engagement of people living with neurotrauma that ensures our work is informed by their experience and that they participate in the implementation of solutions that improve outcomes.

The investment of **\$ 2-million** a year for three years makes the progress necessary to address a **\$ 2-3 billion** burden to the economy of the province. The return on this investment is clear but more importantly the benefits to Ontarians living with a neurotrauma injury and their families that ensures that the right care is provided in the right place at the right time no matter where you live and no matter how they were injured, is incalculable.

Appendix B – Presentations to the Ministry of Health and Long-term Care



**TRANSFORMING THE CARE
OF ONTARIANS LIVING WITH
NEUROTRAUMA
THROUGH NEUROTRAUMA CARE PATHWAYS**

WHY THIS IS CRITICAL TO THE SUSTAINABILITY OF OUR HEALTHCARE SYSTEM IN ONTARIO



Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie



SPINAL CORD INJURY ONTARIO
LÉSIONS MÉDULLAIRES ONTARIO



OBIA
ONTARIO BRAIN INJURY ASSOCIATION
education • awareness • support



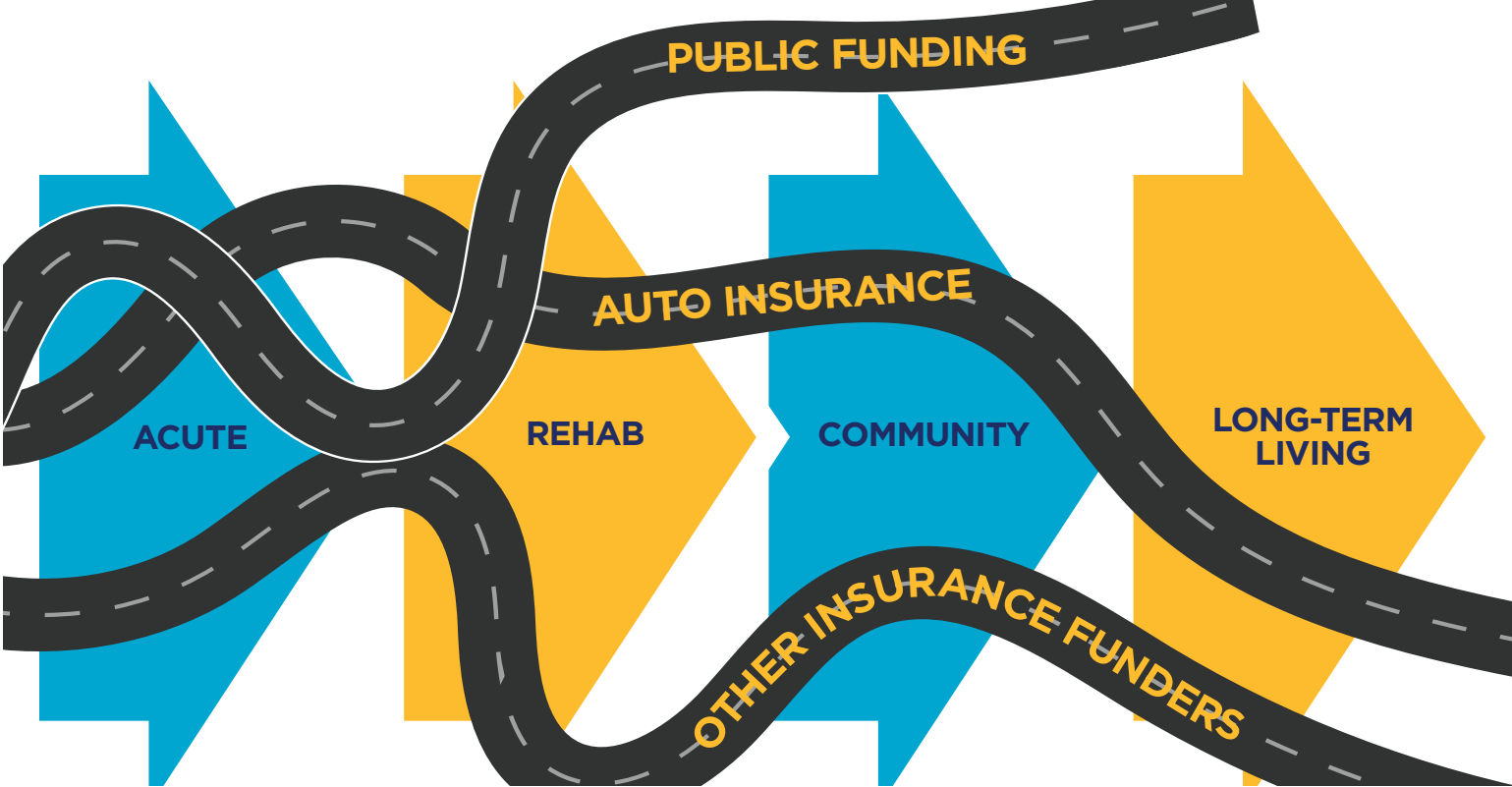
ONTARIO DOES NOT HAVE A COORDINATED NEUROTRAUMA SYSTEM

To maximize neurotrauma recovery and reduce the burden of health care costs from a fragmented and complex system, Ontario requires a Neurotrauma Care Pathway similar to the best practice pathways implemented by Cancer Care Ontario and the Ontario Stroke Network.

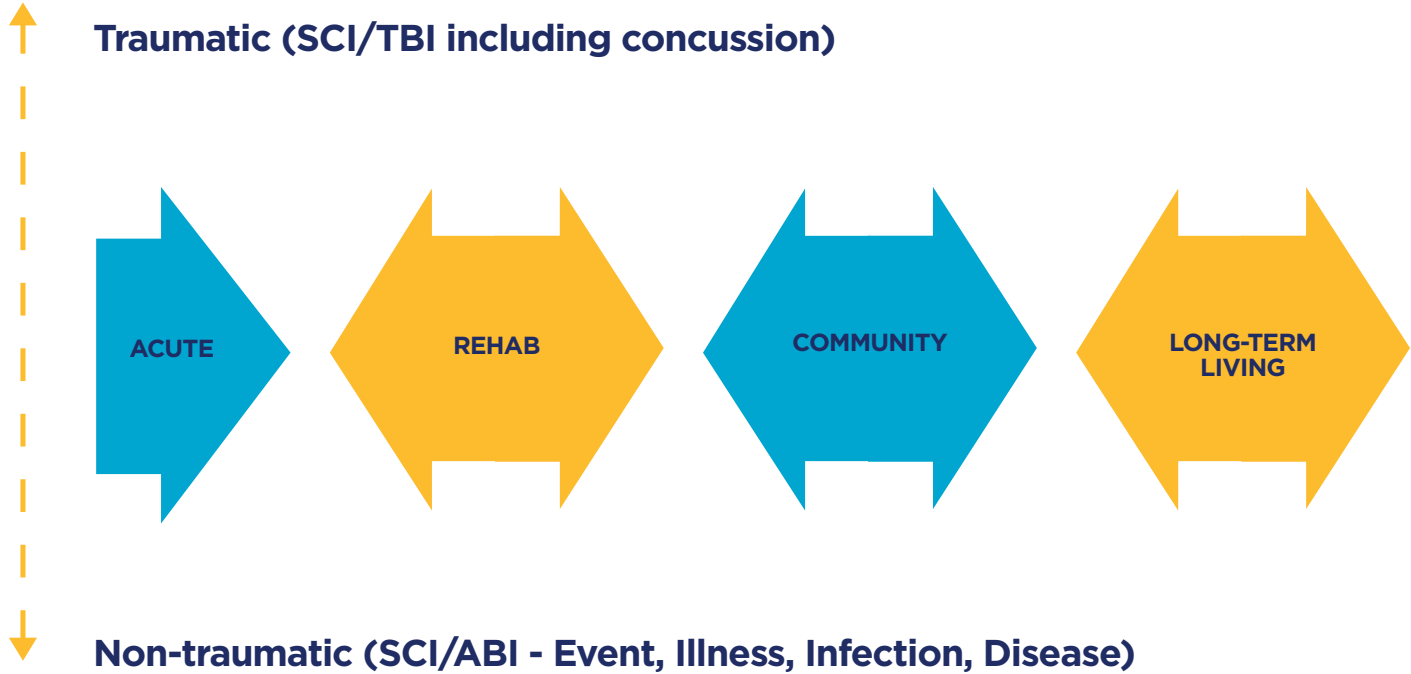
The Benefits:

- Highest level of functional recovery
- Health Equity
- Cost Avoidance
- Keeping people out of hospital
- Right place, right time, right care
- Evidence informed best practice

THERE IS A COMPLEX INTERPLAY BETWEEN PUBLIC & PRIVATE FUNDING STRUCTURES/MECHANISMS AND THUS INCONSISTENT CARE



NEUROTRAUMA PATHWAYS OF CARE



OUR COMMUNITY



- PROVINCIAL
- NATIONAL
- INTERNATIONAL

ENDING HALLWAY MEDICINE - IMPROVING HEALTH CARE OUTCOMES

IMPACT OF NEUROTRAUMA



1/2 MILLION ONTARIANS



\$3 BILLION ANNUALLY

Improving Outcomes & Reducing Costs through Evidence Informed Solutions. To address:

- **Overdependence on Emergency Department Use**
- **Over Hospitalization to manage preventable secondary complications**
- **Lack of Access to Primary and Community Care**
- **Uncoordinated and disjointed care**
- **Unjustifiable regional variations in standards of care and practice**
- **Preventable occurrences such as Seniors, falls**



COMMITMENT

- Our community, through ONF, will **maximize impact** to the \$2-3 billion cost of neurotrauma injuries in Ontario.
- At a cost of only \$6 Million **over 3 years.**

Appendix C – Terms of Reference: Steering Committee

Neurotrauma Care Pathways

Steering Committee

Terms of Reference

Preamble

Neurotrauma Care Pathways (NCP); a system focused project led by the Ontario Neurotrauma Foundation (ONF) in partnership with Spinal Cord Injury Ontario and the Ontario Brain Injury Association, will develop coordinated, appropriate care trajectories for people with brain and spinal cord injuries in Ontario for the first two years following their injury, and develop plans for implementation of the pathways. NCP aims to result in a more harmonized, evidence-informed and coordinated system of care delivery for people with spinal cord and brain injuries in Ontario, regardless of payor source. The purpose is to assess and address the gaps and imbalances in health care and through evidence-informed implementation strategies, working with all stakeholders to begin the change process to improve outcomes and reduce costs.

Over a three-year period Neurotrauma Care Pathways will:

1. Define and develop ideal pathways of care for each neurotrauma sub-population.
2. Evaluate gaps between the current state of neurotrauma in Ontario and the ideal pathways of care.
3. Develop an implementation plan for change and supporting tools that address the key gaps identified.

This will be done by:

- Utilizing existing evidence, best practices, system models and standards of care within the neurotrauma space; developed for brain and spinal cord injury across the lifespan from provincial, national and international sources.
- Undertaking quantitative and qualitative evaluations of the current state of neurotrauma in Ontario through robust data inquiry.

- Undertaking consultations with all stakeholders in public and private sectors associated with spinal cord and brain injury; relying strongly on the views and real experiences of people with the lived experience of spinal cord and brain injury.
- Addressing system pressures and the changing landscape of healthcare management in Ontario.
- Mapping trajectories for neurotrauma sub-populations at several time points to design pathways for the two years following injury against longer-term health needs of living with neurotrauma.
- Mapping current state against the ideal state and conducting gap analyses; considering outcomes, costs and impacts to identify what needs to change.
- Validating the pathway through follow-up consultation with all stakeholders.
- Utilizing implementation science principles and evidence; identification of barriers, facilitators and targets for behaviour change.
- Designing a strategy for implementation to move forward, using continuous consultation and engagement and using existing capacities within the neurotrauma space.
- Developing specific tools and resources to support the implementation plan for stakeholder groups and sectors.

Purpose and Mandate

The Steering Committee will serve as the central direction, guidance and decision-making function for Neurotrauma Care Pathways. Four Sub-Committees (Data, Community Engagement, Ideal Pathway and System Issues) will be established to report into and receive feedback and directions from the Steering Committee. The Steering Committee will set goals and deliverables and ensure that the information being gathered is meaningfully coordinated to inform and drive forward the work of all Sub-Committees in a timely and coordinated manner and achieve the goals for NCP.

Composition

The Steering Committee will be composed of 10-12 members. Membership includes voting and non-voting members:

- The Chair; appointed by ONF and requiring expertise of acquired brain injury and spinal cord injury, healthcare coordination and/or utilization, and strategic planning and development.
- The Executive Directors or CEOs of Spinal Cord Injury Ontario and the Ontario Brain Injury Association.
- Individuals selected by ONF and the Chair based on knowledge and expertise in areas required to lead the four NCP Sub-Committees; including professional and personal knowledge of neurotrauma, experience in wide-scale implementation and thorough knowledge of and

experience with the Ontario health care system. The Co-Chairs of each of the following Sub-Committees will serve on the Steering Committee.

- Data
 - Ideal Pathway
 - Community Engagement
 - System
-
- The CEO of the Ontario Neurotrauma Foundation who shall be an ex-officio, non-voting member of the Committee.
 - Two Ministry of Health and Long-Term Care representatives shall be ex-officio, non-voting members of the Committee.
 - Other experts as required to ensure a provincial focus.

Mandate

The Committee will contribute health system knowledge and utilization and patient representation to Neurotrauma Care Pathways, including:

- Developing a three-year roadmap for the Committee that links the work of the four Sub-Committees, ensures continuity and progress, and maps to NCP deliverables;
- serving as the central coordinating and oversight function for the work of the four Sub-Committees;
- providing direction and feedback to the four Sub-Committees and making decisions on recommendations and products of the Sub-Committees as needed;
- informing as to relevant industry developments, programs, activities, policies or other developments that may be relevant to the success of Neurotrauma Care Pathways;
- advising on communication strategies with relevant groups that will come from the Secretariat AND acting as ambassadors and communication agents for NCP within their own networks
- advising on the development and/or refinement of key processes;
- guiding approaches to presenting and disseminating information to key audiences;
- informing the criteria for a future evaluation of the Committee's effectiveness, including an update to terms of reference following its first year of operation.

Meetings

- It is intended that the Committee will hold 5-6 meetings per year within the first year of NCP operations. Meetings will be 2-3 hours in length dependent on timelines and expected developments.
- In subsequent years it is expected that the Committee will hold 4 meetings per year.
- Where members cannot attend in person, the Committee will offer access to video and teleconference facilities to assist members.
- Out of session meetings may be held from time to time by teleconference.

- Out of session documents may be circulated for member's attention from time to time. If a decision is required, a digital process will be used to obtain decisions of Committee members.
- Consideration will be given to any arising need to meet more frequently based on advice from the Chair to the Committee.

Terms of Appointment

- Members are appointed for terms of up to three years. Following each term, a review occurs.
- Member terms may be renewed, dependent on participation and contribution over the initial term and the degree of required expertise for future work within subsequent terms.
- Members may resign from the Committee by notifying the Chair (and copying ONF) in writing, stating their intention to resign at least four weeks prior to the date of resignation.
- The Chair will consider appointments to vacancies, as appropriate.
- The Chair retains the discretion to terminate a member's appointment to the Committee if there has been failure to attend and contribute to the Committee.

Support for Committee

In collaboration with the Chair, in order to follow the project plan and meet deliverables for Neurotrauma Care Pathways, the NCP staff at ONF will:

- develop agendas and materials for Committee meetings;
- schedule committee meetings;
- distribute relevant information in a timely manner to promote robust discussion, feedback and decision-making;
- ensure all members are kept informed of issues and information relevant to the work of the Committee;
- send reminders and provide support to ensure the work of the Committee progresses;
- coordinate the meeting schedules of the Sub-Committees in alignment with the Steering Committee to ensure flow of information for planning purposes and decision-making;
- arrange venues and catering for meetings;
- arrange appropriate travel and accommodation; and
- verify reimbursement of eligible expenses.

Operation of the Committee

The Chair

The Chair is ultimately responsible for the operations of the Committee, which includes the coordination of progress of the Sub-Committees. The Chair will preside at all meetings at which they are present. If the Chair is absent from a meeting, they will identify another member of the Committee to Chair in their place.

In collaboration with the Committee, the Chair is responsible for:

- chairing the meetings;
- engaging all members to participate meaningfully;
- providing leadership on matters relating to the work of the Committee and NCP as a whole;
- reporting to the ONF Board of Directors on Neurotrauma Care Pathways;
- the work of the Committee; and
- ensuring any conflict of interest disclosures are appropriately managed and confidentiality is adhered to.

Members' obligations and expectations

Membership will be for a term of three years.

Members are appointed for clinical, health system or patient experience.

Members are to review materials provided for each meeting and actively participate in all meetings and excluding situations of confidentiality of their own organization and networks; share information that may be instrumental in planning or important to the decision-making process.

Members will declare any potential competing interests with the Committee, including any change or update as required.

Where members have missed two consecutive meetings, it will be at the discretion of the Chair to declare the seat vacant and seek a replacement member.

Members will sign a confidentiality agreement.

Members' expenses will be remunerated according to the ONF Expense Claim Policy. Members will not be eligible to be remunerated if they are full-time employees of the province of Ontario.

Other participants

The Committee may invite other individuals or groups to present or observe at individual meetings. Advisors and observers are not voting members.

HOW THE STEERING COMMITTEE WILL OPERATE

Guiding Principles and Values

In guiding Neurotrauma Care Pathways, the Steering Committee will embody the following guiding principles:

Transparency

Bound in realism but looking towards the optimal

Based on the needs of people with NT

Consultative

Unbiased and independent approach

Driven by evidence, best practices

System focussed Care focused

Health Equity

Provincial focus

Solutions for NT

Reporting

The Steering Committee, through the Chair, will be responsible to the Ontario Neurotrauma Foundation for providing ongoing updates and presenting to the Board of Directors on the plans and progress of Neurotrauma Care Pathways.

Confidentiality

Committee members may, on occasion, be provided with confidential material. Members are not to disclose this material to anyone outside the Committee and are to treat this material with the utmost care and discretion and in accordance with terms of their confidentiality agreement. Such material will be used for planning purposes and may eventually be publicly distributed in some form, however, is required to remain confidential until agreed upon by the Steering Committee.

Conflict of Interest

Conflict of interest is defined as any instance where a Committee member, partner or close family friend has a direct or indirect financial or non-financial interest in matters under consideration or proposed matters for consideration by the Committee. A member must disclose to the Chair any situation that may give rise to a conflict of interest or a potential conflict of interest and seek the Committee's agreement to retain the position giving rise to the conflict of interest. Where a member gains agreement to retain their position on the Committee, the member must not be involved in any related discussion or decision-making process.

All members of the Committee are expected to abide by the confidentiality policy and conflict of interest policy.

Committee members are not to participate in Committee business until the Confidentiality and Conflict of Interest form has been signed.

Proxies

Due to the expert nature of the Committee, proxies for meeting attendance cannot be accepted.

Quorum

A quorum for a meeting is half the Committee membership plus one. Any vacancy on the Committee will not affect its power to function.

In the absence of a quorum, the meeting may continue at the Chair's discretion, with any items requiring decision to be deferred and circulated to members as an out of session item following the meeting.

Decision-Making

Disagreements will be discussed during Committee meetings to strive for consensus on decisions where possible. When unable to reach agreement, decisions will be made by vote and will be determined by majority of members (fifty plus one). If an equality of votes occurs, the Chair will be granted a second casting vote.

Discussion and advice will be inclusive of all members as far as possible and project timelines will be taken into consideration in reaching a preferred position.

Communication

ONF staff will provide communications and issue management support to NCP. Committee members are requested to refer all media enquiries to ONF's Communications Lead. The Chair is typically the public spokesperson for the Committee. Members will be positive ambassadors for the importance of the project and the process within their networks.

Agenda and minutes

The agenda and related papers are normally circulated to members one week prior to the meeting.

The minutes of the meeting will be prepared by NCP staff. They will provide a concise and focused report of decisions, actions taken and required next steps. Minutes will be made available to members in a timely manner and next steps followed up on in order to ensure momentum and progress.

Personal Information

The personal information a Committee member provides to NCP Staff and/or the Chair will be kept in compliance with relevant privacy legislation.

Appendix D – Letters of Support by Community Partners

February 7, 2019

The Honourable Victor Fedeli
Minister of Finance
c/o Budget Secretariat
Frost Building North, 3rd Floor
95 Grosvenor Street
Toronto, Ontario M7A 1Z1

Re. Budget submission for Neurotrauma Care Pathways

Dear Minister Fedeli:

Spinal Cord Injury Ontario (SCIO) is in full and enthusiastic support of Neurotrauma Care Pathways as this is an initiative that is firmly grounded in the needs of people living with spinal cord injuries in Ontario.

Neurotrauma Care Pathways will gain from the stellar work of the Ontario Neurotrauma Foundation (ONF), the community driving the need and collaborations with stakeholders across public and private health care sectors.

Sustaining a spinal cord injury can be a devastating occurrence with life-long consequences to the individual and their family. SCIO has been working closely with ONF to advance Neurotrauma Care Pathways and our communities across the province are anxious to get involved in this work. We look forward to the provincial improvements in health care that will result.

Neurotrauma Care Pathways is the right thing to do. We strongly support the excellence of this work and the opportunity to improve the system of care and outcomes for people who sustain spinal cord injuries in Ontario.

Yours sincerely,



Dr. Stuart Howe,
Chief Executive Officer

February 5, 2019

The Honourable Victor Fedeli
Minister of Finance
c/o Budget Secretariat
Frost Building North, 3rd Floor
95 Grosvenor Street
Toronto, Ontario M7A 1Z1

Re: Budget Submission for Neurotrauma Care Pathways

Dear Hon. Fedeli,

The Ontario Brain Injury Association (OBIA) has been supporting people living with brain injury and their families for over 30 years. We see first-hand the devastation and extraordinary challenges that are immediate and last a lifetime, when an individual sustains a brain injury.

OBIA is in full and enthusiastic support of Neurotrauma Care Pathways, as this is an initiative that is firmly grounded in the needs of people living with brain injuries in Ontario.

Neurotrauma Care Pathways will gain from the stellar work of the Ontario Neurotrauma Foundation (ONF), the community driving the need and collaborations with stakeholders across public and private healthcare sectors.

OBIA has been actively involved and working with ONF in planning for Neurotrauma Care Pathways.

OBIA has 21 affiliated community associations across the Province, representing tens of thousands of people with brain injury and we are ready to get involved in this work. We look forward to the improvements in healthcare that will result from Neurotrauma Care Pathways.

We strongly support the excellence of this work and the opportunity to improve the system of care and outcomes for people who sustain brain injuries in Ontario.

To put it simply, Neurotrauma Care Pathways is the right thing to do.

Sincerely,



Ruth Wilcock
Executive Director