

PLEX Engagement in Research

Community of Practice

September 2025: How to Make Caregiving ‘E.A.S.I.E.R’? Advocating for Better Caregiver Support for After Brain Injury

This document provides a summary of engaging people with lived experience (PLEX), specifically caregivers in advocating for better caregiver support.

Key Presentation Points

- Caregivers provide an enormous but largely overlooked amount of care
- Researchers, clinicians and support practitioners **MUST** engage caregivers in care and support planning
- Caregiving is a 24/7 job with very little training and support
- Engaging in research can be therapeutic for caregivers
- Flexibility is key for engaging caregivers in research

What did we discuss?

- **Remaining flexible:** Caregivers are balancing several priorities, researchers need to be flexible with meeting times and providing options to connect to support their engagement
- **Plain language is critical:** Co-developing materials to engage PLEX and make science accessible to a general audience is important
- **Get to know the PLEX on your team!:** Make time to hear the stories, comments and concerns from the PLEX participants outside of simply conducting the research
- **Next Steps to get the system to change:** Raise awareness among government, healthcare practitioners and community support; Keep the conversation going
- **Any others? Make things E.A.S.I.E.R:**
 - **E – Empower the caregiver through resources and collaboration**
 - **A – Advocate for better caregiver services and support**
 - **S – Support caregivers in all areas of need (e.g., health, social, financial etc.)**
 - **I – Improve the availability and appropriateness of brain injury care and support in the community**
 - **E – Educate health and service providers across all stages of care on brain injury and its impacts**
 - **R – Research the effects of long-term caregiving on the brain**

Relevant Resources on PLEX Engagement in Research:

1. [Neurotrauma Care Pathways](#): A link to the Neurotrauma Care Pathways website which provides care pathways and resources for healthcare professionals and people with lived experience.