Families: How Best To Support A Relative with A Brain Injury

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Compassionate People. World-Class Care.

Des gens de compassion. Des soins de calibre mondial.
The Ottawa Hospital
Emergency and Trauma Service

• Regional Adult Trauma Centre for Eastern Ontario
• Level one Trauma Service
• More than 3500 trauma patients per year
The Ottawa Hospital Rehabilitation Centre

**Acquired Brain Injury Services**

- 16 bed Inpatient Unit
- Behavioural Rehabilitation
- Day Hospital
- Outpatient Services
- Robin Easey Centre residential and outreach services

Robin Easey Centre

*Acquired Brain Injury Rehabilitation Program*

- A “home away from home” in an Ottawa neighbourhood
- 5 residents, 40-60 active outreach clients and 22 staff
- Community based
If You've Seen One Brain Injury, You've Seen One Brain Injury.

Every Injury is Unique.
A Family Experiential Model of Recovery After Brain Injury, Klonoff et al., 2008

• Studied the experiences of 87 relatives of patients with acquired brain injuries
• Focused on what it was like in their journey, how they coped, adapted and adjusted to their circumstances
• Identified 7 distinct phases.
# Family Experience While in Hospital

<table>
<thead>
<tr>
<th>Phase 0</th>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Life Before</strong></td>
<td><strong>Sudden Impact of Injury</strong></td>
<td><strong>Early Adjustment</strong></td>
<td><strong>Seeks Help</strong></td>
</tr>
<tr>
<td>Longing for life as it was before.</td>
<td>Bedside Vigil</td>
<td>Brain Injured traverses through acute hospital services.</td>
<td>Family recognizes severity of injury and tries to solicit help.</td>
</tr>
<tr>
<td>“Just want things to return to normal”.</td>
<td>Disconnected from Life</td>
<td>Family wants loved one to beat the odds.</td>
<td>Schedule, life and financial upheaval.</td>
</tr>
<tr>
<td></td>
<td>Numbness, Surreal</td>
<td>Family needs to orchestrate and discuss medical care and decisions.</td>
<td>“Wow, we really need help here.”</td>
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<tr>
<td></td>
<td>“Everything is on Hold”</td>
<td>“Waiting for the other shoe to drop”</td>
<td>Looking for treatment resources.</td>
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<tr>
<td></td>
<td>“If only…..”</td>
<td>“Just trying to figure out what we are dealing with.”</td>
<td>Consumed with 24 hour care.</td>
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<tr>
<td></td>
<td>“Why did it have to happen ......”</td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
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<tr>
<th>Phase 4</th>
<th>Phase 5</th>
<th>Phase 6</th>
<th>Phase 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Holistic Treatment Starts</td>
<td>Re-Training</td>
<td>Transition from Therapy</td>
<td>Future</td>
</tr>
<tr>
<td>Awareness of the effects of injury.</td>
<td>Acceptance of the deficits.</td>
<td>Realism of the “new normal”</td>
<td>Family and brain injured maintain, collaborative dialogue about the brain injury, effects and compensations needed</td>
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<tr>
<td>Results from assessments completed which offers direction.</td>
<td>Compensatory strategies are practiced.</td>
<td>Rebalancing of life.</td>
<td>Life continues in meaningful ways</td>
</tr>
<tr>
<td>Witness to impairments.</td>
<td>“Things take time.”</td>
<td>Observe brain injured’s new freedoms, independence and community integration.</td>
<td>Balance of roles and there is a healthy social support network</td>
</tr>
<tr>
<td>Uncertainty of situation yet appreciate professionals role.</td>
<td>Expectations are adjusted.</td>
<td>Family prepares to assume more responsibility juggling work, finances and caregiving.</td>
<td>Regularly scheduled respite times.</td>
</tr>
<tr>
<td>“We are grieving and have tentative hopefulness.”</td>
<td></td>
<td>New strength and courage. Engaged in support system</td>
<td></td>
</tr>
</tbody>
</table>
Traumatic Brain Injury Continuum of Care
for individuals with moderate and severe TBI

In each phase of the journey...

• What is happening to the Brain
• What is the survivor’s experience
• What is happening to the family/caregiver
• Coping strategies
Phase 1

Time of Brain Injury: Sudden Impact

Understanding:

• Witnessing or notification of the injury

• Family is operating in crisis mode

• Complex Medical Terminology
Phase 1

Time of Brain Injury: Sudden Impact

Coping:
• Basic needs
• Physical contact
• Information
Phase 2

Early Adjustment: Initial Problems

Understanding:
• Loved one has survived
• Details about the injury emerge
• Begin to “hear” information about prognosis
Phase 2
Early Adjustment:
Initial Problems

Coping:
• Gaining information on the Brain
• 3-D Brain App
Phase 2
Early Adjustment: Initial Problems

Brain Apps:
• 3-D Brain App
• Brain Tutor App
Phase 3
Seeks Help:
How To Cope

Understanding:
• Moving from survival to “what is next”
• Guilt may arise
• Financial stress
Phase 3
Seeks Help:
How To Cope

Coping:
• Try to establish a balance
• Be open to receiving help from others
• Attend to financial matters (MVA Benefits; EI sick benefits; Work Disability Plans; CPP Disability; or any provincially supported programs)
• Consult legal representative
Phase 4
Confronting Reality:
Awareness

Understanding:
• Assessment and rehabilitation begins
• Family experience changes caused by ABI
• Grieving process begins and realization that help is needed
• Transition back to community
Phase 4
Confronting Reality:
Awareness

Coping:
• Ask for copies of assessment reports
• Arrange meetings with therapists
• Become familiar with Community Resources
GUIDE

BRAIN INJURY
DISCHARGE PACKAGE

Coping with brain injury
A guide for patients

GUIDE

BRAIN INJURY
CAREGIVER

Coping with brain injury
A guide for caregivers and family
Phase 5
Re-Training: Acceptance

Understanding:
• Enhance knowledge of the effects of the brain injury in relation to behavioural and emotional challenges
Phase 5
Re-Training: Practice

Coping:
• Practice functions repetitively
• Learn Compensatory Strategies
Brain Injury Functional Recovery

![Graph showing the recovery of brain injury intensity over time.]

- Intensity轴范围从0到1
- 时间轴范围从0到30秒

Compensatory Strategies

Compensatory Strategy is any strategy used to compensate for the difficulties the brain is experiencing.

A Few Examples:

- Memory strategies = post it notes, check lists, white board, diaries, voice reminders, agendas

- Planning and Organizing Strategies = Problem Solving Models like “Goal Plan Do Review”, or Apps like “Wunderlist”

- Initiation Strategies = prompting from alarms found on ipad, smart phones, various forms of cueing

- Impulsiveness Strategies = Stop Think Go, Risks and Consequences, Incentives

- Fatigue Strategies = pacing routine and schedule, limit noise, chaos
Phase 5
Re-Training: Support

Coping:
• Brain Injury Organizations
• Research
• On line education and newsletters
• Family Support groups
Phase 5

Re-Training:

Support

Coping:

• Most discussed group topic is impaired self awareness

• Develop tolerance for witnessing struggle
Model from Crosson et al. (1989)
Phase 6
Transition From Therapy:
Reality Check

Understanding:
• Gain knowledge of realistic expectations
• Difficult because of the invisible nature of brain injury
• Lack of understanding or awareness
Warning Signs of Caregiver Stress:

- Physically – exhausted and worn out
- Emotionally – resentful, stressed, bitter
- Relationally – feeling used or unappreciated
- Financially – overwhelmed or depleted
I LOVE MY
TRAUMATIC BRAIN INJURY
SURVIVOR FAMILY
Modified Caregiver Strain Index

Directions: Here is a list of things that other caregivers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

Yes, On a Regular Basis = 2 Yes, Sometimes = 1 No = 0

- My sleep is disturbed ____________ ____________ ____________
  (For example: the person I care for is in and out of bed or wanders around at night)

- Caregiving is inconvenient ____________ ____________ ____________
  (For example: helping takes so much time or it's a long drive over to help)

- Caregiving is a physical strain ____________ ____________ ____________
  (For example: lifting in or out of a chair; effort or concentration is required)

- Caregiving is confining ____________ ____________ ____________
  (For example: helping restricts free time or I cannot go visiting)

- There have been family adjustments ____________ ____________ ____________
  (For example: helping has disrupted my routine; there is no privacy)

- There have been changes in personal plans ____________ ____________ ____________
  (For example: I had to turn down a job; I could not go on vacation)

- There have been other demands on my time ____________ ____________ ____________
  (For example: other family members need me)

- There have been emotional adjustments ____________ ____________ ____________
  (For example: severe arguments about caregiving)

- Some behavior is upsetting ____________ ____________ ____________
  (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)

- It is upsetting to find the person I care for has changed so much from his/her former self ____________ ____________ ____________
  (For example: he/she is a different person than he/she used to be)

- There have been work adjustments ____________ ____________ ____________
  (For example: I have to take time off for caregiving duties)

- Caregiving is a financial strain ____________ ____________ ____________

- I feel completely overwhelmed ____________ ____________ ____________
  (For example: I worry about the person I care for; I have concerns about how I will manage)

[Sum responses for “Yes, on a regular basis” (2 pts each) and “yes, sometimes” (1 pt each)]

Total Score =


The Hartford Institute would like to acknowledge the original author of this Try This® issue: M. Terry Sullivan.
Phase 7 Future

- Understanding
- Prevents social isolation
- Advocates for brain injured’s ongoing needs
- Adjusts environment

- Coping
- Regular respite