



## **Managing Grief After a Serious Brain Injury**

By Loretto Brickfield, PhD

Serious traumatic brain injury (TBI) can lead to significant changes in cognition and behavior that survivors and their families experience as a sudden, catastrophic loss of identity and functioning. Families endure a rollercoaster of emotions in their grief that is often overlooked while trying to provide urgent care to survivors. Understanding and normalizing complex grief reactions in families of TBI survivors helps in mastering this painful transition and regaining a sense of control in managing this life-altering injury.

TBIs most frequently occur in young adults involved in motor vehicle accidents. Many experience permanent loss of employment, intimate relationships, independence, and require years of rehabilitation. TBI survivors may exhibit mood changes, poor self-monitoring and insight, depression, anxiety, sleep difficulties, and other behavioral problems that can disrupt family rhythms and routines.

Many families report the disruption in personality and consequential loss of interpersonal intimacy, connection, and relationship to be the most devastating dimension of brain injury. Partners may experience a loss of identity and struggle to find a place and role when faced with a dependent mate who is unable to attain adult milestones or parent children. Marriages and friendships dissolve under the pressure and the TBI patient is frequently returned to the care of parents. Siblings may be resentful, jealous, and guilt ridden and parents angry, self-blaming, and conflicted.

The losses due to a serious TBI are as devastating as death, however with TBI there is no finality or ritualized way to mourn. In *Ambiguous Loss; Coming to Terms with Unresolved Grief*, Pauline Boss, PhD coined ambiguous loss to describe a loss in which the mourned person is physically present, but psychologically or cognitively absent. Family members grieve a person who is still alive, but altered in fundamental ways. Families boomerang from hope to hopelessness, from relief as the person survives a coma to sorrow over the alteration in cognition and demeanor. Grief appears frozen with no closure because of uncertainty over whether the person will return to previous levels of functioning. Family dynamics are strained, attachments and rituals disrupted, and confusion over roles and relationships abound. In short, this type of loss is one of the most stressful experiences a family may undergo.

Validation of the complexities of grieving is important throughout a long brain injury rehabilitation process and the stress of living with a family member who is simultaneously present and absent. Gaining information to understand the TBI, sort through treatment options, manage daily challenges, and implement behavioral management techniques is helpful for adaptive coping. Reducing disruptive behaviors by using strategies such as decreasing overstimulation, creating checklists and daily structure, and employing psychiatric medications can re-establish a stable home environment.

Over time, families become more affected by the psychological consequences of the injury and experience what may appear to be complicated grief or depression. However, these mood issues are better understood in relation to the TBI, stress of ambiguous loss, changes in relational status, and shattering of family structures rather than through a psychiatric model of individual pathology. Family members may benefit from psychotherapy to process the relational challenges in dealing with a newly dependent adult relative. Naming ambiguous grief can be a powerful intervention to help families understand its impact and move forward. Acknowledging the pain in mourning lost possibilities without getting lost in revelry allows one to embrace the present in all its ambiguity and absurdity. Psychotherapy can bolster inner resiliency and capacity for coping while strengthening tolerance for a less than perfect TBI recovery.

There are many ways beyond psychotherapy for families to rebuild their shared identity, develop a renewed sense of purpose, and regain hope. Support networks within and beyond the traditional family reduce isolation and promote wellness. Families who take advantage of respite opportunities without guilt find renewal and are less likely to burn out by caregiving. Stress management practices such as involvement in a faith community, meditation, exercise, recreational pursuits, hobbies, and resumption of cherished family rituals with modifications to accommodate the disabled family member help restore family balance. By developing creative outlets to deal with the loss, such as art, music, and volunteering, families improve coping, mood, and wellbeing.

Families who successfully address crucial grieving tasks seem to be more adept at sustaining genuine long-term supportive involvement and managing the stressors of caregiving for a TBI survivor. Their work with the brain injury rehabilitation team runs smoother and is more collaborative. They are better able to modify family roles, adapt expectations, and accept imperfect outcomes. Families can re-engage in a world beyond the confines of the rehabilitation setting and find meaningful attachments with the survivor grounded in realistic hope. They may experience a revised sense of purpose, and greater tolerance for the absurdity, frustration, and ambiguity of a brain injury. As a result, the TBI survivor is valued as a different, but vital and important member of the family.

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