

# **Loss, Grief and Brain Injury**



**Presented by:**

**Mandi Zucker, LSW, Program Director**

**[Mandi@imajinenj.org](mailto:Mandi@imajinenj.org)**

**Connie Palmer, LCSW, Clinical Training Director**

**[Connie@imajinenj.org](mailto:Connie@imajinenj.org)**

**Imagine, a Center for Coping with Loss**

*Located in Mountainside, Imagine, a Center for Coping with Loss provides free year-round peer grief support for children age 3-18 and young adults 18-30 who are coping with loss due to the death of a parent or sibling. Groups are provided for children and youth who have a parent or sibling coping with illness or injury. There are also concurrent support groups available for parents/guardians. Imagine provides community education about grief and loss to schools, community agencies and businesses.*

*Contact Imagine at 908-264-3100 or visit us online at [www.imajinenj.org](http://www.imajinenj.org) .*

## **Grief Rights for a Person with a Brain Injury**

**1. I have the right to have my own unique feelings about the brain injury.**

I may feel mad, sad, scared or lonely. I may feel numb or sometimes not anything at all. No one will feel exactly like I do.

**2. I have the right to talk about my grief whenever I feel like talking.** When I need to talk, I will find someone who will listen to me and love me. When I don't want to talk, that's OK, too.

**3. I have the right to show my feelings of grief in my own way.** When they are hurting, some people like to have fun and laugh so they feel better for a while. I might also get mad or start to cry out of the blue. These are just feelings and having them is normal.

**4. I have the right to need other people to help me with my grief.** Mostly I need people to realize that my grief is normal and people who will listen to me without judgment.

**5. I have the right to get upset about normal, everyday problems.** I might feel irritable and have trouble getting along with others.

**6. I have the right to have "griefbursts".** Griefbursts are sudden, unexpected feelings of sadness that just hit me sometimes—even long after the brain injury.

**7. I have the right to grieve the loss of my former self even as I move toward a new identity, a new normal.**

**8. I have the right to identify and grieve the losses that occurred because of my brain injury.** I have lost the person I once was. My relationships with others are now different. My brain injury has changed the lives of friends and family members. I may discover additional losses as I continue to recover.

**9. I have the right not to “think positive” or “be grateful” when I am grieving these losses.**

**10. I have the right to move toward and feel my grief and, over time, to heal.** I'll go on to live a happy life, but the loss of the person I was will always be a part of me.

Adapted from the Grief Bill of Rights by Alan Wolfelt.



## **Grief Rights for the Family and Friends of a Person with a Brain Injury**

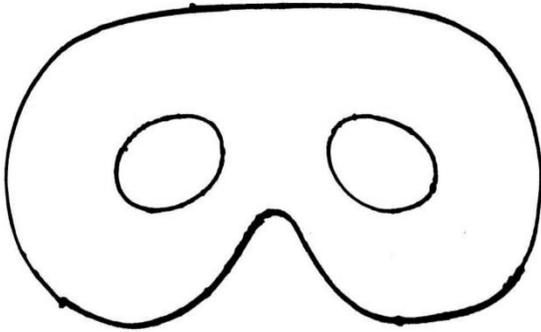
- 1. I have the right to have my own unique feelings about the brain injury.** I may feel mad, sad, scared or lonely. I may feel numb or sometimes not anything at all. No one will feel exactly like I do.
- 2. I have the right to talk about my grief whenever I feel like talking.** When I need to talk, I will find someone who will listen to me and love me. When I don't want to talk, that's OK, too.
- 3. I have the right to show my feelings of grief in my own way.** When they are hurting, some people like to have fun or laugh so they feel better for a while. I might also get mad or start to cry out of the blue. These are just feelings and having them is normal.
- 4. I have the right to need other people to help me with my grief.** Mostly I need people to realize that my grief is normal and who will listen to me without judgment.
- 5. I have the right to get upset about normal, everyday problems.** I might feel irritable and have trouble getting along with others.
- 6. I have the right to have "griefbursts".** Griefbursts are sudden, unexpected feelings of sadness that just hit me sometimes—even long after the brain injury.
- 7. I have the right to try to grieve the loss of the person I was before the brain injury.** I may miss my old life before the brain injury.
- 8. I have the right to identify and grieve the losses that occurred because of the brain injury.** The brain injury has changed me and it has changed the relationship I had with the person before the brain injury. I have the right to grieve over the changes even as we move toward a new and different relationship, a new normal. I may discover additional losses during the ongoing recovery.
- 9. I have the right not to “think positive” or “be grateful” when I am grieving these losses.**
- 10. I have the right to move toward and feel my grief and, over time, to heal.** I'll go on to live a happy life, but the loss of the person I once knew will always be a part of me.

Adapted from the Grief Bill of Rights by Alan Wolfelt.

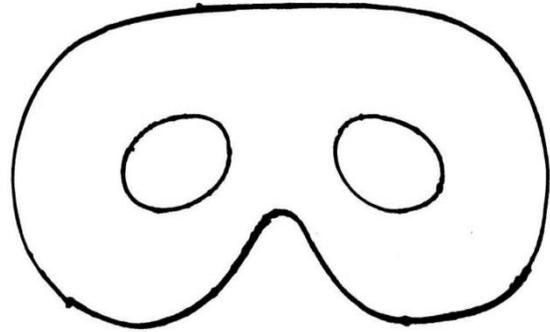
1. *Behind The Mask* A poem by Melisa Bernards

*Hiding the hurt, hiding the pain, saying I'm fine, when I'm anything but...*

2. What feels safe to people see?



What do I hide?



3. Three behavior masks we wear: fight, flight and/or caregiving. Which is your favorite? What is the benefit and cost of wearing it?
4. Grief belief: Alan Wolfelt says that, “In America, grief is seen as shameful and should be gotten over as quickly as possible.” People try to control or hold in their grief because they feel ashamed of it, as if it were a problem we have failed to solve, an indication of weakness or because we are afraid others will judge or shame us.
5. Shame is the painful experience of believing that there is something wrong with you or with certain part of you. Shame makes us hide who we really are. We wear masks for a good reason. As you find safe people with whom you can share who you really are you need to wear your mask less and less.

## Alan Wolfelt's Companioning Model of Grief Support

>Companioning is about honoring the spirit;

it is not about focusing on the intellect.

>Companioning is about curiosity;

it is not about expertise.

>Companioning is about learning from others;

it is not about teaching them.

>Companioning is about walking alongside;

it is not about leading.

>Companioning is about being still;

it is not about frantic movement forward.

>Companioning is about discovering the gifts of sacred silence;

It is not about filling every painful moment with words.

>Companioning is about listening with the heart;

it is not about analyzing with the head.

>Companioning is about bearing witness to the struggles of others;

it is not about directing those struggles.

>Companioning is about being present to another person's pain;

it is not about taking away the pain.

>Companioning is about respecting disorder and confusion;

it is not about imposing order and logic.

>Companioning is about going to the wilderness of the soul with another human being;

it is not about thinking you are responsible for finding the way out.



# **Companioning/Listening Skills**

- 1. Help the person “feel felt”**
- 2. Let the person have all their feelings**
- 3. See behavior as information**
- 4. Set compassionate limits and boundaries**
- 5. Follow the grieving person’s lead**
- 6. Avoid problem solving, cliché’s and advice**
- 7. Ask yourself, “Why am I talking?” (W.A.I.T?)**
- 8. Get support for yourself**
- 9. No rewards for speed**
- 10. Don’t be attached to outcome**



## Resources and References

### Videos

1. YouTube videos by Craig Phillips- speaks on the topic of shame and brain injury. Found at <https://www.youtube.com/watch?v=24GOjOLn4fs&feature=youtu.be>
2. Brene Brown TED talk, Listening to Shame and Vulnerability. Found at: <http://www.ted.com/>
3. Taryn Stejskal, The Process of Dealing with Loss after a Brain Injury. Found at: <http://www.brainline.org/content/multimedia.php?id=7596>
4. Brain Injury and Resilience <http://www.brainline.org/content/multimedia.php?id=9130>

### Books/Brochures

1. Overcoming Grief and Loss After Brain Injury by Janet Niemeier
2. Over My Head, Claudia Osborne Website-Claudiaosborne.com
3. Ambiguous Loss: Learning to Live with Unresolved Grief by Pauline Boss
4. After Brain Injury Telling Your Story: A Journaling Workbook by Barbara Stahura
5. Where is the Mango Princess? A Journey Back From Brain Injury by Cathy Crimmins
6. Brochure about loss, grief mourning and brain injury <http://www.lapublishing.com/loss-grief-mourning-tbi/>
7. Mindstorms: The Complete Family Guide for Families Living with Traumatic Brain Injury, by John Cassidy
8. Overcoming Grief and Loss After Brain Injury. Janet Niemeier
9. Living with a Brain Injury: A Guide for Families. by Richard Senelick
10. My New Brain. Lori Williams
11. Meditations on a Brain Injury by Mike Strand

### Articles/Blogs/websites

1. The Effect of Traumatic Brain Injury on Caregivers found at: <http://www.apa.org/pi/disability/resources/publications/newsletter/2015/03/brain-injury-caregivers.aspx>
2. Janelle Breese Biagioni, *Brain Injury and Grief: Fact or Fiction?* Found at: [http://www.brainline.org/content/2013/03/brain-injury-and-grief-fact-or-fiction\\_pageall.html](http://www.brainline.org/content/2013/03/brain-injury-and-grief-fact-or-fiction_pageall.html)
3. Rosemary Rollins, *Bouncing Forward*. Found at: <http://www.brainline.org/content/2013/02/bouncing-forward.html>
4. Rosemary Rollins, *Learning About Ambiguous Loss*, Found at: <http://www.brainline.org/content/2013/02/bouncing-forward.html>
5. Laura Taylor, *Coping with Loss and Change*. Found at: <http://www.brainline.org/content/2009/06/coping-with-loss-and-change.html>
6. Diane Stoller, *Brain Injury Awareness: Grieving the Loss of Self*. Found at: <https://www.psychologytoday.com/blog/the-resilient-brain/201403/brain-injury-awareness-grieving-the-loss-self>
7. Rachael Goldsworthy, *The Effect of Traumatic Brain Injury on Caregivers*. Found at: <http://www.apa.org/pi/disability/resources/publications/newsletter/2015/03/brain-injury-caregivers.aspx>
8. Loss and Grief After Brain Injury, Found at: <http://www.braininjury-explanation.com/life-with-brain-injury/loss-and-grief-after-brain-injury>
9. Recover is a State of Mind. An article about the holistic approach to brain injury practiced by Yehuda Ben-Yishay, PH.D. of the Rusk Institute Brain Injury Treatment Program in NYC <http://brainworldmagazine.com/recovery-is-a-state-of-mind/>