



*Support through the Journey of Grief*



*FROM LOSS AND SORROW TO  
HEALING, HOPE AND RENEWAL*

Our purpose is to provide appreciation, support, encouragement and information to our donor families and to those families whose intent was to donate their loved ones' organs, tissues and corneas.

We are dedicated to assist you in your grieving process with compassion and strength. We are grateful that you have entrusted us as you travel on your painful, fearful and uncertain path to renewed hope and healing.

We will always remember your loved ones for their precious gifts of life, as well as those who decided to give of themselves and were not able to do so. The intention to give and enhance life adds brilliance and purpose to the spirit of humanity. This spirit inspires and humbles us. We cannot thank you enough.

If we can be of service to you now or at any time in the future, please contact our Aftercare Support Team at [317.685.0389](tel:317.685.0389) or [888.275.4676](tel:888.275.4676).

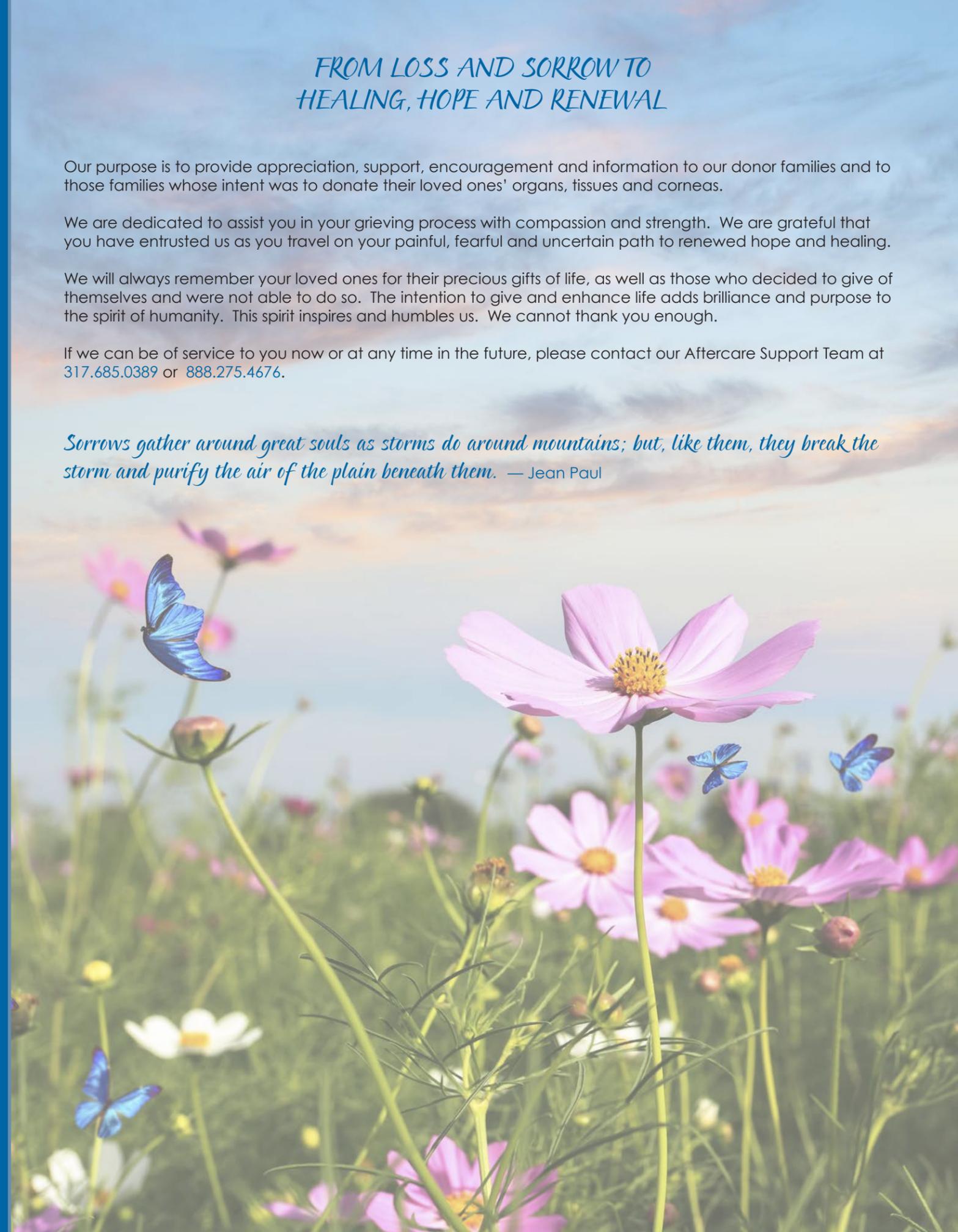
*Sorrows gather around great souls as storms do around mountains; but, like them, they break the storm and purify the air of the plain beneath them. — Jean Paul*

---

*“Faith is not simply a patience that passively suffers until the storm is past. Rather, it is a spirit that bears things – with resignations, yes, but above all, with blazing, serene hope.”*

— Corazon Aquino

---





## Grief

Grief is the emotional suffering we experience when we lose someone who means a lot to us. It is a healthy and normal response and a necessary process for adjusting to living without the person we love. Grieving is the work we must do before we are fully able to embrace life again. We each grieve in our own way. Our expression of grief is determined by our culture, earlier experiences with loss, our gender, our age and other factors. Some cultures permit and even encourage open expression of feelings, while others discourage it.

Intuitive vs. instrumental people demonstrate their grief differently because of the way they have been socialized.

- The intuitive griever can have: feelings that are intensely experienced; expressions such as crying and lamenting that mirror the inner experience; prolonged periods of confusion, inability to concentrate, disorganization and disorientation; physical exhaustion and/or anxiety.
- The instrumental griever characteristics are: thinking is predominant to feeling as an experience, and therefore feelings are less intense; general reluctance to talk specifically about feelings; mastery of oneself and the environment are most important; problem-solving as a strategy enables mastery of feelings and control of the environment in creating a new "normal".

As children, we express grief as it relates to our level of understanding, our age and the way significant adults share their grief with us. Because each of us is different in our upbringing and experiences, it is important that we respect one another's ways of dealing with grief.

## The grieving process

The grieving process is experienced by each of us in our own way and on our own timetable. Grief is the journey and you will find that the process moves you from heartache to hope in your own time. There is no right or wrong way to experience your grief. Please be gentle and patient with yourself as you travel this new world of living without your loved one.

Most of us respond initially to a sudden death with shock and disbelief. We just cannot believe what has happened. This is what can lead to a period of denial because we do not want to accept that the person is gone. As we gradually begin to accept the reality of the death, we often feel confused. This confusion is made up of many feelings that seem to conflict with one another.

The feelings that surface for us after a loss relate to the manner of death and our relationship to that person. If the death was expected, we may have had time to say "goodbye". However, when death is unexpected, there is no time for "goodbye" or to take care of unfinished business with our loved one. These factors tend to complicate the grieving process and intensify feelings.

It is in recognizing our feelings and expressing them that we can begin to feel better. Acknowledging our feelings helps us to learn more about the meaning of our relationship with our loved one and the impact of this loss in our lives. It is in this process that healing begins. With this healing comes a sense that life is starting to feel "normal" again – not "normal" as it was but a new "normal". It can never be "normal" as it was again. The following is a description of common reactions and feelings you may experience as you grieve for your loved one.

## Shock and disbelief

Shock and disbelief are the most common reactions to the sudden death of a loved one. The general feeling is one of numbness, which allows us to function and thereby helps us accomplish what we need to do regarding our loved one's death. This numbness is nature's way of protecting us from becoming overwhelmed by the impact of our loss.

You may also experience physical symptoms in the first weeks, including aching in the chest and arms, heart palpitations, feeling as if you can't take a deep breath, or constant sighing. If your loved one was ill, you may find that you are experiencing similar symptoms. Your appetite and sleep patterns may be affected. You may experience disruptive sleep patterns or trouble sleeping. Some people experience visions of their loved one or think they hear them crying or calling out. This is a normal response to the loss of a loved one and it disappears in time.

## Denial

When we experience a tragedy we do not want to believe it has happened. This is why you may find yourself wondering, at times, if this is just a bad dream and you will soon awaken to find that it is not true. You may feel the need to tell the story over and over again, which can help convince you of its truth. Accepting the reality of your loved one's death will help you move forward in your grief. Acceptance comes in time and may increase your feelings of loneliness and sadness. When you can no longer deny your loved one's death you have a greater sense of the loss and its effect on your life.

## Confusion

As the numbness wears off, many feelings can begin to surface – strong feelings that seem to be all mixed together. At this point, we tend to feel unsure of what it is we think or believe because it seems to change from day to day. Our emotions feel out of control. Talking about your feelings and writing them down can be helpful in gaining some clarity during this period of confusion.



## Fear

Fear is a normal reaction to the sudden and unexpected death of another person. We are confronted with how helpless we are in the face of death and that bad things can happen to all of us. The universe no longer feels like a safe place. This sense of vulnerability is compounded by the fear that we must go on living without that special person. Since we do not know what this will be like, the future seems uncertain and scary.

## Anger

Anger stirs within us when someone we love is taken away by death. It is quite natural to feel angry because we feel abandoned and victimized. Even when our loved one did not have control over his or her death, we can feel angry at him or her for leaving us. Some of us get angry with God, while others express anger toward the medical system for not being able to save the person. It is important that you express feelings of anger in an appropriate manner by channeling them into activities such as exercise, listening to music, journaling, hobbies, etc. Failure to do so can result in depression.

## Guilt

Guilt is present when we feel that we “should have” or “could have” prevented the death and when we have unfinished business with the person who has died. We often show our guilt by being angry at others while we are really angry with ourselves. You may find yourself saying things like, “If only I had not let him take the car that night” or “If only I had apologized to her for what I said during our argument.” These statements show the reasons behind our guilt. It is important to resolve guilt because it can negatively affect how you feel about yourself. The following are some of the steps you can take to help with your healing process:

- Talk about your feelings of guilt with family, friends, a counselor or someone you trust.
- Acknowledge/recognize your feelings and that you are being affected by them.
- Writing about your feelings of guilt is another way to express them and may prove easier than trying to make yourself understood in a conversation.
- Explore the reasons for your guilt and determine if your guilt is founded.
- Recognize your need to grieve in order to heal and give yourself the time necessary for that.
- Allow yourself to cry if needed.
- Remind yourself that ultimately you have no control over death. When you realize this, it will become easier for you to release your guilt.



## Emptiness and Loneliness

Emptiness and loneliness occurs because a part of us goes with our loved one. The emptiness is felt both inside of ourselves and in the world around us. No one can fill the empty place or take away the loneliness, because the relationship you had with that person was unique. Learning to live without your loved one is the most difficult task of the grieving process.

## Depression

Depression is the sadness that seems to stay with us for a long time after the death. It is characterized by low energy and a lack of interest in the pleasures of life. As you learn to accept and express your feelings, the depression will begin to ease. You will realize that it is lifting when you are able to have a fairly good day and not cry every time you talk about your loss.

Be gentle and patient with yourself. It may take a long time for you to get to the point of feeling really good about life again. As time passes you should begin to notice improvement in your sleeping habits and appetite, as well as an increased ability to concentrate, work and find joy in living.

If you do not notice improvement in these areas, feel “stuck” in your grief or have thoughts about wanting to hurt yourself or die, you may be experiencing complicated grief, a depression that requires professional help. Complicated grief is an intense, long-lasting form of grief that takes over someone’s life. For most people the intensity of grief fades with time. For people with complicated grief it can feel like grief is taking over your life as compared to acute grief where there are typically “good and bad days.” Factors that contribute to the chance that one may experience this type of grief include suddenness of the death, the gender of the person in mourning and the relationship to the deceased (for example, an intense, extremely close, or very contradictory relationship). If you are experiencing complicated grief, please contact us for support resources in your area.

## Recovering after your loss

Learning to live without your loved one is the most difficult part of enduring grief. You learned to depend on his or her presence, and their death leaves a void that cannot be filled. As you become accustomed to their absence, you will develop a new routine and begin to feel like you are more in control. You will eventually notice that your concentration has improved and the “good” days will start to outnumber the “bad” ones. Life is interesting again and you may begin to form some new relationships. You may even recognize some ways you have grown through this difficult time. The journey is uniquely yours.

## Suggestions to help with your grieving

1. As you already know, grief is work. Get plenty of rest and eat a nutritious diet.
2. Avoid the use of alcohol, tranquilizers, sleeping pills and other drugs. These give only temporary relief and may complicate your grief. Feeling the pain is one of the necessary steps of grieving your loss.
3. Try to get some daily exercise, even if it is only a short walk. Exercise can help manage your anger and frustration.
4. Ask for and accept support from family and friends. They will be eager to help but often are unsure about what to do. Let them know what you need.
5. Keep a journal of your thoughts and feelings. This provides you with a way to express yourself and a perspective on your progress.
6. Talk about your feelings and thoughts with someone who listens well and will not tell you how you should be feeling.
7. Speaking with your religious leader or clergy may be helpful during this time.
8. If you find yourself preoccupied with your loved one's gifts of donation or the process of organ or tissue donation, please get in touch with one of our Aftercare Support Team members.
9. Be gentle with yourself about your grief journey. If people indicate that “you should be over this”, remind them that everyone experiences grief differently. Tell them how they can help you. You cannot “get over” death or grief – you must go through it to move beyond the grief.
10. Avoid getting over-involved with work or other activities. While work provides some necessary relief and structure, you also need time to reflect on and experience the pain of your grief. If all the hours of your day are filled with activities – leaving no time for anything else – you may be avoiding your feelings. Try to find balance.
11. Reading books about grief that are related to the type of loss you have experienced can be very comforting and provide you with a deeper understanding of your grief experience.
12. Delay major decisions until you are able to think more clearly. Moving or changing jobs will drain you of energy and complicate your grief work.
13. Find ways to take a break from your grief, like going to a funny movie or reading a good novel. It is okay for you to laugh and have fun. Finding enjoyment can provide relief and help create balance in your life.
14. Share memories about your loved one. This can help you feel closer to them and ease your pain. Putting together a picture album of your loved one's life can provide comfort and also creates a wonderful keepsake.

## What to tell children

Adults often try to protect children by sheltering them from information or participation in death rituals. What you choose to share with your children or the children in your family may vary depending on the age of the child, their prior experience with loss, their relationship to the deceased and the cause of death.

Generally, children need simple explanations of the truth. They can sense when adults are not being truthful, which can result in a loss of trust and develop insecurity. It's better to tell them in simple terms that the person has died. If you show that you are open about your feelings and are interested in their feelings, they will be more comfortable asking questions and expressing themselves. This is what they need in order to learn about death and feel protected.

Children from birth to two years of age have no understanding of death, do not have words for feelings, are aware of the absence of a loved one, and notice changes in routine and in family emotions. He/she may feel longing; missing the contact, sounds, smell and sight of a loved one; anxiety and fear of being abandoned. Possible behaviors are crying, sickliness, indigestion, thrashing, rocking, throwing, sucking, biting and sleeplessness. How to help: physical contact, cuddling and reassurance; maintain routines; meet immediate physical needs; include the child in the mourning process when possible; and be gentle and patient.

Many younger children (age three to five) see death as reversible. You may need to repeat the conversation about the death in order for them to begin to understand. The distinction between any accident and a tragic accident may not be understood. Attention to the child's questions, with repeated simple and consistent messages, should increase their comprehension. How to help: allow the child to regress; give physical contact; encourage children to play and have fun; allow safe ways to express feelings; maintain structure and routines; let the child cry; include child in family rituals and mourning.

Children age six to nine will require a more detailed explanation of the death. For example, describing the differences between routine illness and terminal illness may be important. Sharing your emotions with children this age may be helpful for them to identify and express their own feelings. Adults should also reassure children that they do not bear any responsibility for the death.

Explaining the death and helping preteens and teenagers understand emotions is important. Many adults assume teenagers will take care of themselves. Adult support is necessary to allow teenagers to discuss any anger, guilt or responsibility they feel.

Explaining suicide and murder to children requires thought. Honesty remains an underlying requirement. Anger toward the loved one is natural in suicide, and children should be told that feeling angry does not mean they did not love the person. Older children will probably seek a more detailed explanation, which should be provided as appropriate.

The explanation of murder to a child should be as simple as possible regarding who did it and why, if known. A suggestion for explaining the murder of a loved one is, "A terrible thing happened over which we had no control."

Withdrawal, problems in school, misbehavior, appetite and sleep problems are normal in children after the death of a loved one. Children may also fear that remaining family members will abandon them or die as well. If these or other problems persist, it may indicate the child would benefit from professional help.

## Words that can help

Offering support to a grieving child can begin with a simple statement or open-ended question. Here are some conversation starters:

- I'm sorry your mom/dad/sister died.
- What was your dad/mom/brother like?
- Tell me about your \_\_\_\_\_.
- What was his favorite food?
- What do you miss the most?
- What is the hardest part for you?
- What is the hardest time of day for you?
- I cannot know how you feel, but I remember how I felt when my \_\_\_\_\_ died.
- I care about you.
- I care about how you are feeling.
- Is there anything I can do in the classroom to help?
- Is there anything in the classroom you would like to change to feel more comfortable?
- Would you like to talk about it?
- I'm available at this time, if you would like to come by and talk.
- Whenever you want to talk about it, I'm here for you.
- I'm thinking about you especially today because I'm aware that today is your mother's birthday (anniversary of the death, your birthday, etc.).
- I'm here to listen if you want to talk, or just spend time together if you don't want to talk.
- When is your recital (game, rehearsal, etc.)? Would it be okay if I stop by?

## Words that can hurt

The following are a few of the potentially harmful comments that are often offered to children grieving the loss of a parent:

- I know just how you feel.
- I know just how you feel...my dog died last year.
- Lick your wounds and move on.
- You'll get over it.
- It will be okay.
- Don't think about it.
- You are better off without him.
- Don't cry.
- It's your fault.
- You drove your father to drink.
- If only you had \_\_\_\_\_.
- Tears won't bring her back.
- Be strong.
- Forget about it.
- You are the man/woman of the house now.
- You should feel.... (proud, relieved, happy, sad, etc.).

## LOSS AND GRIEF TO HEALING, HOPE AND RENEWAL

As a donor family, you will continue to receive information for one year following the death of your loved one. This literature about grief and bereavement is designed specifically for our donor families. If you do not wish to receive the above-mentioned information or any additional bereavement materials from our organization, please notify our Aftercare Support Team members.

As you travel your unique journey through the storm of loss and grief, we want you to know we are here to be your helpful beacon - to guide you toward healing, hope, renewal, peace and comfort. Our Aftercare Support Team members is available to provide the support and resources you may need. If there is anything we can do for you or your family, please get in touch with us at [317.685.0389](tel:317.685.0389) or [888.275.4676](tel:888.275.4676).

### Opportunities for remembrance?

It is our privilege to support you and your family and to pay tribute to the generous men, women and children who save and heal lives through donation. In this spirit, we invite you to create a quilt square to be woven with the squares submitted by other donor families into quilts. These squares make up a patchwork of memories, lovingly created by families in our region. You need not be a quilter or artist to contribute. We invite you to view photos of our quilts and patches on our website, [www.indianadonornetwork.org/resources/donor-families/](http://www.indianadonornetwork.org/resources/donor-families/) as well as instructions for submitting your square. Or feel free to contact us at [317.685.0389](tel:317.685.0389) or [888.275.4676](tel:888.275.4676).

We also hosts remembrance events during the year to provide opportunities for donor family members to come together and share memories of their loved ones. There is an annual Gift of Life Celebration held in October; Spring is Hope, a workshop held in April; the Donor Wall Remembrance event held in June; and Handmade Hope, a workshop held in December. If you would like to continue receiving support materials from us, your family will be invited to these events and we hope you will join us.

### References

Harper, Kathryn Petro, A Mindful Life (2005), Intuitive and Instrumental Grieving.

Heisler, Jennifer, RN, About.com (2014). Organ Donation Types, written/reviewed by About.com's Medical Review Board.

Hogan NS; Coolican M; Schmidt LA. Prog Transplant (2013); 23(2):180-7 (ISSN: 1526-9248).

MEDLINE Abstract, Loyola University Chicago, Illinois 60153, USA. Nhogan@luc.edu.

Indiana Organ Procurement Organization Family Aftercare: Tissue Donation: How It Helps Others (2011).

Lifesource Aftercare Booklet (Organ & Tissue Donation, St. Paul, MN).

Lyles, Mary M., MSW, LCSW (2004). Navigating Children's Grief: How to Help Following Death, Children's Grief Education Association, and [www.childgrief.org](http://www.childgrief.org).

Lyles, Mary M., MSW, LCSW (2004). Words That Can Help & Words That Can Hurt, Children's Grief Education Association.

MedTerms -Medical Dictionary of MedicineNet.com (2014). Definition of Complicated Grief.

Merchant, Shaila J., Yoshida, Eric M., Lee, Tim K., Richardson, Penny, Karlsbjerg, Kari M., & Cheung, Elsie (2008). Exploring the psychological effects of deceased organ donation on the families of the organ donors, Clinical Transplantation, 341-347.

Tousley, Martha M. CNS-BC, FT, DCC. (1999-2014). Finding Meaning in Your Loss, [www.griefhealing.com](http://www.griefhealing.com).

Wright, Alexandra (June 25, 2014). eHow Contributor. How to Cope with Guilt After a Death.





---

*Hope is the whisper of earth  
When the stars pale  
And the dawn-winds hail  
A new day's birth,  
The hazy beacon of light  
Glowing in the distance beyond  
The headlong sweep  
Of the sea...  
Hope is the memory  
Time can't erase,  
The cherished days gone by that hover  
Above our consciousness like a soft caress,  
Wrapping us in the eternal light  
Of that beacon of faith,  
The comforting silence that trembles  
And seems to fill the heart  
When the storm is finally still.*

— MLJackson

---

