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A Gift for Life



A GUIDE FOR FAMILIES

Forward



We understand that this is a difficult time for you and your family. May the concern and sympathy of those who care help you through this time of sorrow. This booklet is written to provide you with some information on the grief process and help answer your questions about organ and tissue donation. It serves as a reference for much of what has already been shared with you. We want you to feel as comfortable as possible about your loved one's gift and know that it has been respected. If you have questions or concerns, please contact the LifeSource Family Services Coordinator.

Thoughts from the Parents of a Donor



We overheard our son talking one day. He said, "I know how I will live forever. When I die, I'll give my heart to a baby, the baby will live and grow old and when he dies, he will give my/his heart to another baby and on and on. I'll give all my parts to different people." His friend said, "Whoever gets your eyes will be very lucky as they are so beautiful." A year or so after stating his scheme for immortality, our son died. He was 18 years old. He gave all that he could. Yes, he lives forever in our hearts and in the hearts of hundreds of people who have benefited from his donation. Yes, the ones who received his beautiful corneas are lucky.

*Becoming a donor family was purely a selfish decision...a
continuance of his life through others. It has been our salvation.
He lives and we are very proud to have made that possible.*

Living Through Grief



The grieving process following the death of someone close to you is the same whether or not there have been organs and tissues donated. However, such a gift given in the face of tragedy can offer comfort to the survivors. The donation provides some meaning and the feeling that the person lives on in some way. One mother said, “It doesn’t feel so final since some of my son lives on in others.” This section of *A Gift for Life* is to help you know what to expect from grief and to serve as a guide through the grief process and beyond.

What Is Grief?



Grief is the emotional suffering we experience when we lose someone or something that is important to us.

It is a healthy and normal response and a necessary process for adjusting to living without the one we love. Grieving is the work we must do before we are able to fully embrace life again. Each of us grieves in our own unique way – and the way we express our grief is determined by our culture, earlier experiences with loss, gender and age. Some cultures permit and even encourage open expression of feelings, while others discourage it. Men and women demonstrate their grief differently because of the way they have been socialized. As children, we express grief as it relates to our level of understanding, 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 each other’s way of dealing with grief.

The Grieving Process



The grieving process involves several phases that are experienced by each of us in our own way and on our own timetable.

Most of us respond initially to a sudden death with shock and disbelief. We just cannot believe what has happened. This is what leads to a period of denial because we do not want to believe the person is dead. As we slowly begin to accept the reality of the death, we often feel confused. This confusion is made up of many feelings that seem to fight with one another. It is in recognizing the feelings and expressing them that we can begin to feel better. Dealing with the feelings helps us to learn more about the meaning of our relationship with the person and the impact of its loss on our lives. It is in this process that healing begins. With this healing comes a sense that life is beginning to feel normal again. The following is a description of common reactions and feelings you may experience as you grieve for the one you love.

Shock and Disbelief



Shock and disbelief are the most common reactions to the sudden death of a loved one. The general feeling at this time is one of numbness, which allows us to function and thereby helps us to accomplish what we need to do regarding the death. This numbness is nature's way of protecting us from becoming overwhelmed by the impact of the loss. There may also be physical symptoms in the first weeks. These can include aching in the chest and arms, heart palpitations, feeling as though you cannot get a deep enough 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 and you may experience nightmares. Some people experience visions of the dead person or think they hear them crying or calling out. If this happens, you may wonder if you are going crazy. You are not. 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. To move forward in the grieving process, it is necessary to accept the reality of the death. Acceptance comes in time and may increase your feelings of loneliness and sadness. When you can no longer deny the death you have a greater sense of the loss and its affect on your life.

Confusion



As the numbness wears off, many feelings 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. We feel that our emotions are out of control. Talking about and writing down your feelings can be helpful in gaining some clarity during this period of confusion.

Feelings



The feelings that surface for us after a loss relate to the cause of death and our relationship to that person.

If the death was expected, we may have had time to say “goodbye.” However, when the death is caused by suicide, sudden illness, homicide or an accident, there is no time for “goodbye” or to take care of unfinished business with the individual. These factors tend to complicate the grieving process and intensify the feelings. Some of the feelings we experience in relationship to loss are described on the following pages.

Fear



Fear is a normal reaction to the sudden and unexpected death of another person because we are confronted with how helpless we are in the face of death and that bad things can happen to us. The universe no longer feels like a safe place. This sense of vulnerability is compounded by the fact 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 snatched away by death. It is quite natural to be angry because we feel abandoned and victimized. Even when our loved one did not have control over his or her death, we are angry at him or her for leaving us. Some of us get angry at 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); failure to do so can result in depression.

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 leave. 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 the loss. Be gentle with yourself and give yourself time. It may take several years for you to get to the point of feeling really good about life again. Within six months of the death, you should start to notice improvement in your sleeping habits and appetite, as well as an increased ability to concentrate, work and find pleasure in living. If you notice no improvement in these areas or have thoughts about wanting to hurt yourself or die, you may be experiencing a depression that requires professional help.

Recovering After Your Loss



Learning to live without that special person is the most difficult part of the grieving process. You had learned to depend on his or her presence. The death results in a void that cannot be filled. As you become accustomed to the absence, you will develop a new routine and begin to feel like you are more in control. You will notice that your concentration has improved and the “good” days will begin to outnumber the “bad” ones. Life is of interest again and you may be forming some new relationships. You may even recognize some ways you have grown through this tough time. At this point, you are well on your way to recovery. The timetable is uniquely yours.

Some Suggestions to Help with Your Grieving

As you already know, grief is work, so you need to get plenty of rest and eat a nutritious diet.

Avoid the use of alcohol, tranquilizers, sleeping pills and other drugs. These give only temporary relief and may complicate the grieving process. Feeling the pain is one of the necessary tasks of grieving your loss.

Try to get some daily exercise, even if it is just a short walk. Exercise can help manage your anger and frustration.

Ask for and accept support from family and friends. They will be eager to help but are often unsure about what to do. Let them know what you need.

Keep a journal of your thoughts and feelings. This provides you with a way to express yourself and a perspective on your progress.

Talk about your feelings and thoughts with someone who listens well and will not tell you how you should be feeling. Speaking with your rabbi, minister or priest may be helpful at this time.

If you find yourself preoccupied with the donation of organs or tissues and worrying about the donation process itself, please contact the LifeSource Donor Family Services Coordinator.

Be gentle with yourself about the time needed for you to grieve. When people indicate that “you should be over this,” gently remind them that each person’s grief is different and tell them how they can help you.

Avoid getting over-involved with work or other activities. While work provides some necessary relief and structure, you also need time to think 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.

Reading books on grief related to the type of loss you have experienced can be very comforting and provide you with a deeper understanding of your grief experience. Ask the LifeSource Donor Family Services Coordinator for a bibliography.

Delay major decisions until after the acute stage of grief when you will be able to think more clearly. Moving or changing jobs will drain you of energy and complicate the grieving process.

Find ways to take a break from grief like going to a funny movie or reading a good novel. It is okay for you to laugh and have fun because this provides relief and helps create a balance in your life.

Share memories about your loved one. This can help you feel closer to the person and ease your pain. Putting together a picture album about the life of the person can provide comfort and a way to share memories.

If after six months you see no improvement in your ability to function, or at any time you have thoughts of wanting to hurt yourself or die, you may be experiencing a depression that requires professional help. Talk with a mental health professional about the difficulties you are having.

Holidays and special days, such as the anniversary of your loved one’s birth or death, can be difficult because the person’s absence is more pronounced. This may be true for many years. Plan ahead for how you will spend this time and develop some rituals for remembering your loved one. For example, light a candle at mealtimes or play his or her favorite music.

The belongings of your loved one can provide comfort for you. Holding their belongings or looking at mementos can help you feel close to him or her. The decision of what to do with their belongings should be made by you and those close to the person. Make this decision only when you are ready.

If your loved one died by suicide, you may tend to isolate yourself because of the guilt and shame you may feel. You may want to consider seeking the help of a support group to better understand the confusing feelings and to receive support. Ask the LifeSource Donor Family Service’s Coordinator for a list of available support groups.

Obtaining counsel from an accountant or lawyer regarding management of the affairs of an estate or will can help you feel confident that these matters are being handled properly. This can help reduce your stress.

Being touched, held, or hugged by someone who cares about you can be very healing. A massage can help to reduce the effects of stress on your body and provide comfort.

Spiritual readings in line with your beliefs may help give you some perspective and sustain you through this time.

What to Tell the Children



Many times adults try to protect children by denying them information or their participation in death rituals. Depending on the age of the child, their prior experience with loss, their relationship to the deceased and the type of death, the type and amount of helpful information will vary. Generally, children need simple explanations of the truth. They can sense when they are not getting the truth, which results in a loss of trust in the adults around them and increases their sense of insecurity. It's better to tell them simply that the person died in the accident because she was so badly hurt that her body would not work anymore. If you show that you are open about your feelings and interested in those of the children, they will feel more comfortable to ask questions and tell you

how they feel. This is what they need in order to learn about death and feel secure.

Many younger children (ages three to five) see death as reversible. The simple explanation of an accidental death described in the preceding paragraph may have to be repeated in order for the child to understand. The distinction between any accident and a tragic accident may not be comprehended. Attention to the child's questions, with repeated simple and consistent messages, should increase understanding. Encouraging younger children to understand and express their emotions is important.

Children age six to twelve will require a more detailed explanation of the death. For example, describing the difference 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 make sure the child does not hold personal guilt feelings about the death.

Explaining the death and helping teenagers understand emotions is important. Many adults assume teenagers will take care of themselves. Adult support is necessary to allow the teenager 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 the child should be advised that the anger does not mean you did not love the person. Adults may wish to consult a

professional to help form an explanation for any child having continuing emotional difficulty. Stress to younger children that the remaining family members will not abandon them. Older children will probably seek a more detailed explanation, which should be provided as appropriate.

In explaining murder to a child, the explanation should be as simple as possible as to what happened and 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, regressive behavior, problems in school, misbehavior, appetite and sleep problems are normal in children after the death of a loved one. If these problems are persistent, it may indicate that the child would benefit from professional help.

Life Times



It can happen, though, just as it does with all other living things that people become ill or they get hurt. Mostly, of course, they get better again, but there are times when they are so badly hurt or they are so ill that they die because they can no longer stay alive.

*So, no matter how long or how short they are, lifetimes are really all the same. They have beginnings, and endings, and there is living in between.**

*From Life Times by Bryan Mellonie. Copyright 1983 by Bryan Mellonie. Used by permission of Bantam Doubleday Dell Publishing Group, Inc.

Questions About Organ and Tissue Donation



Perhaps the hardest thing for many families to understand is the concept of brain death. The doctors have said that your loved one is medically and legally dead. The only thing that is keeping them functioning is the machine (ventilator) that breathes for them. And yet, as you stand watching them and touch their warm skin, they merely look asleep. You almost expect that at any minute they'll open their eyes and say, "What happened?" This expectation is normal. When the brain ceases to function, the person is permanently unable to think, breathe, see, hear or feel. They are no longer the person you once knew. Without oxygen, the heart stops beating and vital organs such as the kidneys and liver are unable to function. Medical equipment, such as the ventilator, can keep the heart and other vital organs functioning after the brain has died. Without the machine, the person would not breathe on their own and their heart would stop beating within minutes. The following will help you better understand organ and tissue donation.

What is brain death?



A severe head injury or brain hemorrhage (bleeding) usually causes brain death. When the person initially receives emergency treatment, they are connected to a ventilator to maintain breathing until further assessment can be made of the condition. The determination of brain death is made only after a thorough evaluation in which numerous tests are done. Brain death must be determined by a physician. The physicians determining brain death are in no way connected with the transplant team, nor can they, by law, perform the organ recovery or transplantation.

Who can donate organs?



Organ and tissue donation is only possible after death has occurred. The option of organ donation is most often offered after brain death is declared. Persons who die of brain death are maintained on a ventilator, which, in turn, allows the heart to continue to pump blood through the organs, which is necessary for organ recovery. In some situations involving severely injured or ill patients who are not brain dead, the option of organ donation may be offered after the family has decided to withdraw support.

The age of a donor is less important than physical condition. Each organ is evaluated individually. Organ donors may also donate tissue.

How are the vital organs used?



Hearts are transplanted into persons with severe heart disease; in the event the whole heart cannot be transplanted, the heart valves can be used for children and adults with defective valves.

Kidneys are used for persons with chronic kidney failure.

Lungs are used for persons with severe lung disease.

Livers are transplanted into persons with liver failure as the result of cirrhosis or other liver disorders.

Pancreas can be used to treat diabetes.

Intestines can be used to treat individuals with digestive disorders.

Who can donate tissue and how is it used?



LifeSource evaluates all deaths for potential tissue and cornea donation even when organ donation is not possible. The transplantation of heart valves, skin, bone, cornea and other tissues can restore thousands of people to normal, active and productive lives.

Skin is used as a protective covering for extensive burn victims.

Bone can be used for reconstruction or replacement in persons with traumatic injuries, cancer or bone disease.

Corneas can restore sight to those suffering from injuries or diseases of the cornea.

Other Tissues such as veins and ligaments can be used for a variety of disorders.

What happens once the decision to donate organs has been made?



Donor evaluation is performed. The testing includes an extensive medical and social history and multiple laboratory tests to rule out the possibility of infection or other problems that may prevent transplantation; screenings are routinely performed on all donors to avoid the spread of infectious disease to recipients.

While testing is being done, the person must be maintained on the ventilator. This may take several hours. Recipients are then located and transplant teams assembled.

Physicians in the operating room perform the recovery of the organs. Your loved one is treated with great respect and dignity the entire time. Your funeral home is notified once the procedure is completed.

Is an autopsy performed?



An autopsy may be necessary to determine the cause of death. In certain cases, the medical examiner or coroner is involved and may order an autopsy. An autopsy can provide valuable medical information for your family and can be requested at the time of death. An autopsy will not prohibit an open casket viewing.

Will the body be disfigured?



Organ and tissue donation is a surgical procedure. In rare circumstances, a change in appearance could occur. Every effort will be made to minimize any visual change to your loved one's body.

Will there be pain?



No, because upon death the nerve pathways that would conduct the feelings of pain no longer work. Therefore, no pain is experienced.

Is there any cost to the family?



No. There is no cost to the family for organ and tissue donation. If you have questions about your hospital bill, please contact LifeSource as soon as possible.

Will I be told who receives the donation?



To respect the recipients and your confidentiality, names are not released as to those benefiting from your loved one's gift. However, you will be informed as to what organs and/or tissue was recovered.

Occasionally, organ recipients send cards or write letters to their donor's family, which LifeSource forwards. You may also choose to write a letter to the recipients when you feel ready. Please contact a LifeSource Donor Family Services Coordinator for more information about how this is done.

Since the reporting of tissue recipients by hospitals is voluntary, and because certain tissues may not be transplanted for several years, personal information about tissue recipients is often unavailable. Please be assured that your loved one's generosity will always be remembered by those whose lives have been restored.

How is the decision made about who gets what organ?



A computer listing of all persons in the United States waiting for organ transplants is kept by the United Network for Organ Sharing (UNOS), located in Richmond, Virginia. When an individual dies and there is potential for organ donation, UNOS is notified and a computer list of compatible recipients is generated. The recipients are ranked according to specific medical and scientific criteria.

My loved one has 'donor' marked on their driver's license and/or in their state's organ and tissue donor registry. What does this mean?



Your loved one made a generous decision to give the gift of life through organ and tissue donation by marking 'donor' on their driver's license or in their state's donor registry. In the LifeSource region, this documentation means that your loved one gave their permission for organ and tissue donation to occur. This is a legally binding document and LifeSource is obligated to help ensure that your loved one's final wish to help others is fulfilled.

Suggested Readings



The list below is a sampling of what is available on the subject of grieving. There are many more very helpful books. A LifeSource Donor Family Services Coordinator can offer additional reading suggestions.

GRIEF IN GENERAL

How to Go On Living When Someone You Love Dies by Therese Rando

National Kidney Foundation: For Those Who Give and Grieve

The Journey Through Grief by Alan D. Wolfelt

When Bad Things Happen to Good People by Harold Kushner

Companion to Grief by Patricia Kelley

The Mourning Handbook by Helen Fitzgerald

CHILDREN AND GRIEF

When Dinosaurs Die: A Guide to Understanding Death by Laurie K. Brown

Explaining Death to Children by Earl A. Grollman

Straight Talk About Death for Teenagers by Earl A. Grollman

LifeTimes: The Beautiful Way to Explain Death to Children by Bryan Mellonie

The Empty Place: A Child's Guide Through Grief by Roberta Temes

WIDOWHOOD

The Widow's Handbook: A Guide for Living by Charlotte Foenher and Carol Coyant

Widow to Widow: Thoughtful, Practical Ideas for Rebuilding Your Life by Genevieve Ginsburg

Suggested Readings (continued)



SUICIDE/SUDDEN DEATH

Healing After the Suicide of a Loved One by Ann Smolin

No Time to Say Goodbye: Surviving the Suicide of a Loved One by Carla Fine

Living with Grief after Sudden Loss by Kenneth J. Doka

LOSS OF A CHILD

Recovering from the Death of a Child by Katherine Donnelly

Sunrise Tomorrow: Coping with a Child's Death by Elizabeth Brown

Parental Loss of a Child by Therese Rando

We hope this booklet has answered many of your questions and concerns about the grieving process and organ and tissue donation. If you need further assistance, please feel free to contact a LifeSource Family Services Coordinator or your donation coordinator.



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LifeSource thanks the talented staff at LifeNet for developing and sharing the information in this valuable resource.