

As Change Comes: A Guide for Families Experiencing Loss



What is grief?



Grief includes the thoughts and feelings a person has when faced with a loss. Everyone experiences grief differently. The death of a child is not something a caregiver expects or prepares for, even if your child has been sick or injured for a long time. Grieving the loss of a child is a life-long process. No matter how your grief may look or feel, it's important to know that your grief is unique to you. Grief can feel like a variety of different emotions, or sometimes, it can feel like nothing at all. Some caregivers may feel sad, shocked, angry, hopeless, anxious, numb, or others not included in this list. Physical responses, including difficulty sleeping, changes in appetite, stress, and loss of energy, are also common as one is grieving. These emotions and physical responses may make it difficult to concentrate or to complete normal daily tasks. This is a normal grief response. Crying openly is a common and normal expression of grief, as is not crying at all. Be patient with yourself as you grieve in the way that feels natural to you.

Caring for yourself

After the loss of a child, it is important that you continue to care for yourself. Sometimes caregivers get sick following a loss. Your body needs rest, exercise, and nutrients. Be careful not to rely on drugs and alcohol. Try to find outlets for your energy that are healthy. This could include writing in a journal, talking about your child with others, creating a special memorial, or planting a garden. Your heart also needs time to heal. Remember that grief is a process so give yourself time. You will have good and bad days. Allow others to walk this path with you and accept help from friends and family. Some grieving families also turn to their faith community for support. Those who care about you may want to provide you with love and encouragement. It can be helpful to find tasks such as cleaning, preparing meals, answering phone calls, caring for other children and pets, or planning the memorial services that others can do to help you.

How to move forward

There is no right way to return to life following the loss of a child. Life will be different, and your family will need time to adjust to this change. If you can, avoid big decisions while you are grieving, including career changes or large purchases. In the days following your child's death, try not to make any decisions about your child's belongings. You may choose to close the door to your child's room or ask a relative or friend to help you organize and store your child's belongings until you are ready. Make sure to take care of yourself and that you are eating and resting, even when it feels difficult. It is okay to slowly ease back into daily activities.

Maintaining relationships

Maintaining relationships during the grieving process can be hard. You may find that others in your life are grieving the loss of your child in their own way. With a partner or spouse, it is important to talk honestly even if you are both grieving in very different ways. Other family members and friends will also experience grief following your child's death. Surround yourself with others who allow you to grieve at your own pace and in your own way. Find supportive friendships that give you both company and space for healing-or give yourself the time and quiet you may need as you process your feelings.

Parenting other children after the loss of a child

If you have other children, it is normal for parenting to feel more difficult following the death of a child. There will be a period of adjustment within your home as your family adapts to life after loss. As your other children also grieve the loss of their sibling in their own ways, they will look to you for guidance and reassurance. Don't feel as though you need to hide your emotions or grief from your other children. Seeing the ways that you handle challenging emotions can help your children learn to do the same. It can be helpful to keep family routines as much as possible during this time. You may also find it helpful to ask family members or friends to help you in caring for your other children.

This packet also includes a resource to help you talk with your other children or child family members about death. This includes words to use and common responses to loss for different age groups.

Holidays and important milestones (find rituals that honor your child)

After your child's death, holidays, birthdays and milestones may be emotional for the whole family as you learn to cope with life after loss. It is natural to think of new ways to recognize these days that are important to your family. While it may seem hard to face traditions after the loss of a child, you will find ways to honor your child as a part of these celebrations. Finding a way to remember and include a child who has died while also continuing special rituals and traditions can help your family cope with these moments.

Expectations of others

Based on your family, gender or cultural roles, you may feel pressure to show your emotions or support your family in certain ways. These expectations of others may fit the way that you are grieving the loss of your child, or they may feel stressful and difficult. It is okay to experience emotions and grieve in the way that is natural for you, regardless of how others expect you to feel or react. If you are the primary wage earner for your family, you may feel pressure to return to work after the loss of your child before you feel ready. It may be helpful to speak with your employer or explore programs or charities that can help with financial expenses to allow you additional time to grieve before returning to work.

Grief is different for everyone

Remember that your grief experience may sometimes look like, and sometimes be different than, how others in your family or community grieve. Because it is unique to each person, it is important for you to tell others how you are feeling and what kinds of help or support you need. Whether you are talking to a spouse, loved one, friend, or employer, know that it's okay to ask for help during this difficult time.



Grandparents and grief



Losing a grandchild is a unique and difficult experience for many people. As a grandparent, it may be difficult seeing your own child's grief process while also managing your own grief experience. Remember to give yourself the gifts of patience and grace. No grandparent ever expects to have to walk this path. Even though you may not have been the primary caregiver for your grandchild, the grief you are feeling is valid and real.

It is natural for you to want to support your child as they grieve the loss of your grandchild. You may find that you are grieving your grandchild differently than your child is grieving their loss. You can help your child and their family by giving them permission to grieve in the way that feels right for them, even if it is different from yours. You may feel the desire to help your child by completing daily tasks such as running errands or providing meals. These helpful acts are supportive of your child's grief. It is also important that you take time for yourself during this difficult time. It is just as helpful if you ask others outside of your family to complete these tasks.

Your other grandchildren will feel supported by your familiar and loving presence. This packet contains information about how to best support children who are facing loss and provides suggestions for how to speak with them about these challenging topics. You may find it helpful to review this information and speak with your child about how you can support and communicate with your other grandchildren. Your grandchildren will benefit from receiving a consistent and thoughtful message from grandparents that they love and trust.

Support children experiencing grief



It may be hard to think about telling your other children about the death of their sibling. It is natural for you to want to protect other children in your life from receiving difficult news. It is normal to be worried about how they may react. Children can handle difficult information when it is shared by someone they trust. You can best support your children by speaking with them using words they can understand and language that is honest, clear and concrete. It may be hard to use the words “death” and “died,” yet these words will best help children understand. Phrases such as ‘went to sleep’ or ‘passed away’ might be confusing for children. If you need help in choosing which words to say, you can use the age specific resource provided in this packet.

As you share information with the other children in your life, it is okay - and even helpful - to share your own emotions about the loss of your child. This will help your child know that their feelings are normal and allows you to show them how to cope with these difficult feelings. You can also help by telling them that any emotion they are feeling when thinking about the child who has died is okay, whether it is sadness, anger, fear, regret, or even happiness.

If you feel that your other children would like to talk about the loss, but may not know where to start, it can be helpful to ask open-ended questions. An example could include, “I wonder if there is anything that you are worried about/scared of/curious about right now?” If they ask a question that you do not know how to answer, it is okay to say, “I don’t know” or “let me think about that for a minute.”

You can support children by letting them know that you will always remember the child that has died. He/she/they will be a part of your family through memories and stories, even though they can’t be here with you. Other children in your life may be comforted to know that they have choices in how they want to remember the child that has died. You can ask your other children if they would like to share a story or create a memorial as part of their grieving and healing process. Examples could include a drawing, a poem, a song, a bracelet or another item that is meaningful to the child.

You may have questions about how to support your other children as they move forward in the coming days and weeks. When thinking about how to include children in a funeral or memorial service, there is no answer that is best for every family. What is most important is to offer your children the choice of whether to attend a funeral or memorial service. This honors their choice in their grieving journey.

If you feel that your child may have a difficult time staying for all of the event, you might ask a trusted family member or friend to care for them if they choose to leave early. Or you can bring additional activities that the child enjoys and takes comfort in should they feel overwhelmed.

Parents also wonder how soon they should send children back to school or other activities after the death of a child. The answer will depend on what feels best for your family. It may seem strange to quickly return to typical activities but remember that children are often comforted by the routine of these activities. It may be helpful for you to reach out to the child's teacher, counselor, or school staff to make them aware of the loss your family has experienced. Siblings may want to talk about the child who has died, may be feeling strong emotions, or have difficulty concentrating at school. These challenges are normal and often get better with time.

It can be hard to know when to find additional support for your child. Because grief responses can be different based on your child's age and personality, it can be difficult to know if they are grieving in healthy ways. Generally, children's grief should start to calm over time as they build a new normal with their family and friends. However, if a child's grief starts to increase over time, or makes it difficult for them to eat, sleep, attend school, or play, these are signs that more help is needed. Talking with a counselor from their school or your community can be a great way for children to express their grief and learn ways to help them cope with their feelings and loss.

Developmental understanding, responses, and ideas for support

Infants and toddlers

Understanding

Very young children do not have a concept of death and will not understand that your child has died. They will be aware of the changes in their routine and notice the emotions of those around them.

Responses

At this age, it is common for children to be fussier and more clingy than usual. Infants and toddlers may change their patterns of eating and sleeping following the loss.

Support

You can best support infants and toddlers who are grieving by keeping routines and rituals as much as possible. Show healthy coping behaviors - such as seeking support from another person or expressing emotions. A quickly changing environment can be stressful for young children. You can help restore their sense of security by limiting the number of people in and out of your home when possible. Small actions can help your young child cope with the death of a sibling, for example, you can keep items around that smell like the person who has died or begin collecting photos and items to help your infant or toddler learn about their sibling who has died. Toddlers will benefit from being given choices whenever possible, even related to small things. Remember that acting more clingy or having challenging behaviors during this time is not poor behavior but is how your child is showing their grief.

Preschoolers

Understanding

Children at this age do not think of death as something that is permanent. It is not uncommon for them to ask when the person who has died will come back. Preschool aged children may also not understand cause and effect and might think that they did something to cause the death.

Responses

When a preschool aged child first learns of the death, they may ignore the information or try to change the subject. They may choose to talk about their loss at times that feel unexpected or inconvenient, such as in the middle of the grocery store. Children in their preschool years may respond to grief or sadness by going back to younger habits, such as sucking their thumb or wetting the bed. Children might seek out more attention from trusted adults by acting more clingy or by acting out. As preschool aged children process the death, it is common for them to ask the same question multiple times. It is also common for children to process loss and death through their play. Do not be surprised or worried if you see your child including themes of death into their pretend play. This is how children make sense of the things they are experiencing.

Support

You can best support preschool aged children by providing consistent care and information. It is helpful to speak with them in words they understand about the death and to give consistent answers each time they ask the question. Common phrases used by adults, such as ‘passed away’, may be confusing to children at this age. It is important to use the words death and died and to remind your child that once a person has died, they cannot come back to life. It is also important to avoid telling your child that the person who died went to sleep. This may cause your child to be afraid to go to sleep. It may be helpful to make connections to other experiences with death, whether this is a family member or pet who has died, or even a house plant. You can also use simple, terms such as “When someone dies, their body does not need to eat or drink anymore.” Tell your child that they will continue to be cared for and keep the same routines. You can help your child to give name the emotions they may be feeling and show them the ways to handle these emotions.

School-aged children (ages 6 to 12 years)

Understanding

School aged children are beginning to understand that death is final. Children at this age have a very concrete understanding of the world and can better understand cause and effect relationships. School aged children often are aware of death because they know of someone who has died, even if it was not a close family member.

Responses

School aged children will experience a wide range of emotions regarding the death of a loved one, but may feel uncomfortable expressing their emotions or worries. Sometimes, emotions children express will match the situation, such as feelings of anger or sadness. Other times, it can seem like a school aged child is coping through denial, joking or acting tough. It is common for school aged children to seek out attention and support from trusted caregivers. Following a death, school aged children may return to habits that they have grown out of or try to act adult-like. Difficulties in school are also common following the death of a loved one. School aged children may be afraid other loved ones will die or fear their own death. School aged children will also want some time to themselves to process the information they are receiving. Giving them space to process and grieve in their own way can be helpful.

Support

You can best support your school aged child by talking about death in concrete terms. You might say something like, “Your brother died. This means that his lungs stopped breathing, his heart stopped beating and his body died. When someone dies, their body cannot start working again.” The clear language will help your child to understand what has happened. You can also reassure your child that no other family members are dying. Your school aged child will look to you as a guide for how to manage difficult emotions. You can help them by letting them know that their feelings are normal and helping them find ways to cope with their emotions. School aged children may want to participate in planning a memorial service or creating a memorial for their sibling who has died. It may be helpful to contact your child’s teacher or school to make them aware of the death so that they can best support your child.

Adolescents

Understanding

Adolescents have a more adult concept of death, meaning that they know death is permanent and are able to think abstractly about it. Adolescents, however, may not have the same coping skills as adults. Although they have an understanding of death, adolescents often believe that they are invincible and will not die. Children in the adolescent years may begin to explore their own belief system of what they think happens once someone dies and often try to find meaning in their spiritual beliefs.

Responses

Following the death of a loved one, adolescents often seek support from peers over family members. Adolescents may engage in risky behaviors after the death of a sibling. While adolescents may express a wide range of emotions, sadness, moodiness and irritability are common during this time. Although many of these responses are common, such as sadness and wanting to spend time alone, you can seek out additional help for your adolescent if they are showing signs of depression or expressing wanting to harm themselves.

Support

You can best support your adolescent child following a death by providing them with honest information and open conversation. Giving an adolescent space and time to grieve in their own way can be helpful.

Memorial activities for siblings

Your children may want to participate in an activity to help them remember the person who has died. These activities can be unique to each situation and child to serve as a creative way to remember their loved one.

Examples of memory activities include:

- Writing a letter to the person who has died
- Creating a memory box with photos and favorite items
- Creating a bracelet with beads that have a special meaning about the person who has died (for example, a bead to represent their birth month or a bead to represent their favorite color or holiday)
- Planting a tree or garden in honor of the person who has died
- Select an article of their clothing, a favorite stuffed animal, or accessory to keep
- Share stories about your child who has died
- Create family traditions (for example, eating your child's favorite meal on their birthday or anniversary of their death)



Grief rights



Parent

As a grieving parent, I have the right to...

- Experience grief in my own unique way
- Take moments to care for myself
- Ask the medical team any question that comes to mind
- Spend private moments with my child
- Ask my child's medical team to help me identify family members for support
- Ask for help, whether it be for family support or counseling resources
- Feel unsure of my next steps
- Select a trusted family member or friend to help me make decisions
- Receive or decline memory-making items like handprints and memory boxes
- Feel a wide range of emotions that change from one moment to the next

Patient

As a grieving patient, I have the right to...

- Experience grief in my own unique way
- Ask for privacy or time alone with my family and friends
- Understand my medical condition and participate in decision making about my care
- Ask the medical team any question that comes to mind
- Choose who I want to visit me
- Feel a wide range of emotions
- Ask for what I need to feel supported
- Continue to do things I enjoy in the ways that I can
- Share my wishes for the end of my life and the way I am celebrated and remembered

Sibling

As a grieving sibling, I have the right to...

- Experience grief in my own unique way
- Take moments to care for myself
- Get answers to my questions about my sibling's death
- Spend private moments with my family
- Ask for what I need to feel supported
- Feel a wide range of emotions
- Remember my sibling in the way that is most special to me
- See my brother or sister if I would like to
- Choose whether I would like to participate in memory-making activities
- Continue to do things I enjoy doing
- Talk about and remember my sibling

Spiritual care



The days and months after a death can be a time of confusion. The death of a loved one may cause you to question your beliefs. We want you to know that this is normal, and that there is space for you to ask the hard questions. It may be helpful to do so with your faith community. Many communities have resources available to those who are grieving, so consider those services when you are ready. If you are visiting the hospital, the spiritual care department is here to walk alongside you. We are here to hold space for the pain and suffering you might have while helping you find hope and meaning in the days to come. The spiritual care team can be reached at 615-936-0425.

Resources for remembrance

The memories and experiences you've shared with your child will always be your most prized possession. This will always be true. Below are some additional ideas for honoring your child's memory and legacy in the days, months, and years to come.

While in the hospital, it may be meaningful to:

- Save mementos that remind you of your child, including a lock of hair, your child's clothes, or your child's artwork
- Take pictures as a family
- Create handprints and footprints

In the future, it may be comforting to:

- Create a memory box for your child
 - Plant a tree in your child's honor
 - Wear jewelry that carries a special meaning
 - Donate to a charity in your child's name
 - Support research efforts for your child's condition
 - Donate to the hospital where your child was treated
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Bibliography



Books for caregivers coping with the loss of a child

After the Darkest Hour the Sun Will Shine Again: A Parent's Guide to Coping with the Loss of a Child By Elizabeth Mehren

This inspiring guide to coping with the loss of a child combines the author's own story with the experiences and wisdom of others who have gone through a similar tragedy.

The Bereaved Parent By Harriet S. Schiff

The author of this classic book incorporates her own experiences as a bereaved parent to provide step-by-step suggestions to help parents cope.

A Broken Heart Still Beats: After Your Child Dies By Anne McCracken and M. Semel

This collection of poetry, fiction, and essays written by many authors was selected and compiled by two women coping with the death of their children. It offers a different approach in the search to find meaning in the death of one's child.

How Do We Tell the Children: Helping Children Understand and Cope When Someone Dies By Dan Schaefer and Christine Lyons

A step-by-step guide for helping children (ages two to teen) cope when someone dies.

The Worst Loss: How Families Heal from the Death of a Child By Barbara D. Rosof

This book seeks to help families who have experienced the death of a child know what they are facing, understand what they are feeling, and appreciate their own needs and timetables.

It's OK That You're Not OK: Meeting Grief and Loss in a Culture that Doesn't Understand By Megan Devine

This book encourages readers to see their grief as a natural response to death and loss, rather than an aberrant condition needing transformation.

Empty Arms: Coping with Miscarriage, Stillbirth and Infant Death By Sherokee Ilse

This unique and encouraging book reaches out to all who have been touched by infant death or miscarriage. The author offers compassionate and sensitive support and acknowledges the range of emotions in the grieving process.

Empty Cradle, Broken Heart: Surviving the Death of Your Baby By Deborah L. Davis

Helping families deal with the heartache of miscarriage, stillbirth, or infant death and offers reassurance to parents who struggle with anger, guilt, and despair during and after tragedy.

When the Bough Breaks: Forever After the Death of a Son or Daughter

By Judith Bernstein

This author speaks from the dual perspective of a bereaved parent and psychologist. Excerpts from interviews with 50 parents who lost a child from five to forty-five trace the road from utter devastation to a revised view of life.

When Bad Things Happen to Good People By Rabbi Harold S. Kushner

Wise and compassionate advice on how to cope with tragedy, what to do about anger, and how to keep from feeling guilty.

I Wasn't Ready to Say Goodbye: Surviving, Coping and Healing After the Sudden Death of a Loved One By Brook Noel, Pamela D. Blair, Ph.D

This book offers a comforting guide through the grieving process, from the first few weeks to the longer-term emotional and physical effects.

Books for Grandparents Coping with Loss

A Grandparent's Sorrow By Pat Schweibert

Suggestions on how grandparents can help themselves as they grieve, how to better understand their child during this difficult time, and how to hold close the precious memory of their grandchild.

Healing a Grandparent's Grieving Heart: 100 Practical Ideas After Your Grandchild Dies By Alan Wolfelt

The ideas offered in the book clarify the basic principles of grief and mourning and offer immediate suggestions for things grandparents can do to embrace their grief, honor and remember their grandchild, and begin to heal.

Books for Children Coping with the Loss of a Sibling

Young Children

Sad Isn't Bad: A Good-Grief Guide Book for Kids Dealing with Loss (ages 3-8)

By Michaelene Mundy

A comforting, realistic look at loss loaded with positive, life affirming helps for coping with loss as a child.

Gentle Willow: A Story for Children about Dying (ages 5-9) By Joyce C. Mills

The willow tree's friends struggle to understand and grieve when she becomes sick and dies.

The Invisible String (ages 4+) By Patricia Karst

Offers a very simple approach to overcoming loneliness, separation, or loss with an imaginative twist that children easily understand and embrace and delivers a particularly compelling message in today's uncertain times.

When Dinosaurs Die (ages 3-6) By Laurie Krasny Brown

This helpful book provides answers to kids' most-often asked questions and also explores the feelings we may have regarding the death of a loved one, and the ways to remember someone after they have died.

When Someone Very Special Dies (ages 5-12) By Marge Heegard

A practical format for allowing children to explore and understand the concept of death and develop coping skills for life.

When Something Terrible Happens (ages 5-12) By Marge Heegard

Creates ways for children to explore the fright, confusion, and insecurity caused by traumatic events in their lives.

Badger's Parting Gift (ages 5-12) By Susan Varley

This story uses animals to discuss what loved ones who have died have taught us and how we can remember them.

Lifetimes: The Beautiful Way to Explain Death to Children (ages 4+) By Bryan Mellonie and Robert Ingpen

This book shows children how death is a part of life in a sensitive, caring, and beautiful way.

Aarvy Aardvark Finds Hope (ages 8+) By Donna O'Toole

A classic read-aloud story about loving and losing, friendship and hope.

I Miss You: A First look at Death (ages 3-6) By Pat Thomas

This book helps children understand that death is a natural complement to life, and that grief and a sense of loss are normal feelings for them to have following a loved one's death.

The Memory Box: A Book About Grief (ages 3-6) By Joanna Rowland

This book describes what it is like to remember and grieve a loved one who has died. The child in the story creates a memory box to keep mementos to help in the grieving process.

Adolescents

Straight Talk about Death for Teenagers: How to Cope with Losing Someone You Love (ages 12+) By Earl Grollman

This book discusses experiences and feelings of teens when someone they care about dies. A journal section is also included for recording memories, feelings, and hopes for the future.

The Grieving Teen: A Guide for Teenagers and Their Friends (ages 12+) By Helen Fitzgerald

In this unique and compassionate guide, renowned grief counselor Helen Fitzgerald turns her attention to the special needs of adolescents struggling with loss and gives teens the tools they need to work through their pain and grief.

I Will Remember You: What to Do When Someone You Love Dies (ages 12+) By Laura Dower

A book written specifically for the teenage reader who is coping with death and all the complex emotions that accompany it.

Help for the Hard Times: Getting Through Loss (ages 12+) By Earl Harp

A beautifully illustrated book which helps explain how teenagers go about grieving and how it is okay for them to be themselves. It explains how society sees their problems and how they can release their feelings.

Deconstruction, Reconstruction: A Grief Journal for Teens (ages 12+)

Whether a teen has experienced the death of a parent, sibling, grandparent, close friend, or other family member, this Deconstruction/Reconstruction journal is an advice-free place where teens can draw, write, paint, and transform whatever they're thinking and feeling.

Websites

The Dougy Center (www.dougy.org)

The Dougy Center provides support in a safe place where children, teens, young adults, and their families grieving a death can share their experiences. They provide support and training locally, nationally, and internationally to individuals and organizations seeking to assist children in grief.

Bereaved Parents of the USA (www.bereavedparentsusa.org)

Bereaved Parents of the USA was founded in 1995 by a group of bereaved parents from across the country to offer support, understanding, encouragement and hope to fellow bereaved parents, siblings and grandparents after the death of their loved one.

Organizations



Alive Hospice, Inc. – Bereavement Services

1718 Patterson Street
Nashville, TN 37202-3588
Phone: 615.327.1085
Toll-Free: 800.327.1085
www.alivehospice.org

Alive Hospice Bereavement Services offers support groups for parents, children, and others experiencing the loss of a loved one. The Children's Grief Support Program offers support for children and teens, school-based bereavement support groups, and individual counseling. Counseling is also available to families coping with grief.

Compassionate Friends – Nashville Chapter

1604 Elm Hill Pike
Nashville, TN 37210
Phone: 615.356.4823
www.TCFNashville.org (local website)
www.compassionatefriends.org (national website)

The Compassionate Friends is a national self-help organization with local chapters that offers support to bereaved parents and siblings. Its purpose is to educate families, friends, employers, and others in the community about the needs of parents and siblings who are grieving. To locate chapters outside of the Nashville area, please refer to the national website.

Gilda's Club of Middle Tennessee

Nashville Clubhouse
1707 Division Street
Nashville, TN 37203
Phone: 615.329.1124
www.gildasclubnashville.org (local chapter)
www.gildasclub.org (national website)

Gilda's Club provides meeting places where adults and children living with cancer and their families and friends can find emotional and social support. Gilda's Club also offers support groups for adults and children who have a family member or friend with cancer, or who have lost a loved one to cancer. Services include advocacy, health education, support groups, nutrition information and youth services.

SHARING of Middle Tennessee

615-753-1942

www.sharingmiddletn.org

SHARING is an acronym for Sharing Help and Reassurance in Normal Grieving to parents who have suffered a miscarriage or pregnancy or infant loss. SHARING is a support group for parents who have experienced miscarriage, stillbirth, or early infant loss. Their meetings are designed to help a parent sort through the grief process in a safe environment among others who have experienced similar losses. Each meeting is facilitated by a parent who has experienced loss and a professional (nurse, doctor, social worker, or chaplain).



Junior League Family Resource Center
Monroe Carell Jr. Children's Hospital at Vanderbilt
2200 Children's Way, Suite 2125
Nashville, TN 37232-9200
P: (615) 936-2558