

# YOUTH ALIVE

AN ALIVE HOSPICE RESOURCE FOR ADULTS AND KIDS  
SPONSORED IN PART BY THE GANNETT FOUNDATION



## Emily Johnson Alive Pediatrics

**E**ighth grader Baylie Pegram looked into her baby sister's eyes and said in a cooing voice, "We love her a lot!" Baylie's sister, Emily, smiled and giggled as Baylie played with her in their family's living room.

When Emily was an infant, she was diagnosed with an illness that would likely cause her to have a short life expectancy. At eight months old, she became an Alive Hospice patient.

Hospice is a special kind of medical care for people who have serious illnesses and may not get better. Alive Hospice caregivers make sure that patients are as comfortable as

*Baylie Pegram, center, holds her sister and Alive Pediatrics patient Emily Johnson with mother Terri Johnson at their side.*

possible during their illnesses. They also provide emotional and spiritual support to patients and their loved ones. Patients can receive hospice care in a variety of settings, including at home, in hospitals and at Alive Hospice inpatient facilities.

Alive Hospice provides this care for patients of all ages who face life-limiting illnesses. Physicians, licensed nurses, certified nurse technicians, social workers, chaplains, volunteers and bereavement support staff make sure that patients are free from pain and other unpleasant symptoms. Two pediatricians work with patients and families as part

of the agency's Alive Pediatrics program to aid with symptom management.

In addition to end-of-life care, Alive Hospice offers palliative care, a service that provides pain and symptom relief for adults and children who don't require end-of-life care but face chronic, life-threatening illnesses.

Emily and her family have benefited from home visits by an Alive Hospice pediatrician and nurse as well as a social worker, a chaplain, a children's grief counselor and a teen volunteer. Alive Hospice caregivers visit as needed and are committed to maximizing quality of life for patients.

"She's being comforted," Baylie said about Emily. "They're trying to help her as long as they can. They've done a lot. They make me feel comforted, too."

Interacting with an Alive Hospice teen volunteer has been helpful to Baylie, said her mother, Terri Johnson. Baylie said she enjoyed the time they've spent together and

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## Kids' Frequently Asked Questions: Hospice

### What's the difference between a hospice and hospital?

A hospital is a place where patients receive medical care with the goal of curing an illness. Hospice is a special kind of care that focuses on making patients comfortable while they face a life-threatening illness. Hospice caregivers focus on quality of life, which means helping patients live as fully as they can, even with an illness.

### Does it hurt?

Hospice patients face illnesses that can cause pain and other symptoms, but hospice caregivers

do everything they can to make sure patients don't hurt and don't experience other unpleasant symptoms, such as nausea, shortness of breath and depression.

### Is hospice a sad thing?

Nobody likes being sick, and it's sad when someone dies. But hospice is also a very positive thing. By doing their best to make patients comfortable and feel as little pain as possible, hospice caregivers make it possible for loved ones to enjoy their time together.

### Where do patients receive hospice care?

Many patients receive care in their homes. Others receive care in hospitals and in special places run by Alive Hospice. No matter where patients receive care, they'll be visited by people who do all they can to make patients feel comfortable and loved. We encourage our patients to keep seeing their regular doctors.

### Do hospice patients get to see friends and family?

Absolutely. In fact, Alive Hospice encourages its patients to enjoy time with friends and family as much as possible.

### Do hospice patients ever get better?

Hospice patients sometimes get better. But whether a patient gets better or dies, hospice caregivers want to make sure they don't experience pain and other symptoms.

## Emily Johnson

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learned more about hospice care. Terri said it was beneficial for her daughter to have someone close to her age to talk to about hospice.

Alive Hospice also provides a children's book, "Meet Mabel and Able," to help kids understand the hospice journey and significant life changes. A group of quilters adds to the warmth of Alive Hospice's loving care by providing colorful quilts for pediatric patients.

In addition, Alive Grief Support Services offers a variety of services to assist adults and children following the death of a loved one. (More information about these services can be found in this publication.)

Terri recalled that her family "didn't really know what to expect" when Emily became a hospice patient. It was a completely new experience for her family, one that proved to be a great comfort.

"They've been very supportive of our family," Terri said. "Having hospice there, to always be there if you need something is special. You're not walking that long road alone."

*For more information about Alive Hospice, call (615) 327-1085 or 1-800-327-1085, or visit [www.alivehospice.org](http://www.alivehospice.org).*



## An Adult’s Guide to Hospice Care

### Who is eligible for hospice care?

Hospice care is available for people of all ages, including pediatrics, who require end-of-life care and pain and symptom management due to a life-threatening illness. Alive Hospice also offers palliative care, a branch of medicine that provides pain and symptom management for patients with chronic, life-threatening illnesses who may have a longer life expectancy or who are still undergoing curative treatment. Both types of care offer patients the benefits of not only medical care, but also emotional and spiritual support.

### How do I set up hospice care for my loved one?

Consult with your loved one’s

primary care physician/pediatrician. Alive Hospice will contact the patient’s physician to make sure he or she agrees that the patient is eligible for hospice care. Alive Hospice encourages anyone with questions about hospice to call (615) 327-1085 or 1-800-327-1085, or visit [www.alivehospice.org](http://www.alivehospice.org).

### Do hospice patients have to stop aggressive treatments?

No. Alive Hospice patients can take advantage of a variety of aggressive treatments that promote quality of life.

### Does getting hospice mean giving up hope?

One never has to give up hope. While hospice and palliative care

involve serious illnesses, we believe that every day is precious and should be enjoyed. Taking advantage of hospice and palliative care means receiving expert pain and symptom management. This not only offers hope of being comfortable, it also makes it possible for patients to continue enjoying life and complete the end-of-life journey with peace and dignity.

### Who will care for my loved one?

Alive Hospice’s interdisciplinary team of caregivers includes physicians, licensed nurses, certified nurse technicians, social workers, chaplains, volunteers and bereavement support staff.

## Jessica Parshall Teen Volunteer

“I just want to be able to put a smile on someone’s face,” said Alive Hospice volunteer Jessica Parshall. “When people smile, it lights up everything.”

Jessica has volunteered for Alive Hospice since she was 16. The high school senior felt it was important to help make a difference in the lives of others and has found volunteering for Alive Hospice a rewarding experience.

She has helped feed patients at Alive Hospice Residence Nashville and Alive Hospice at Saint Thomas Hospital. She holds their hands and keeps them company as they talk about family and memories. She listens and knows that offering her presence can do much to brighten a patient’s life.

Volunteering has given Jessica a variety of heartwarming experiences. One of her favorite memories involved an 8-year-old patient and several of Jessica’s friends who also volunteer for Alive Hospice. After learning that the patient liked Spider-Man, Jessica and her friends surprised him with toys and made Spider-Man-themed decorations for his room at Alive Hospice Residence Nashville. The smile on his face is something Jessica will never forget.



*Teen volunteer Jessica Parshall enjoys brightening the lives of Alive Hospice patients.*

Alive Hospice has a variety of volunteer opportunities for teens. Some, like Jessica, provide companionship to hospice patients. Others can provide office support and help with special events that raise funds to support the mission of Alive Hospice. Volunteer coordinators work with teens to determine how they can serve and to work out a schedule.

“It’s been a blessing for me,” Jessica said.

*To find out more about Alive Hospice volunteer opportunities, call (615) 963-4667.*

## Helping the Grieving Child

Losing a loved one is difficult at any age, not least for a child. As a parent or guardian, it’s perfectly natural to want to do all you can to make sure your child navigates the stormy straits of grief as smoothly as possible.

Bereavement support is a key component of Alive Hospice’s mission. We invite you to take advantage of our many grief support services and to read the following tips for helping your child cope with the loss of a loved one.

**Be available to talk.** It’s important for kids to know that they’re not alone and that their parents or guardians are there to love and support them during the grieving process.

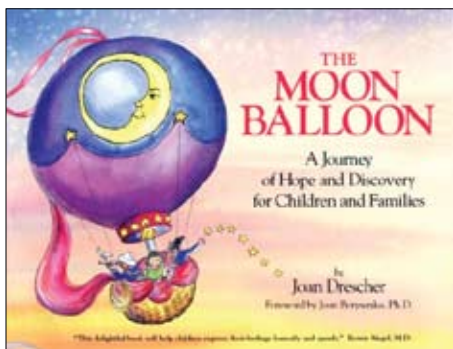
**Give them space.** Being available to talk is important, but kids may not always be ready to share their  
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## The Bookshelf

Alive Hospice Children’s Grief Counselor Lauren Thurman offers reviews of two books she recommends for grieving children and teens.



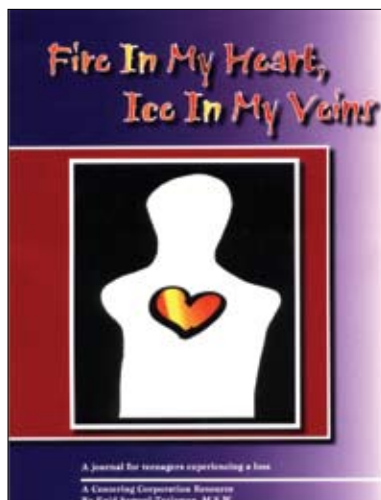
**For Children: ‘The Moon Balloon’**  
 “The Moon Balloon” is a beautifully written and illustrated book by Joan Drescher. It was created for children who are dealing with a serious illness of their own or that of a loved one.

The book’s interactive approach allows children to share their own unique experiences throughout the story. It takes them on a journey through a field of hot air balloons, each representing a common emotion children experience when

faced with serious illness or death, including anxiety, anger, sadness, warmth, peace, stress, laughter and love. The book offers a wonderfully creative way for children to use their imaginations, allowing them to write and draw in the balloons as the story unfolds.

“The Moon Balloon” helps children explore their emotions and can be used for coping with a variety of traumatic childhood issues.

*For more information, visit [www.themoonballoon.com](http://www.themoonballoon.com).*



**For Teens: ‘Fire In My Heart, Ice In My Veins’**

“Fire In My Heart, Ice In My Veins” is a valuable resource for helping teenagers explore their grief-related thoughts and feelings after the death of a loved one.

The journal format asks teen readers specific questions about the loved ones they’ve lost and the relationship they shared. It walks readers through some challenging topics about their experiences and how they are managing their grief.

The book helps readers envision the future, what is important to them and how they can carry their loved ones’ legacies with them throughout their lives.

This book is highly successful in promoting self-expression and dialogue about grief and loss.

*For more information, visit [www.fireinmyheart.org](http://www.fireinmyheart.org).*



## Things Every Kid Should Know About Grief

**You're not alone.** Losing a loved one may be a new experience for you. It may feel like others don't know what you're going through. But chances are, other kids at your school and family members have gone through the same thing. Don't forget that your loved ones, teachers, other trusted adults and friends are there to help.

**It's OK to play, have fun and be a kid.** Losing a loved one is sad, but don't forget that it's perfectly OK to have fun and play. That doesn't mean you care for your loved one any less. There's room for tears and laughter.

**It's OK to cry and express your feelings.** Let it out! Expressing your

feelings is perfectly natural and is a healthy way to get through the tough times.

**Seeing a counselor isn't a bad thing.** It's not weird to see a doctor if your stomach hurts, is it? A doctor has special knowledge and skills to help make you feel better. So does a counselor! A counselor is a person you can trust who can help you understand what you're feeling – and how to make those feelings a part of your life and still be a happy kid.

**The love never ends.** Your special bond with a loved one can't be broken by death. You'll always have the love and memories you shared. Nothing can ever take them away from you.

## Helping the Grieving Child

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feelings when a concerned adult feels the need to talk. Not knowing what your child is thinking or feeling can be unnerving, but sometimes the best solution is to let them engage you when they're ready.

**Kids and adults grieve differently.** They often experience the same emotions, but there's a major difference in how they experience those emotions. Feelings associated with grief are often constant for adults. Kids, on the other hand, grieve more sporadically. They may feel sad one moment and ready to play the next. This mixture of emotions is perfectly normal.

**Grieving can take many forms.** Everyone reacts to a loss differently, and signs of grief vary by age. Many kids may cry after a loss. Some may show signs of depression, act out or have trouble with schoolwork. Some may want to crawl into bed with a parent at night to avoid being alone. These are perfectly normal grief responses.

**Know where to turn.** It's important for kids to know they're not alone as they grieve. It's just as important for adults to know they're not alone, either. Alive Grief Support Services can help. We're in this together.

## Activity: Make A Memory Box

Calling all kids! We have a special project just for you.

Losing a family member or friend is tough. We'll bet that you had some good times together. But even after you say goodbye, the bond you have with your loved one will never end. We know a special way that you can celebrate the special relationship you shared with your loved one: making a memory box.

It's fun and easy! Ask an adult to help you pick out some supplies, and off you go! Once you've completed your

memory box, you can fill it with photos or special items that remind you of your loved one.

Show us what you can do! Our friend Charley, who is 10 years old, will show you how to make a memory box. Follow along with the photos and directions we've provided.

**Materials:** A plastic or wooden box or a shoebox, some glue and your choice of colorful tiles, paint, markers, construction paper and other colorful craft materials.

**Time:** 20 minutes to an hour.



Paint your box in your favorite color – or colors!



Decorate your box with letters, colorful tiles and stickers, construction paper and other materials. There's no right or wrong way to do it!



Put the finishing touches on your box with other decorative items.



Fill your box with photos and other special items.

# Youth Alive

Alive Hospice is pleased to offer "Youth Alive," made possible by a grant from the Gannett Foundation. Please take a moment to fill out the following brief survey.

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Please clip this survey and return to:

Sara Pérez  
Alive Hospice  
1718 Patterson St.  
Nashville, TN 37203



## Alive Grief Support Services

Alive Hospice offers a variety of bereavement support services for adults and children. These services are available to anyone in the community who has faced a loss.

Children's grief counselors offer year-round individual counseling and help children express and understand what they're feeling through play. Alive Grief Support Services also offers individual counseling for bereaved parents and adults.

In addition, Alive Hospice offers grief support groups for adults, teens and younger children. These groups allow participants to learn about the grieving process, help them understand that what they're

experiencing is normal and find strength in each other through shared experiences.

Two summer day camps help bereaved children develop healthy coping skills through recreational and artistic activities. Camp Evergreen is for kids ages 7-14 who live in Cheatham, Davidson, Dickson, Robertson, Sumner, Williamson and Wilson counties. Camp Forget-Me-Not is for kids ages 6-14 who live in Bedford, Cannon, Coffee, DeKalb and Rutherford counties.

Call (615) 963-4732 or visit [www.alivehospice.org](http://www.alivehospice.org) for more information about Alive Grief Support Services.

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